

Shared Plan of Care:

A Tool to Support Children and Youth with Special Health Care Needs and Their Families

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INTRODUCTION

For children and youth with special health care needs (CYSHCN) requiring multiple services and supports, 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. As described by the American Academy of Pediatrics, shared plans of care are “developed and implemented with input from members of the team caring for a child, including community partners, educational specialists, primary care providers, dental providers, medical subspecialists and surgical specialists, and, most importantly, the family and patient themselves.”¹

Shared plan of care differs from the terms *plan of care* or *care plan*, which are often used by health care providers to describe a specific treatment plan developed by a clinician for a patient's medical condition. By contrast, the shared plan of care focuses on a comprehensive compiling of the information, in partnership with the family, needed to support coordination of care for the multiple needs of an individual child or youth, and his or her family. This includes clinical and nonclinical needs and services that support the health and wellness goals of the patient, family, and other caregivers.²

Research has shown that the use of a shared plan of care can

- Improve family-clinician relationships.
- Support provision of family-centered care.
- Provide information that enhances the planning and delivery of health care services that meet the medical and social needs of children, youth, and their families.^{3,4}

Recommendations for shared plans of care have been cited by the US Department of Health and Human Services,⁵ the National Committee for Quality Assurance,⁶ Title V National Performance Measures,⁷ meaningful use certification measures,⁸ the National Quality Forum,⁹ and Section 2703 health home

“When appropriately developed in partnership with patients and families, a single, comprehensive, integrated and shared plan of care strengthens relationships, enhances communication, and improves outcomes.”

– *Jeanne McAllister, BSN, MS, MHA*

requirements.¹⁰ In addition, the “National Standards for Systems of Care for Children and Youth with Special Health Care Needs” cites a shared plan of care as a critical and inherent component of a health care system that improves health for all CYSHCN.¹¹

Although no standard currently exists for a shared plan of care, this document provides recommendations on suggested content to include in the plan, as well as examples of templates and tools to guide clinicians, families, and state Title V programs, among others, in the development of a shared

plan of care. Discussion of other considerations for the medical home team, organizations, and agencies intending to develop a shared plan of care for CYSHCN and their families is also included. The examples included in this document illustrate how state agencies and programs have incorporated shared plans of care into their health care delivery systems to encourage coordinated and comprehensive patient- and family-centered care.

For the purposes of this fact sheet, the term *state agency* is used to describe a department or agency of a state government. This can include a state Medicaid agency, a Title V program, or a health department. The term *state program* is used to describe any initiative of a state agency.

WHAT INFORMATION SHOULD BE INCLUDED IN A SHARED PLAN OF CARE?

A shared plan of care includes a comprehensive compiling of the information needed to support coordination of care for the multiple needs, that is, medical, social, developmental, psychological, behavioral, educational, and financial, of an individual child or youth, and his or her family.² The plan may also include information on how families and patients access health care services, such as transportation and phone numbers to call during weekend and evening hours.

The process for developing a shared plan of care is equally as important as the content included within. Clinicians and families should work together to determine family and child needs, goals, and negotiated actions and/or strategies for achieving desired outcomes. As such, the process of creating a shared plan of care involves a culturally effective patient and family–professional partnership.

The Lucile Packard Foundation “Achieving a Shared Plan of Care with Children and Youth with Special Health Care Needs” report provides additional recommendations on the *process* of developing a shared plan of care, the elements to include in the plan, and a 10-step implementation guide (see box below for details).¹²

Achieving a Shared Plan of Care With Children and Youth with Special Health Care Needs

This report outlines the principles for the shared plan of care model and recommends core content for an integrated and comprehensive shared plan of care for children, youth, and their families. The report includes a 10-step process, outlined below, for creating an effective shared plan of care.

- Step 1:** Identify who will benefit from having a care plan.
- Step 2:** Discuss with families and colleagues the value of developing and using a comprehensive and integrated plan of care.
- Step 3:** Select, use, and review multifaceted assessments with the child or youth, and family.
- Step 4:** Set shared personal (child and family) and clinical goals.
- Step 5:** Identify other needed partners, that is, subspecialists, community resource providers, and others, and link them into the plan of care process.
- Step 6:** Develop the plan of care “Medical Summary” and merge with “Negotiated Actions” in step 7.
- Step 7:** Establish the plan of care “Negotiated Actions” and merge with the “Medical Summary” in step 6.
- Step 8:** Ensure that the plan of care is accessible, retrievable, and available.
- Step 9:** Provide tracking, monitoring, and oversight for the plan of care.
- Step 10:** Systematically use the plan-of-care-model process as a life course and a population health approach.

