

Implementing Community-Based Care Coordination

INTRODUCTION

One of the greatest challenges facing state Title V programs is the need to expand mechanisms for assuring integrated, culturally competent, community-based systems of care for all children and youth who fit the broad definition of CYSHCN. Although the demographics of some states necessitate that direct services continue to be offered for un- and underinsured CYSHCN, many states are building partnerships and developing models that improve the infrastructure and capacity to serve larger numbers of CYSHCN.

DEFINITIONS

Increasingly, families, state Title V programs, and their community partners view care coordination as a valuable tool for organizing services so that families can access them more easily. It is important to recognize that other state agencies and programs may have mandates and funding mechanisms to provide care coordination to some portion of CYSHCN and their families. Likewise, the actual definitions of care coordination as well as the services and supports offered by each agency vary. For example, Title V statute describes **care coordination services** as services to promote the effective and efficient organization and utilization of resources to assure access to necessary comprehensive services for CSHCN and their families. The Centers for Medicare & Medicaid Services (CMS) refers to **targeted case management** as services that assist an individual eligible under the plan in gaining access to needed medical, social, educational, and other services for a specific condition. Multiple definitions contribute to overlapping responsibilities across agencies providing some form of care coordination which often leads to confusion and frustration for families. An expanded list of these terms and definitions can be found under **Useful Links & Resources**. In many states, case management is the accepted term used by insurance companies. Interagency discussions with family input is needed to build an understanding of what families need and want among all the partners.

THE FAMILY'S PERSPECTIVE

Families of CYSHCN are quick to remind us that care coordination begins with the family who is on call 24 hours a day/7 days a week. That being said, most families of CYSHCN will benefit from the assistance of a professional care coordinator for specific activities and during particular time periods. From the family perspective, a system of services should include a community-based mechanism for letting families "know what is out there and how they can get it." Parents know best what they need and one of those things is a care coordination system that values the family's role and expertise in understanding their family's needs and resources.



CARE COORDINATION STRATEGIES

Given these factors, a number of care coordination models and strategies are evolving within states and communities.

- Parent advocates are being paid to assist in care coordination activities. More states are employing part/fulltime parents in local health departments and in medical home practices to help educate families, identify services and providers, and serve as child/family advocates during IEP and care planning meetings.
- Colorado developed a care coordination model to offer support to all families of CYSHCN in the state; to minimize the overlap with other care coordinators, e.g. early intervention; and as a guideline for differential reimbursement. The three levels of care coordination are: 1) resource/referral information for initial contacts made by any family; 2) short term care coordination for targeted needs; and 3) intensive care coordination for

children with complex needs. Reimbursement for Level 3 is sought through contracts with public and private entities.

- Some states have experienced the loss or reallocation of funding for care coordination; others are looking for ways to build care coordination into their current systems of services. In New Hampshire, the Title V program recognized the new federal MCHB definitions of **Family-Centered Care** (http://www.championsforprogress.org/resources/Family_Centered_Care_Definition.rtf) and **Cultural Competence** (http://www.championsforprogress.org/resources/Family_Centered_Care_CC.rtf) as powerful mandates and build them into their strategic plan so that designated funds can be directed for the provision of family-centered, culturally competent care coordination.

- Certain aspects of care coordination can be streamlined and reduce duplication of effort on the part of both families and programs. Web-based systems that use the internet to help families complete and submit paperwork for multiple state programs minimize some of the duplication for families. For example, **Utah Clicks** (www.utahclicks.org) allows families to complete the paperwork for a variety of programs, such as Medicaid, Early Intervention, CSHCN, and others and submit the applications electronically. Oregon and Indiana are also in the process of replicating this web-based system in their states. Family satisfaction ratings on this type of system are very high.

DISCUSSION QUESTIONS FOR STATE & COMMUNITY TEAMS

At a series of Multi-State Meetings hosted by the Champions for Progress Center in 2005, state CSHCN staff and parent representatives discussed the topic of Implementing Community-Based Care Coordination Systems. The questions below can be used by interagency community teams and councils in order to share information and to build relationships.

1. What models of family-centered care coordination are being used at the community level in your state, such as the medical home, regional CSHCN care coordinators, others? Are some more successful than others?

2. Are there any examples of how the application/enrollment process is being streamlined for families? How are service plans being coordinated across agencies in your state, e.g. health, education, mental health, social services?

3. What efforts are being made to design/implement care coordination strategies to address the cultural and linguistic diversity in communities?

4. How have interagency councils been used as a mechanism for improving/supporting care coordination?

Useful Links and Resources:

Care Coordination Definition document: <http://mchb.hrsa.gov/programs/research/issues.htm#carecoordination>

Care Coordination: Integrating Health and Related Systems of Care for Children With Special Health Care Needs: <http://aappolicy.aappublications.org/cgi/content/full/pediatrics;104/4/978>

Colorado's Levels of Care Coordination: <http://www.cdphs.state.co.us/ps/hcp/form/carecoordination/carecoordination.pdf>

MCHB And JSI Report: A Review Of Care Coordination Activities: DSCSHN State Implementation Grantees: <http://www.championsforprogress.org/main/communityBasedSystemsDocs.cfm?CFID=97743&CFTOKEN=10286238>

MCHB Family Centered definition: http://www.championsforprogress.org/resources/Family_Centered_Care_Definition.rtf

MCHB Cultural Competence definition: http://www.championsforprogress.org/resources/Family_Centered_Care_CC.rtf

Medical Home Definitions: <http://www.medicalhomeinfo.org/tools/Downloads/Definitions.doc>

Medical Home Listserv Archives: <http://www.medicalhomeinfo.org/model/bulletinReimburse.html>



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The work reported in this document was supported through a cooperative agreement (#U42MC00241) from the Health Resources and Services Administration, Maternal & Child Health Bureau to the Early Intervention Research Institute at Utah State University