

Moving Down the Pyramid: Supporting Care Coordination & Access

INTRODUCTION

As state CYSHCN programs evolve from providing direct services to limited numbers of children and youth to assuring a system of care for all, one of the more promising services being offered to families is care coordination. Terms, such as case management, service coordination, case coordination, and care management are often used in health, social services, and education, which may lead to confusion and perhaps duplication and fragmentation of services. Ideally, coordination of health care occurs at the point of service, (i.e. in the medical home). The concept of medical home refers to an approach to providing health care services in a high-quality and cost-effective manner. Children and their families who have a medical home receive the care that they need from a pediatrician or physician whom they know and trust.

Families report that:

- To help families maintain sanity, care coordination, helps families to break through red tape.
- Care coordination improves access because families receive help in the application process and are better informed about the existence of services and resources.
- When families receive assistance in scheduling and coordinating services and resources, care coordination helps to reduce the daily “burden of care.”

Service providers report that:

- Care coordination “touch points” should follow the child to introduce or remind families of available resources.
- Improved access to timely services improves child and youth outcomes.
- Proactive care helps prevent secondary disabilities and prepares families and youth for adult transition.
- Care coordination improves efficacy of care, increases effective utilization of resources, and is more satisfying.

Payers report that:

- Care coordination may decrease long-term costs, although in the short-term, it may increase costs when children and youth receive the services and supports they need.
- When a proactive approach to care coordination is taken, there is a resulting reduction in the use of emergency services, fewer unplanned admissions, and fewer absences from school and work.

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The Medical Home is responsible for advocating for the child’s health needs in all arenas of life and can facilitate integration of health

into all plans including early intervention (IFSP), school (IEP or 504 plan) and work preparation programs/job accommodations. Models of coordination of services vary across states and may take place within the medical home or the medical home may be facilitated by Title V or others in this function. In order to be successful, interagency care/service coordination must interface with case management and utilization review of third-party payers. Teamwork across multiple agencies and individuals that provide care and service coordination or financial case management is essential.

What is High-Quality, Family-Centered Care Coordination?

- First and foremost, care coordination is based on relationships. Ultimately, families and youth choose care coordinators that they feel comfortable with and trust. Care coordinators may change over time as family needs evolve and change.
- Not all families/youth want or need care coordination services all of the time. However, care coordination services should always be available and families/youth should know how to access these services as their circumstances and needs evolve over time.
- Good quality care coordination is responsive in a culturally sensitive way to the needs and concerns of the family/youth. Listening to the priorities of families and youth is essential.

- Quality care coordination attends to transition issues.
 - > Transition planning begins early...at birth or upon entry into the system.
 - > Children and youth are prepared for the future in a developmentally appropriate manner.
 - > Families and providers learn to “let go” and allow the youth to develop self-management skills to the greatest extent possible.
 - > Transition planning should be comprehensive and integrated, not separate from school plans, Vocational Rehabilitation, Independent Living Centers and others.
 - > Youth should be assisted in finding quality adult health care providers and a means to fund their health care.

Strategies to avoid potential difficulties, such as funding adult health care, the need for full or partial guardianship, preparing wills and trusts, must be built into care coordination.

STATE & COMMUNITY STRATEGIES

- South Carolina’s CSHCN program tries to keep all the pots “simmering.” For example, regional programs use a self-assessment tool that is based on the six CYSHCN performance measures and Family Resource Coordinators are available for all families in the community to focus on all six performance measures.
- Some states have felt the pressure to “do it all” without seeking help from others. In North Carolina, the medical home effort decided to analyze and map services to see what gaps the CSHCN program could fill. One result was linking with their State Early Childhood Systems planning grant, which is housed in MCH, to further examine how other state systems approach the coordination of services and resources.
- Rhode Island’s system of CEDARR Family Centers serves children with special health care needs. CEDARR stands for Comprehensive, Evaluation, Diagnosis, Assessment, Referral and Re-evaluation—a one-stop source of information for

Rhode Island families—to provide information, professional assessment, specialty clinical evaluation, care planning, coordination of services, and ongoing referral assistance and support www.dhs.state.ri.us/dhs/dcedarr.htm

- In Louisiana, stakeholders are examining direct services provided by the state CSHCN program via a needs assessment and now have data for regional offices to refer to when planning services.

DISCUSSION QUESTIONS FOR STATE & COMMUNITY TEAMS

At a series of Multi-State Meetings hosted by the Champions for Progress Center in 2004, state CSHCN staff and parent representatives discussed the topic of Moving Down the Pyramid: Supporting Care Coordination & Access. The questions below can be used for discussion by interagency community teams and councils in order to share information and to build relationships.

1. What interagency mechanisms are being used to develop/facilitate access to care in our community, (e.g. one-stop shopping, interagency application/eligibility, integrated data systems)?
2. What mechanisms are being used in our community to engage organizations/agencies from diverse communities? List some examples.
3. What efforts have been made in our community to address racial and ethnic health disparities? Has our community developed any strategies to provide culturally competent care coordination?
4. List our community’s greatest accomplishments related to Supporting Care Coordination and Access for families of CYSHCN.
5. List our community’s greatest challenges related to Supporting Care Coordination and Access for families of CYSHCN.

Useful Links and Resources:

For Primary Care Providers: <http://www.medicalhomeinfo.org/tools/coding.html>

For Families: <http://www.familyvoices.org/BrightFutures/home.htm>

Parent Care Coordination Notebooks: http://www.medicalhomela.org/all_about_me.htm and <http://www.cshcn.org/resources/carentbk.cfm>



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