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CATALYST CENTER
IMPROVING FINANCING OF CARE for Children & Youth WITH SPECIAL HEALTH CARE NEEDS

Designing Evaluation Studies of Care Coordination Outcomes for Children and Youth with Special Health Care Needs

There is growing interest nationwide in the use of care coordination as an integral component of comprehensive, quality care provided within the medical home model for children and youth with special health care needs (CYSHCN)*. A broad range of stakeholders – family members, advocates, state Title V Children with Special Health Care Needs program staff, health insurers and providers – have expressed a need to the Catalyst Center to be able to evaluate the benefits of investing in care coordination. The purpose of this brief is to help provide some guidance in thinking through the requirements for doing so.

We begin with a look at the bigger picture: the national context for care coordination within the medical home, and the practical need to be able to demonstrate the outcomes, particularly the cost effectiveness, of specific care coordination programs. We then identify and respond to questions that often arise when designing such an evaluation. Finally, we provide a worksheet to assist readers in addressing these questions within their own states or organizations.

Context

The national agenda of the federal Maternal and Child Health Bureau calls for the development of systems of care for children with special health care needs (CSHCN) that are family-centered, community-based, coordinated and culturally competent. A key indicator that progress is being made toward this goal will be evidence that CYSHCN receive care through a medical home:

* The Catalyst Center uses the term 'children and youth with special health care needs' (CYSHCN) to highlight the fact that adolescents have particular needs, especially around transition to adult services.

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defined by the American Academy of Pediatrics (AAP) as a source of ongoing, routine health care in the community, where providers and families work as partners to meet the needs of children, youth and families. The medical home assists in the early identification of special health care needs; provides ongoing primary care; and coordinates with a broad range of other specialty, ancillary, community-based and related services.

A critical component of the medical home model is the provision of care coordination services "in which the family, the physician, and other service providers work to implement a specific care plan as an organized team"[1]. Although there is wide agreement among professional and family leadership organizations about the desirability of achieving care coordination within a medical home for all CYSHCN, there is inconsistent progress toward this goal. One barrier to achieving the medical home model for quality care is the question of whether the outcomes associated with providing care coordination are beneficial to all stakeholders. In order to promote the availability and use of care coordination – and to secure financing for this service as one element of medical home – program leaders and advocates plan to document positive outcomes of care coordination and a potential return on investment.

Questions to Ask (and How to Find Answers)

While there are no hard and fast rules for assessing the cost effectiveness or other outcomes of care coordination, there are a set of basic questions that must be addressed. The following list provides a framework in which to design and conduct this type of evaluation in your state or organization:

Question: What outcomes should we assess?

Care coordination models might achieve a range of desirable outcomes. Examples include:

- An increase in the quality of care provided to CYSHCN;
- Greater efficiency in access to needed services and care delivery, including transition of YSHCN to adult health providers;
- Cost-savings to a variety of stakeholders, including payers, providers and families
- Increased family satisfaction with care;
- Reduced stress on families;

- Increased provider satisfaction; and
- Reduced emergency room use, hospitalizations, hospital length of stay.

In a particular evaluation not every outcome will be applicable but a thoughtful determination at the onset of the project of what is important to stakeholders (which may include providers, patients, families, payers, purchasers, practice administration, etc.) to measure is key.

To find answers: Determine overlapping or shared interests.

Before you begin to evaluate a care coordination model, we recommend that you discuss the full range of outcomes you want to assess with a range of stakeholders. Not every stakeholder will want to achieve the same outcomes and it will be important to determine which outcomes matter most to the stakeholders in your state or organization.

Question: What care coordination model are we evaluating?

Care coordination is a service that has been interpreted and implemented in a variety of ways across a range of settings. While the AAP has defined a set of core elements of care coordination[1], different care coordination models may vary extensively in how they incorporate these elements.

To find answers:
Define the essential elements of your model.