Several resources exist to support clinicians and families in creating shared plans of care for use within practices. In particular, many state agencies, including Title V and Medicaid, are available to support clinicians and families in this endeavor.

For example, through the Children's Health Insurance Program Reauthorization Act medical home initiative, several **Massachusetts** health care organizations and MassHealth created the National Institute for Child's Health Quality care plan template. A set of common elements were identified for inclusion in a shared plan of care template, such as medications, therapies and equipment, and acute care action plans.¹³

In some cases, the shared plan of care is developed by agencies or entities outside the clinician's office in partnership with the child or youth, and family. In these circumstances, it is important to notify the primary care clinician about the shared plan of care and to include the shared plan of care in the child's medical record. For example, the Integrated Services Program in **Utah** creates the shared plan of care following a referral from its early intervention program and contacts the health care provider to include necessary health information.¹⁴

WHERE DOES A SHARED PLAN OF CARE RESIDE?

A shared plan of care may be developed and managed by an entity outside the clinician's office, in partnership with the family. Wherever the plan resides, successful use and impact of the plan requires it be readily available and shared with family and professionals involved in the care of the child, thereby enhancing effective care coordination and promoting patient- and family- centered care. The shared plan of care can reside in some of the following locations:

- A shared plan may reside within the child or youth's **Electronic Health Record (EHR)**, thus providing easy access for the medical home team overseeing the care of the child or youth. Use of the EHR also provides opportunities to develop reminders and to streamline systems to collect information and monitor progress. Electronically incorporating information from an outside source may be feasible, depending on compatibility of EHR systems.
- Practices without the option to include the plan as part of the EHR may choose to scan and upload the plan into a child's medical record as a **PDF document** and periodically update the plan as needed. This shared plan of care may have been either created within the practice or provided to the practice from an outside source.
- A shared plan of care may also be uploaded onto a practice's **patient portal** or a **common platform**, allowing families the ability to access the plan from the Internet. Use of a common platform has the potential to also allow access by multiple professionals involved in the care of the child or youth.
- For others, the plan may exist as a **paper document** created with and provided to the family, updated during visits, and copied and distributed as needed.

To ensure that the shared plan of care is truly shared and accessible to all families, clinicians may need to house it in multiple locations, for example, as a paper document and on a common electronic platform.

WHAT ROLE DOES THE FAMILY PLAY IN SHARED CARE PLANNING?

At its core, the shared plan of care centers on the actions, needs, and goals of the patient and family. Without the family, a true shared plan of care would not exist. For this reason, a critical feature of a successful and comprehensive shared plan of care is engagement of the family in *all stages* of the plan's development.^{14, 15} A trusting, collaborative family-professional partnership must be central to the creation and maintenance of a shared plan of care. Members of the medical home team must engage the family to clearly identify the needs and strengths of the family, and child or youth.

Family engagement in developing the shared plan of care is also necessary to successfully identify family supports, medical specialists, and community services for inclusion in the shared plan of care. This information is used to set child, youth, and family goals (including medical and social) and determine the steps needed to achieve those goals. The resulting shared plan of care is updated periodically with the family, made available to the family, and shared with other professionals involved in the care of the child or youth.

HOW CAN STATE AGENCIES SUPPORT THE USE OF SHARED PLANS OF CARE?

State agencies have the potential to play a significant role in the development and implementation of shared plans of care for CYSHCN. The role of state agencies can vary, from providing clinicians with a common shared plan of care template to requiring and incentivizing the use of shared plans of care in practice. Additional examples of how state agencies can support the use of shared plans of care are provided below.

Create the template.

State agencies may create the template to be used and either require or recommend its use by clinicians for care coordination. With funding from AcademyHealth, the **Vermont** Child Health Improvement Program based at the University of Vermont, for example, is in the process of creating an electronic shared plan of care for CYSHCN to consolidate health data as well as information on economic, environmental, and social determinants of health.¹⁶

Provide the platform site.

A state agency may also provide access to a common platform to house the shared plan of care outside the clinical setting. These platforms also increase the opportunity for state agencies to link with various data sources, such as immunization registries, and to streamline the collection and updating of health information. Such a platform may be accessible to multiple agencies or organizations, to clinicians, and to the family to facilitate continuous review and updates to the plan. In **Connecticut**, plans developed for CYSHCN reside on

the state's Department of Health care coordination portal (called MAVEN), that is, an electronic record collecting information on the CYSHCN, used by Title V-supported care coordinators. Current work is underway within the Department of Public Health to provide access to the portal for the Department of Social Services and the Community Health Network.¹⁷

"To realize the benefits of comprehensive shared care plans (CSCPs), government, private industry, consumers, academic communities, and an array of clinicians and other providers must work together, not unlike the way in which CSCPs enable clinicians to collaborate on a smaller scale."

