



Shared Plans of Care for Children and Youth with Special Healthcare Needs (CYSHCN)



Location	Focus Area	Policy Type
Colorado	Access to Health Care/Insurance, Service Coordination/Integration	Little P Policy



Target Population
Children and youth with special health care needs

SECTION 1: POLICY DESCRIPTION

The Colorado Department of Public Health’s Title V program partners with Local Public Health Agencies to provide care coordination to children and youth with special health care needs (birth-21 years) and their families. The statewide care coordination program is called [HCP - A Program for Children and Youth with Special Health Care Needs \(CYSHCN\)](#). On average, the program provides care coordination to about 1,100 children, 74% of whom are eligible for Medicaid. In addition, Colorado has a Medicaid Managed Care System and contractors (Regional Accountable Entities or RAEs) are responsible for ensuring the members in their geographic area have access to a medical home and are paid per member / per month to provide members with short term, episodic, care coordination services. The Title V Medical Home priority has focused on the policy and system level coordination across the Title V-funded care coordination program (HCP) and the care coordination



being provided by the RAEs (with a focus on CYSHCN). One key area of improvement identified through efforts to coordinate across systems is the need for a shared plan of care to reduce duplication of services, align priorities in the care plan with the families' capacity, and strengthen communication across other services provided to the family. In 2013, Colorado was the recipient of a D-70 grant that focused on strengthening and integrating systems of care for CYSHCN. Colorado's Title V team leveraged the Medical Home priority policy strategies in the state action plan together with the D-70 grant implementation plans, to focus on creating a process for sharing care plans for CYSHCN across local public health, the RAEs, and Children's Hospital Colorado.

The [HCP program policy](#) was revised to read: ***"Local Public Health Agencies implementing the HCP model of care coordination will jointly develop a care plan with the family and share the plan with the family and at least one other member of the health care team."*** While HCP had an existing program policy to share a printed copy of the care plan that was developed with the family, the care plan was not being shared with community partners who were also providing support to the family around goals in the care plan.

KEY ELEMENTS



The implementation of the policy was aimed at local public health agencies that are contracted by Title V to provide care coordination. However, the intended impact of the policy was to improve the quality of care coordination services for children and youth with special health care needs and strengthen communication across community partners providing care coordination services, for example Medicaid contractors.

The policy's short-term goal is to create a systemic approach to sharing care plans across agencies and to develop a system to track compliance with the policy. Key elements to meet the short-term goals of the policy include creating a mechanism for local public health agencies to track and report fidelity to the policy, training local agency staff and communicating the value of shared care plans, and introducing and orientating the care team across agencies.

The policy's long-term goal is to strengthen communication across agencies that provide care coordination services for children, identify, and reduce duplication of services, and ensure that families' needs are being met. Key elements to meet the long-term goals include identifying areas of duplication, clarifying roles and referral issues, developing MOUs and organizational policy to create systematic processes to communicate and standardize new work, and influencing changes to performance measures for RAEs (Medicaid contractors).





EVIDENCE TO SUPPORT POLICY APPROACH

Shared plans of care are well-maintained as a best-practice in the MCH field. AMCHP's [National Standards for Systems of Care for CYSHCN](#), Standard 4: Medical Home, asserts that "a plan of care is jointly developed, shared, and implemented among the CYSHCN and their family, primary care provider and/or the specialist serving as the principal coordinating physician and members of the health care team". The Lucille Packard Foundation also has an [implementation guide](#) for achieving a shared plan of care for CYSHCN. The guide maintains that "the use of a shared plan of care facilitates implementation of key functions of the medical home model, including, but not limited to, comprehensive care coordination, communication, and patient- and family-centered care."

HEALTH EQUITY

The policy was intended to impact agencies that serve children and youth with special health care needs to improve coordination of care for this population. CYSHCN, by definition, have or are at increased risk for chronic physical, developmental, behavioral or emotional conditions. The CYSHCN population also requires care beyond the type or amount required of children generally. As a result, CYSHCN are disproportionately impacted and experience greater challenges in accessing supports and services than children without special health care needs. Based on 2018/19 National Survey of Children's Health results, CYSHCN in Colorado are less likely than non-CYSHCN to receive care within a medical home (46.2% vs 51.0%, respectively). This is a statistically significant difference. CO CYSHCN were also significantly less likely to receive effective care coordination, among children who needed it, than non-CYSHCN (52.7% vs. 73.5%, respectively).