An essential first step in evaluating care coordination outcomes is to identify and understand fully the elements of the specific care coordination model that you are evaluating. Your care coordination model might include any or all of the following elements, and more:

- Development of a registry of CYSHCN;
- Development of a specific plan of care for each child;
- A central record or database containing all medical information about a CYSHCN;
- Family involvement in decision making and development of a care plan;
- Linkages to community family support services and, for transition-aged YSHCN, adult supports, higher education and employment services;
- Coordination of care provided by specialists and consultants.

Identify key personnel.

Different clinical or non-clinical staff, such as physicians, social workers, nurses, trained parents, office staff or other administrative personnel, can deliver care coordination services. The professional perspective and training of the person providing care coordination services will significantly impact the nature of the tasks that person will be able to conduct and the reimbursement rate allowed for them. As part of understanding the model you are evaluating, we recommend that you identify the specific staff that are involved in coordinating care.

Document variability in implementation.

In addition to understanding the care coordination model being examined, it is important to understand how that model may be interpreted and actualized differently among providers. Even when there is agreement about the care coordination model to be implemented, different care delivery settings may actually provide different variations on the agreed upon model. This type of variation may occur even within practice settings that are connected through the same organization. For example, a smaller pediatric practice may not have the funds to invest in an electronic medical record system, even though a larger practice within the same service network has state-of-the-art systems. This difference in infrastructure will affect how care coordination is implemented at these different sites. In evaluating care coordination outcomes it is essential to document the range of variability among practices in how they apply the care coordination model. That way, if different outcomes are observed within your system, you may be able to link them to variations in implementation of your model.

Question: How can we identify CYSHCN?

Another key decision in planning an evaluation of care coordination is selecting a method for identifying CYSHCN for research purposes. This tells you which children you will look at in the sites you study.

To find answers: Choose a reliable method.

When designing evaluation studies across clinical care sites, most researchers will rely on claims data as the key source of information. A number of options for identifying the target population using claims data have been developed.

For example, an administrative data algorithm was developed by Neighborhood Health Plan and is described as part of a toolkit created by New England SERVE called "Shared Responsibilities: Tools for Improving Quality of Care for CSHCN"[1]. Another method identifies and categorizes CYSHCN through the use of Clinical Risk Grouper (CRG) software[1]. The Child and Adolescent Health Measurement Initiative (CAHMI) CSHCN screener[1] is used in many data gathering activities related to CYSHCN.

We have found use of a method developed by the Massachusetts General Hospital Center for Child and Adolescent Health Policy to be particularly suited to identifying CYSHCN for the purpose of evaluating care coordination outcomes. Researchers at the Center have created a list of chronic and severe conditions for use in case identification for research purposes. This list of ICD-9 codes is based on initial work by the Research Consortium on Chronic Conditions in Childhood and includes specific codes that can be used in a claims database to identify members of the target population. We favor using this model because it has been tested extensively and staff from the Center are willing to share their method at no cost, other than appropriate citations. To obtain more information about this method, contact Karen A. Kuhlthau, PhD or James M. Perrin, MD at the Center for Child and Adolescent Health Policy at the Massachusetts General Hospital at 617-726-1885 or childhlthpolicy@partners.org

Question: What evaluation design should we use?

After deciding how you will identify members of the target population, there are several remaining evaluation design issues that need to be addressed.

To find answers:

Standardize the time frame.

We recommend identifying a specific time period that will be the focus of the evaluation. This time period should include a retrospective one- to two-year time span prior to the implementation of care coordination, as well as a similar span of time after care coordination has been implemented. You want to make sure that you have a long enough time period to assess the impact of care coordination, especially because care coordination programs may take a while to mature and may also cost more at first while previously unmet patient needs are addressed. Over time, this initial investment should lead to greater efficiency in care delivery and then reduced

Establish a comparison group.

It is also advisable to identify a comparison group. The comparison group will not have been enrolled in any type of care coordination program, and thus represents typical care delivery. By comparing outcomes for CYSHCN that have received specifically defined care coordination services with outcomes for CYSHCN who have not, it will be possible to control for a variety of other factors that may influence outcomes. If you use a comparison group, you will need to think about how to match that group on the basis of key characteristics such as severity or type of diagnosis in order to minimize sources of confounding in your evaluation. It is critical that the same method for identifying children be used at care coordination and comparison sites.