– US Department of Health and Human Services

Require recognition or certification programs to include shared plans of care.

In addition to providing a platform or template, state agencies have leveraged their medical home recognition or certification programs to create specific requirements for shared plans of care within participating practices. Two examples include

- The **Oregon** Health Authority Patient-Centered Primary Care Home Program requires the development of a written care plan as one of its certification standards.¹⁸ The plan must include self-management goals, goals of illness care, and an action plan for exacerbations of chronic illness and end-of-life care plans (when appropriate). The patient- and family-centered plan must be developed within 6 months of initial participation and revised as needed. The requirement for clinics to have a care plan for certification led to clinic sites working with hospitals to develop the plans.
- In 2010, **Minnesota** legislation to support medical homes (referred to in the state as health care homes) included standards for medical home certification and standards for a care plan. For certification, providers must actively engage and work with the patient and health care team to complete an assessment of the patient's health risks and chronic conditions, document the use of evidence-based guidelines, and include goals and action plans.¹⁹

Include shared plans of care in Medicaid state plan amendments.

State agencies may apply to the federal government for the optional health home Medicaid state plan benefit to provide care for Medicaid beneficiaries with chronic conditions.²⁰ The intent is to integrate and coordinate the needs of the whole person, including primary care, behavioral health, and long-term services. To support care management and care coordination, states may consider requiring a comprehensive shared plan of care.

- **New York** Medicaid is facilitating development of shared plans of care for all health home beneficiaries. All health care team members contribute to "the comprehensive assessment of a member's needs with an individual care plan carried out through specific interventions designed to provide coordinated, efficient, quality care to achieve the care plan goals and optimize health outcomes for people with complex health issues and needs."²¹

Incorporate shared plans of care into state programs serving CYSHCN and their families.

Various state programs and agencies serve as the primary support for CYSHCN and their families and can require the development and use of a shared plan of care.

- In January 2016, the **Rhode Island** Executive Office of Health and Human Services (EOHHS) issued practice certification standards for their Cedar Family Centers serving Medicaid-eligible children and youth with disabilities and chronic conditions. As part of certification, centers must create a family care plan illustrating comprehensive care management and recognizing the child or youth's health, emotional, social, and educational needs. Standards exist for care plan development with care plan performance measures to be reported to EOHHS. Performance expectations will be developed in 2017. In an effort to promote the use of family care plans, certified Cedar Family Centers will receive incentive payments if they meet performance expectations.²²
- **Massachusetts** MassHealth Youth provides intensive care coordination services for youth with serious emotional disturbances and specifications for a child- and family-centered individual care plan (ICP). The ICP includes goals and actions to address medical, educational, social, therapeutic, or other services needed by the youth and family. To create the shared plan of care, care coordinators partner with the youth, and family or guardian, to identify strengths and needs of the youth and family. Together, the youth, family, and care coordinator develop a plan with concrete interventions and strategies for meeting youth and family needs.²³

Examples of Templates and Tools to Create the Shared Plan of Care

- ["Achieving a Shared Plan of Care with Children and Youth with Special Health Care Needs" report, Lucile Packard Foundation for Children's Health](#)
- ["Care Plans: Best Practices for Development and Implementation" webinar, Patient-Centered Primary Care Institute](#)
- [*Developing an Effective Care Plan* clinical support module for pediatric residency education #3, American Academy of Pediatrics](#)
- [Care planning resources, National Center for Medical Home Implementation](#)
- [Care Plan Template, National Institute for Child's Health Quality](#)
- ["Care Planning Resources" Web page, National Institute for Child's Health Quality](#)

CONCLUSIONS

Care coordination is an important function of the patient- and family- centered medical home and of critical importance for CYSHCN. Engaging diverse team members and families in the creation of a comprehensive shared plan of care has the potential to support all members of the team to better understand and address the holistic needs of children, youth, and families. For CYSHCN in particular, the shared plan of care may include input from multidisciplinary providers and services, including primary, subspecialty, and behavioral health professionals, among others. As such, the shared plan of care plays a critical role in enhancing care coordination for individuals with complex medical needs.

Whether practices develop their own shared plans of care or contribute their portion to an outside entity, the resulting "living document" should serve to clearly communicate the current needs and goals of a specific child or youth with special needs and negotiated plans to achieve those goals. Opportunities exist for state agencies and programs to support the development and implementation of shared plans of care, particularly for CYSHCN and their families who are most in need of comprehensive, coordinated patient- and family-centered care. Private payers also have the opportunity to promote and incentivize care coordination for CYSHCN by providing enhanced payments to physicians, specifically for the development and implementation of comprehensive shared plans of care.

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