

Leveraging Title V Partnerships to Advance National Performance Measure # 15: Adequate Health Insurance

The Catalyst Center, the National Center for Health Insurance and Financing of Care for Children and Youth with Special Health Care Needs, created this brief for Title V staff and family leaders. It highlights collaborative Title V partnerships that hold promise for advancing the Title V National Performance Measure (NPM) #15: *Adequate Insurance Coverage: Percent of children 0 through 17 who are adequately insured*. We also provide important contextual information about the Maternal and Child Health Bureau's 2013 performance measurement framework, which includes NPM #15, and an overview of the methodology the Catalyst Center team used to learn about state Title V partnerships with Medicaid agencies and family leader organizations.

Introduction

In March 2013, the Maternal and Child Health Bureau (MCHB) began a process to transform the Title V Maternal and Child Health (MCH) Services block grant to a system that balances state flexibility in meeting the needs of the MCH population and, at the same time, measures the impact of Title V's efforts to advance the health and well-being of women and children, including children and youth with special health care needs (CYSHCN). The transformation continues to afford the 59 states and jurisdictions the flexibility to perform needs assessments to identify state priorities [Lu, et al 2015]. Additionally, in an effort to increase accountability and more accurately reflect current MCH population needs, MCHB convened a workgroup to create a new, three-tiered performance measure framework [Kogan, et al 2015]. Each Title V program now designs and implements evidence-based/evidence-informed strategy measures (ESMs) to advance its chosen National Performance Measures (NPMs) that will ultimately lead to improvement in National Outcome Measures (NOMs) for MCH populations [Kogan, et al 2015].



Figure 1. Title V MCH Services Block Grant—three-tiered performance measure framework. [Kogan, et al 2015].

The MCH transformation also included an increased focus on partnerships and collaborations not only with federal, state, and local agencies, but also with families and consumers [Lu, et al 2015]. The 2017 Title V Maternal and Child Health Services Block Grant guidance notes, “States should work closely with family/consumer partnerships as they develop ESMS for their selected NPMs” [HRSA, 2017]. Further, diverse partnerships support public health improvements, contribute to accountability, and create evidence that can be translated into practice [IOM, 2003]. Partnerships and collaborations, as measurable components of ESMS [Kogan and Peterson, 2014], can help advance a state’s chosen NPMs by promoting coordination of services across systems of care, leveraging funding, and sharing information, and/or personnel, and/or data. Partnerships and collaborations may be especially important for advancing NPMs for the population domain of CYSHCN who often receive services from multiple agencies as well as supports from community-based organizations [Wolraich, M., et al 2013; National Consensus Framework for Systems of Care for Children and Youth with Special Health Care Needs Project, 2014].

Analysis of the State Title V Priority Needs from 2000 to 2015 found the most common Title V priority for all 59 states and jurisdictions was Access to Care and Health with 48 Title V programs prioritizing Access to Health Care [Kandasamy, 2017]. Availability of and access to health insurance facilitates access to care [NCHS, 2017]. The 2011/2012 National Survey for Children’s Health reports almost half of uninsured children did not receive a well-child visit; 84% of uninsured children had problems accessing specialty care; and 27% of families were frustrated in their efforts to obtain care for their uninsured children [NSCH 2011/2012; Rosen-Reynoso M., et al, 2016]. For children with special health care needs, who by definition require more health services than their peers [McPherson, et al 1998], 56% of uninsured CSHCN had unmet needs for at least one of 14 specific health care services or equipment [NS-CSHCN, 2009/2010].

As the MCHB-funded national center for improving health insurance and financing of care for CYSHCN, the Catalyst Center conducts research and disseminates state-level financing strategies aimed at increasing health insurance coverage for CYSHCN, covering additional services, reducing family financial hardship, and improving health

equity. This work aligns with NPM #15 Adequate Insurance Coverage (Percent of children ages 0 through 17 who are adequately insured) and the associated National Outcome Measures: 1) Percent of children without health insurance and 2) Systems of care for children with special health care needs (Percent of children and youth with special health care needs (CYSHCN) receiving care in a well-functioning system) [Kogan, et al 2015]. In this policy brief, we explore Title V/CYSHCN partnerships that can help advance NPM #15. Note: NPM #15 pertains to all children, birth through 17; however, strategies that work to improve health insurance for CYSHCN generally work for all children.

