Iowa Case Study: Shared Plans of Care to Improve Care Coordination for CYSHCN

Background

In Iowa, 17.7 percent of children have special health care needs and 47 percent of children and youth with special health care needs (CYSHCN) are enrolled in Medicaid and the Children's Health Insurance Program (CHIP).[1,2] The state's Title V CYSHCN program, administered by the University of Iowa's Division of Child and Community Health (UI DCCH), provides services for eligible children up to age 21. Services are delivered by Child Health Specialty Clinics (CHSC), which is a community-based public health agency with 14 regional centers and four satellite locations.[3] Children and youth eligible for Title V program services must have demonstrated an increased risk of or already have a chronic physical, developmental, behavioral condition, and require care beyond what children generally need.[4]

About This Case Study

This case study is part of the issue brief, State Strategies for Shared Plans of Care to Improve Care Coordination for Children and Youth with Special Health Care Needs, which examines strategies and opportunities states can use to advance the use of SPoCs for children and youth with special health care needs.

Iowa's Medicaid agency provides services to the majority of CYSHCN enrollees through the state's Medicaid managed care program.[5] Iowa Medicaid has also implemented the Pediatric Integrated Health Home Program (PIH) through Section 2703 of the Affordable Care Act. Health homes are a model of care that provides whole-person and coordinated care to individuals with chronic conditions. PIH provides care coordination and family support services to children with serious emotional disturbances (SED).[6] UI DCCH contracts with the state's Medicaid managed care organizations to implement PIHs in five CHSC regional centers, which serve 12 counties in the northeast region of the state and approximately 1,190 CYSHCN.[7]

Iowa's Shared Plan of Care Implementation

UI DCCH began implementing SPoCs for children and youth with SED served through the PIH program in 2016 to improve care coordination for this population. In 2017, UI DCCH expanded SPoCs into its nine other CHSC regional centers.[8] The CHSC care teams have flexibility in determining which children or youth enrolled in their centers would benefit from a SPoC. The participating clinics and health homes are using a standardized SPoC template developed by UI DCCH based on the report *Achieving a Shared Plan of Care with Children and Youth with Special Health Care Needs*.

Working closely with families, social workers typically lead the creation of the SPoC for children served by PIH, while nurses lead the development of SPoC at non-PIH centers. The care teams are responsible for educating families about the purpose of the SPoC, supporting them in identifying goals, and guiding them through the development process. The Family Leadership Training Institute in Iowa also conducts formal trainings for families of CYSHCN on leadership, advocacy, and family-professional partnerships, and provides education on the SPoC as an effective way to promote family-centered care.

To support electronic sharing of SPoCs between providers, families, and other care team members, the state uses ACT.md, a web-based care coordination platform. Lead care coordinators, CYSHCN and their families, and other team members approved by families, have access to the SPoC on ACT.md. Families are also given full administrative access to their child's SPoC in ACT.md, which they can use to make changes to the care plan. A history function in ACT.md captures these changes. Recognizing not all may have computer and email access, families also receive a printed copy of the SPoC and are able to share it with other professionals, such as teachers or school social workers, who also may not have access to ACT.md. UI DCCH also uses ACT.md to facilitate care coordination and support goal-setting for CYSHCN whose needs are less complex and do not rise to the level of needing a full SPoC.

Iowa recognized that implementing SPoCs, especially when using a web-based platform, requires a shift in how providers approach care and design their workflow processes. To help address this challenge, UI DCCH focused its initial primary care provider engagement efforts on orienting providers to the process of developing SPoCs. UI DCCH is also now working to strengthen primary care providers' engagement in actively using and contributing to the SPoC, logging on to ACT.md, and utilizing its full functionality to improve care for CYSHCN. In addition to provider engagement, UI DCCH focused on educating families about how the SPoC and ACT.md can help manage care for their child. Iowa recognized that in order for the SPoC to be successful, there had to be provider and family buy-in for the tool, process, and electronic platform.

Currently, Iowa funds its SPoC implementation efforts through its state Title V Maternal and Child Health Services Block Grant program. As of August 2018, more than 150 CYSHCN in Iowa have SPoCs through the PIH program and other regional centers.