In addition, social factors, such as class, race/ethnicity, gender and sexual orientation, are well known to impact health conditions for all children, including CYSHCN. Caregivers of CYSHCN face financial stressors related to cost of care, inadequate insurance coverage and time away from work to meet their child's needs. In 2018-19, CYSHCN in Colorado were almost 4x more likely to have a family member who had left a job, taken a leave of absence, or cut down on hours they work than non-CYSHCN and 2x more likely to experience two or more adverse childhood experiences (ACEs).



Specific to the HCP care coordination program that is the focus of this policy change, 43% of HCP care coordination clients live at or below federal poverty level; 40% of clients are Hispanic and 25% have primary language other than English ([2018-2019 program data](#)).

EVALUATION APPROACH



Collection Methods

Process Measures

HCP state staff developed a process for care coordinators to track whether care plans were shared with the family and any other providers (e.g. primary care provider, specialty care, school, WIC, social services, etc.) and enhanced the CYSHCN Data System (CDS) to include new data entry fields capturing these data. Care coordinators also collected additional data from families related to overall program impact and entered those data in CDS.

Data was also collected via the HCP Family Experience survey sent to all families who have been discharged from HCP or who have celebrated a new anniversary within 30 days of survey administration.

Finally, HCP state program staff participated in conversations with HCP care coordinators as well as a variety of partners (e.g. school nurses, Medicaid contractors, and Children’s Hospital staff) to discuss sharing care plans as well as consent processes, referrals and bidirectional communication.

After analyzing and reviewing data related to whether care plans were shared with the family and at least one other entity, HCP’s data manager sent emails to local care coordination teams and HCP state consultants identifying potential opportunities for quality improvement. HCP state consultants then followed up with local care coordinator teams to troubleshoot how to address any issues together.

Staff also cross-referenced data entered by HCP care coordinators in the CDS with data reported by care coordination clients via the HCP Family Experience Survey. For example, several questions asked whether a care plan was created, whether the care coordinator worked with the family to create goals and next steps on the care plan, whether the family received a copy of the care plan, etc.

Anecdotally, HCP state program staff heard that communication around shared care plans (how we talk about the work and what we share with the care team) was just as important as the shared document itself in terms of coordinating care across systems. This is particularly important when there are system barriers (i.e. different EMR systems) to efficient sharing of the document itself.





Impact Measures

Staff initially compared the percentage of care plans shared with the family and at least one other entity for (1) local public health agencies implementing policy/systems changes and quality improvement efforts at the service delivery level vs. (2) agencies only implementing quality improvement efforts at the service delivery level.

Since most of the agencies implementing policy/systems change were large in size and capacity, Colorado eventually began comparing data for this group to a sub-set of just the larger agencies that were implementing quality improvement efforts at the service delivery level. Larger agencies were defined as those receiving \$60,000 or more in MCH funding. Although not measured directly, improving and expanding the use of shared plans of care improves CYSHCN care coordination which could be fragmented and difficult to navigate without it, leading to disparities in accessing quality health care.

HCP program impact measures related to this policy include: whether care plan goals were met, quality of communication between providers, missed work days, barriers to seeing a medical provider, and whether child received enough care coordination to meet their needs.



Input From Key Populations

Local public health agencies received agency-level data including the percentage of care plans shared with the family and at least one other entity as part of “data quality checks” that were implemented. State staff presented aggregate data to local public health agencies to discuss findings and collect feedback from the group.

Colorado Title V also shared these data with the Regional Accountable Entities (Medicaid contractors). This provided an opportunity to talk about referrals, co-management of children and roles. From these conversations, several agencies were able to develop MOUs with the RAEs to formalize their roles and how data are shared to ensure both agencies are informed of what is happening with a family. Ultimately, this policy also served families by connecting other members of the care team and ensuring there was communication about the family’s goals.

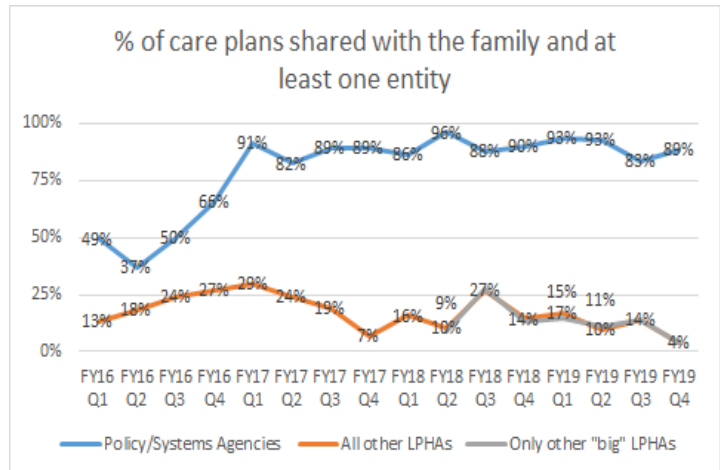
In addition, Colorado staff collected and cross-referenced family experience survey data, including a series of questions about whether a care plan was created to meet the child’s needs, whether the care coordinator worked with the family to create “goals and next steps” in the care plan, whether the family received a copy of the care plan and whether the family was encouraged to share the care plan with the child’s specialists or medical providers.