Methodology

The Catalyst Center conducted a “State Financing Strategies for Children and Youth with Special Health Care Needs in the Era of Health Care Reform” research project with state Title V/CYSHCN programs, Medicaid agencies, and with Family Leaders from the [Family Voices State Affiliate Organizations](#), many of which are also the MCHB-funded [Family-to-Family Health Information Centers](#) (F2Fs) in their state. Catalyst Center staff conducted structured interviews with one or more representatives from 45 Title V/CYSHCN programs, 34 Medicaid programs, and 40 family leadership organizations in the states, the District of Columbia, and Puerto Rico. The survey included questions about innovative strategies states were using to directly finance health care services for CYSHCN, as well as strategies that promote financing of care and coverage, such as benefits counseling to help families understand the full range of health insurance benefits. Staff also asked respondents about any additional coverage options available in their states, as well as policies and practices specifically designed to promote health equity for diverse and underserved subgroups of CYSHCN. Staff used NVivo software, designed for qualitative data analysis, to code the data and identify themes. The Boston University Medical Campus Institutional Review Board reviewed and approved this project.

Findings

The primary goal of this research was to identify innovative strategies states were using to finance and/or promote the care and coverage of CYSHCN. An added bonus was learning that much of the work Title V/CYSHCN programs are doing is accomplished in partnership with Family Leader organizations and other entities. Many of these partnerships support and strengthen the evidence for MCH programs that have selected NPM #15 [Johns Hopkins Bloomberg School of Public Health, 2016]. These partnerships can form the basis of ESMS that states could use to advance the adequate health insurance measure, and in doing so, decrease the percent of children without health insurance, and increase the percent of CYSHCN who receive care in a well-functioning system. Examples of these partnerships follow below, organized by the specific NOMs related to NPM #15.

Partnerships to Advance NPM # 15 by Decreasing the Percent of Children without Health Insurance

Families often need help in understanding the enrollment criteria and applying for the public benefits programs for which their children are eligible. Insurance information and application assistance, one-on-one assistance, and benefits counseling help facilitate enrollment in and use of health insurance benefits [Bachman et al 2012; Jia et al, 2014; Ray et al 2017]. Below are examples of Title V partnerships that facilitate these types of supports to increase children's access to health insurance.

The largest navigator program in Arizona is the Arizona Alliance of Community Health Centers. The Arizona Title V/CSHCN program has enjoyed an ongoing relationship with the Alliance for several years and has worked closely with them to identify some gaps and issues, as well as information and resources of importance to families raising CYSHCN. As a result, the Alliance has worked to train and support navigators who are comfortable working with families with CYSHCN and individuals with disabilities and who have expertise in assisting them to find the plan or group of plans that will meet their needs.

The Kentucky Family-to-Family (F2F) Health Information Center Co-Directors are employed by and housed within the Kentucky Commission for Children with Special Health Care Needs, which is the Title V/CSHCN program. The Co-Directors are Certified Application Counselors (CACs). The Commission Social Workers and F2F Co-Directors went through extensive training through the Federal Marketplace to become certified. They had worked since the opening of the State Health Insurance Marketplaces as "Kynectors," providing health insurance information in an impartial manner to anyone who seeks their help. This includes assisting consumers with submitting eligibility applications, clarifying the distinctions among health coverage options including qualified health plans (QHPs), and helping consumers make informed decisions during the health coverage selection process. The F2F Co-Directors also help families with CHIP enrollment or a QHP offered through the Marketplace or Benefind (a web-based assistance and support program for Kentuckians) and explain the types of financial assistance for which a family might qualify. The F2F staff also provides comprehensive information about deductibles, coinsurance and copayments, coverage limitations or exclusions, and whether a specific provider or hospital is in the plan's network.

The Rhode Island Title V/CSHCN program contracts with the Rhode Island Parent Information Network (RIPIN – home of the F2F and RI Family Voices) to solve health coverage problems. RIPIN serves as Rhode Island's Resource/Call Center for CYSHCN. RIREACH (Rhode Island Insurance Resource, Education, and



Assistance Consumer Helpline) is also part of the Call Center. Trained RIREACH advocates help consumers find and keep insurance, understand and use their health coverage, and respond effectively to benefit denials and other administrative headaches.

Family Connection, the Family-to-Family Health Information Center in South Carolina, contracts with the state Department of Health and Human Services (DHHS) to do outreach on behalf of South Carolina Medicaid and to provide families with the most up-to-date information about eligibility for services. They have two full-time Healthcare Connections (SC Medicaid) employees who are trained by DHHS to assist families in understanding eligibility for TEFRA, Medicaid waivers, and the new Autism services covered under the South Carolina Medicaid EPSDT benefit. Staff also address private insurance questions and provide information in plain language to help families understand the material. They will also meet one-on-one with families.

Partnerships that Advance NPM #15 by Helping to Ensure CYSHCN Receive Care in a Well-Functioning System

Many Title V programs have developed partnerships that help build the capacity of the system of care, which ensures CYSHCN receive care in a well-functioning system. Care coordination that helps ensure CYSHCN receive all needed services and avoids duplication is a component of a well-functioning system of care [National Consensus Framework for Systems of Care for Children and Youth with Special Health Care Needs Project, 2014; Bachman, S.S., 2015].