Monitoring SPoC Implementation

UI DCCH is taking a variety of approaches to evaluate SPoC implementation and the potential impact CYSHCN. Iowa contracted with independent evaluators to assess families' experiences with SPoCs, including engagement in the development process, ease of access to ACT.md, and the value of SPoC as a tool for supporting care coordination. Preliminary results from family interviews revealed that a majority of families found the SPoC development process, including creating shared goals, was easy and a valuable use of their time.

In addition, UI DCCH staff also review SPoCs and critically analyze whether each SPoC is being implemented as intended. UI DCCH currently uses this information to help inform ongoing development of SPoCs in Iowa by highlighting where improvements in the SPoC process are needed. Iowa also plans to conduct more targeted research, specifically focusing on with ACT.md. It is in the early stages of assessing the potential impact of SPoCs on outcomes (e.g., urgent care utilization and hospitalizations, etc.).

Lessons Learned and Future

Lessons learned from Iowa's implementation process include recognizing the value of starting on a small scale and using a systematic outreach effort to engage and educate the multiple partners involved in SPoC implementation. Introducing SPoCs to limited groups of families and providers and testing their use allows workflow issues to be addressed and processes to be improved in a controlled environment. Starting small is especially crucial when introducing new electronic platforms, such as ACT.md, because technology adds another element that families and providers need to be trained in and can require the development of additional processes to support its use. Iowa officials also highlighted the importance of engaging with and obtaining buy-in from stakeholders early in the SPoC implementation process. SPoC implementation can involve a major culture shift within the various entities serving CYSHCN. Devoting significant time to educate and help these entities

understand the value of SPoC early on in the implementation process can better facilitate the transition to SPoCs.

In the future, Iowa's Title V CYSHCN program plans to continue to expand the use of SPoCs throughout the regional centers. Currently, whether CYSHCN have SPoCs is at the discretion of providers. Iowa is interested in providing SPoCs for additional populations of CYSHCN, such as children with medical complexity and children diagnosed with autism spectrum disorder.[9] To facilitate this expansion, UI DCCH is working to build a "proof of concept" for SPoCs to demonstrate their effectiveness and added value before engaging additional partners, such as Medicaid managed care organizations, that can support the spread of SPoC.

Endnotes

1. Child and Adolescent Health Measurement Initiative, "2016 National Survey of Children's Health (NSCH) data query," Data Resource Center for Child and Adolescent Health, accessed June 2018, http://childhealthdata.org/browse/survey/results?q=4562&r=1&r2=17.
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3. "About CHSC," University of Iowa, accessed June 2018, https://chsciowa.org/about-chsc/.
4. "2016 Title V Needs Assessment," Iowa Department of Public Health, 2016, December 2011, http://idph.iowa.gov/Portals/1/Files/HPCDP/2016%20Title%20V%20Needs%20Assessment%20Data%20Detail%20Sheets%2011-12-14.pdf.
5. "State Medicaid Managed Care Program Design for Children and Youth with Special Health Care Needs," National Academy for State Health Policy, https://nashp.org/state-medicaid-managed-care-program-design-for-children-and-youth-with-special-health-care-needs/.
6. "Iowa Serious Persistent Mental Illness Health Home State Plan Amendment," Centers for Medicare and Medicaid Services, June 2014, https://www.medicaid.gov/State-resource-center/Medicaid-State-Plan-Amendments/Downloads/IA/IA-14-009.pdf.
7. "Iowa Maternal and Child Health Services Title V Block Grant: FY 2018 Application/FY 2016 Annual Report," Iowa Department of Public Health, September 2017, https://mchb.tvisdata.hrsa.gov/uploadedfiles/StateSubmittedFiles/2018/IA/IA_TitleV_PrintVersion.pdf.
8. "About CHSC," University of Iowa, accessed June 2018, https://chsciowa.org/about-chsc/.
9. "Iowa Maternal and Child Health Services Title V Block Grant: FY 2018 Application/FY 2016 Annual Report," Iowa Department of Public Health, September 2017, https://mchb.tvisdata.hrsa.gov/uploadedfiles/StateSubmittedFiles/2018/IA/IA_TitleV_PrintVersion.pdf.