POLICY IMPACT

Creating a Systematic Approach to Sharing Care Plans and Tracking Compliance

One question Title V staff asked during planning was “Does implementing policy and systems level improvements along with service delivery improvements impact the success rate of sharing care plans across systems?” In an effort to answer this question, staff reviewed data tracking whether care plans were shared with the family and any other organizations. These data showed a substantial increase in sharing of care plans reported among agencies working on policy and systems change and little to no increase reported for agencies that were only using QI at the service delivery-level (independent of agency-size).



Increased Communication Across Partners

- LPHAs started regularly conducting case conferencing with RAEs and other members of the care team.
- Organizations developed policies that put in place systematic referral and communication processes between agencies. For example, formal agreements were developed between LPHAs and RAEs, as well as HCP and Children’s Hospital Colorado.
- FY 2019 pre- and post- data showed an increase from 91% to 94% of families who reported good or excellent overall communication and working relationships between all those who provide medical care and services to their child/youth (n=233).

Improved Delivery of Care Coordination

Results from the HCP Family Experience Survey suggested high rates of shared plan of care use and sharing with the family (consistent with data reported by care coordinators) and overall satisfaction with the quality of care coordination. In FY 2019 (n=38):

- 91% of families report that their care coordinator created a plan of care to meet their child/youth's needs;
- 94% of families report that their care coordinator gave them a copy of the care plan;
- 93% of families report that their care coordinator gave them the information and support needed to complete the tasks on the plan of care;
- 97% of families reported that since starting care coordination they have met important goals related to their child/youth’s needs;
- 94% of caregivers report that since starting care coordination, they have better knowledge of the roles of their child/youth’s different health care providers.



Meeting Family Needs

FY2019 pre- and post-data suggest the program had a positive overall impact on families. While Title V staff could not determine that these changes were directly attributed to the policy change, the data was used to evaluate the quality of care coordination and its impact on the family, including:

- An increase from 12% to 93% of families receiving enough care coordination to meet their needs (n=252);
- A decrease from 46% to 27% of families who report missed workdays in the past 6 months because of their child/youth's special needs (n=135);
- An increase from 88% to 93% of families who report that their health insurance pays for all of the health services needed (n=345);
- A decrease from 33% to 19% of families who report that their child/youth went to a hospital emergency room in the past 6 months (n=213).

SECTION 2: CONSIDERATIONS FOR FUTURE POLICY EVALUATION

LESSONS LEARNED

1. As we achieved our short-term outcomes, we had to continuously go back to our logic model to revisit outcomes or add new measures. This in turn necessitated revising and updating the evaluation plan as well.
2. A lot of learning took place along the way. During implementation, we realized that we should capture what we were learning about policy implementation (process, challenges, etc.). We used a policy development process and the implementation frameworks to help us capture some of this information.
3. It is essential to understand the scope of the problem (qualitative and quantitative data). In our case, our team needed to revisit our problem statement several times over the first year to ensure we were clear on the nature of the problem, that the policy change would address the problem and that we could measure impact.

FUTURE CHANGES



General

In future evaluation efforts, it could be helpful to tease out which impacts for CYSHCN were directly attributed to the policy change in order to clearly communicate the value of this policy to those considering replication.





Health Equity

Evaluation efforts in the future should disaggregate data by race to assess for racial disparities. If possible, retroactively looking at existing data for racial disparities would also be valuable.



Stakeholder/Advocacy Efforts

Evaluation efforts during implementation could include families impacted by the policy to understand how the process is working for them.



NECESSARY RESOURCES

Please reach out to Jennie Munthali, Children and Youth with Special Health Care Needs Section Manager, with questions regarding resources needed to implement this policy evaluation process.

ADDITIONAL RESOURCES

- [HCP Data Snapshot](#): This document provides a more detailed explanation of the demographics of clients served through HCP and results of the program evaluation efforts
- [HCP Policy and Guidelines](#): This guide includes a full program overview and details the care coordination model and process
- [Shared Plan of Care Communication Tool](#): Title V staff implemented training and developed this communication tool to convey the value of a shared plan of care to local health agency staff

CONTACT INFORMATION



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