Through the Children's Healthcare Improvement Collaborative (CHIC), the Idaho Medicaid and Title V programs, in partnership with practitioners, worked together to regionalize coordination of care for CYSHCN. As Idaho is a very rural state, this effort worked to connect service systems, ensure CYSHCN received the care they needed, and helped parents navigate the system. This was also an effort to work with pediatric clinics to move them towards becoming patient-centered medical homes. The Idaho F2F was a partner in this collaboration and continues to provide "Stop Spinning Your Wheels: Coordinated Care for your Child" trainings and workshops for parents of CYSHCN.

In Massachusetts, the Medical Home component of the Children's Health Insurance Program Reauthorization Act (CHIPRA) Quality Demonstration grant supported pediatric practice transformation through a strong focus on care coordination and support of the use of standardized tools (such as the [CAHMI screening tool](#)) to identify children who could benefit from care coordination. There was also a focus on planning for transitions of care, and supporting the development of care plans. The CHIP-

RA Medical Home project did not require that each practice have a designated care coordinator as part of their team, but instead focused on supporting the provision of care coordination activities, with each team developing its own approach to providing those services based on their unique set of available resources and staffing. Additionally, through a collaboration with the state's Title V/CYSHCN program, based at the Massachusetts Department of Public Health, each of the 13 practice teams received up to eight hours per week of either on-site care coordination resources, or technical assistance for care coordination by a Department care coordinator.

Oral health is an integral component of overall health. Several Title V programs have innovative partnerships that integrate oral health into the system of care for children. In Iowa, Title V and Medicaid work together to expand the availability of oral health services for children enrolled in Medicaid. The Title V agency has legislative funding for dental hygienists, which helps to build the oral health infrastructure. The Title V-funded dental hygienists interface between dentists, the Medicaid program, and patients. They meet face-to-face with dentists, help make appointments, and help families keep their appointments. School nurses can also contact the Title V hygienists for children who may be having problems with attending school due to lack of dental care.

Parents Place of Maryland, which includes the F2F, has funding from Title V to issue four mini grants every year. One of the mini grant recipients was Pathfinders for Autism. This organization sought to improve access to dental care for children with Autism by making the experience less stressful and more "friendly" by creating a Friendly Visit program. As a result of the success of their efforts, Pathfinders is now partnering with the Office of Oral Health to offer these visits in other regions of the state and include Spanish-speaking families. They are also partnering with the University of Maryland Dental School to provide training for dental students so they can better meet the oral health needs of CYSHCN.

Beginning in the fall of 2015, children enrolling in West Virginia public schools needed to provide documentation of certain health screenings, including a dental encounter. Children who are identified as not having had an oral health visit are auto-enrolled in an oral health program for screening in a school-based health center and receive coordination to link them to a dental home. This effort was made possible by the Title V collaboration with the West Virginia state dental director, the West Virginia Department of Education, and medical and dental providers in the community.



Conclusion

In its *National Title V Children and Youth with Special Health Care Needs Program Profile*, the Association of Maternal and Child Health Programs [AMCHP, 2017] reports that Title V/CYSHCN programs rate themselves lowest in their ability to implement new reimbursement and financing systems. At the same time, Title V/CYSHCN programs identify their ability to engage families in programs and initiatives as a strength. Many of the state examples highlighted in this brief provide examples of ways Title V/CYSHCN programs can leverage their ability to partner with families, in particular with their state F2F, to improve their “capacity to contribute meaningfully to the challenges of financing and overseeing the quality of care for CYSHCN [AMCHP, 2017]” thereby, advancing the specific outcomes related to NPM #15.

The Catalyst Center is available to help

Since 2005, the Catalyst Center has been researching and disseminating state-level financing strategies aimed at increasing health insurance coverage for CYSHCN and reducing financial hardship and medical debt for their families. Our staff can assist state Title V programs and their partners, policy makers, family leaders, researchers, and other stakeholders by providing technical assistance to maximize access to health insurance.

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Citations

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The Catalyst Center, the National Center for Health Insurance and Financing for Children and Youth with Special Health Care Needs, is supported by the Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services (HHS) under grant number U41MC13618, \$473,000. This information or content and conclusions herein are those of the Catalyst Center staff and should not be construed as the official position or policy of nor should any endorsements be inferred by HRSA, HHS, or the U.S. Government.

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The Catalyst Center is a project of the Center for Advancing Health Policy and Practice at the Boston University School of Public Health.

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Leveraging Title V Partnerships to Advance National Performance Measure # 15: Adequate Health Insurance, a publication of the Catalyst Center: Improving Financing of Care for Children and Youth with Special Health Care Needs, June, 2017.