Build collaboration for data access.

Another key decision is to identify the sources for data that you will use to assess outcomes. We recommend a multi-source approach, combining cost or utilization data with information on both parent and provider satisfaction to give evaluators a fuller sense of what the investment in care coordination is providing.

Data that are used to document the cost savings to payers associated with care coordination typically include medical services claims data. Although it is possible to use claims data from private payers, many evaluations are completed using Medicaid claims data. A first step in pursuing an evaluation study may be to develop a working relationship with representatives from the state Medicaid program, encouraging their participation in the evaluation. You will not be able to access Medicaid claims data without the support of the Medicaid program.

Other data sources that will be useful in assessing care coordination outcomes include: parent satisfaction surveys, clinician time studies, surveys which look at parental stress and other family outcomes, and clinical outcome improvement data (increased compliance with treatment regimens, etc.).

Question: Who else is doing work in this area?

In addition to staff at the Catalyst Center, many others across the country are knowledgeable about how to evaluate outcomes of care coordination for CYSHCN. The following are some experts you might want to contact:

The Center for Medical Home Improvement
Crotched Mountain Foundation
18 Low Avenue
Concord, NH 03301
Contact: Leah Reed, 603-547-3311
www.medicalhomeimprovement.org

Minnesota Children with Special Health Needs, Minnesota Department of Health
85 East Seventh Place / P.O. Box 64882
St. Paul, MN 55164-0882
Contact: John Hurley, Director, 651-201-3643
E-mail: John.Hurley@state.mn.us
http://www.health.state.mn.us/divs/fh/mcshn/medhome.htm

Partners in Health
The Hood Center for Children and Families
Dartmouth Medical School
One Medical Center Drive, HB 7465
Lebanon, NH 03756
Contact: Ardis Olson, MD, Principal Investigator, 603-650-5473
E-mail: Ardis.Olson@Dartmouth.edu
http://www.nhpih.dartmouth.edu

Children's Hospital and Regional Medical Center
Center for Children with Special Needs
"Care Management for CSHCN: Addressing and Financing an Unmet Need"
Project Period: 2002 - 2006
John Neff, MD, Director
1100 Olive Way, Suite 500, MS: MPW5-2
Seattle WA 98101
Contact: Jean Popalisky, MN, RN, Project Coordinator, 206-884-5326
E-mail: jean.popalisky@seattlechildrens.org
http://www.cshcn.org/projects/CareManagement.cfm

Antonelli, R., Stille, C., and Antonelli, D. **Care Coordination for Children and Youth with Special Health Care Needs: A Descriptive, Multisite Study of Activities, Personnel Costs, and Outcomes**. Pediatrics, 2008; 122(1):209-216.

[1] Medical Home Initiatives for Children with Special Needs Project Advisory Committee; AAP. The Medical Home. Pediatrics. 2002; 110(1): 184-186.
[2] Linov,P; Neighborhood Health Plan. Administrative data algorithm for identifying children with special health care need. Boston: New England Serve; 2001. Available from: http://www.neserve.org/neserve/pdf/NES%20Publications/Shared%20Responsibilities%20Toolkit/Summary_Description_of_NHP.pdf
[3] Neff JM. Sharp VL. Muldoon J. Graham J. Popalisky J. Gay JC. Identifying and classifying children with chronic conditions using administrative data with the clinical risk group classification system. Ambulatory Pediatrics. 2002;2(1):71-79.

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Planning an Evaluation of Care Coordination Services Work Sheet

What outcomes should we assess?

Identify stakeholders (include families, advocates, state agencies, health insurers and providers).

Determine overlapping or shared interests in outcomes of care coordination. Which are most important to your stakeholders?

- An increase in the quality of care provided to CYSHCN;
- Greater efficiency in access to needed services and care delivery;
- Cost-savings to a variety of stakeholders, including payers, providers and families;
- Increased family satisfaction with care;
- Reduced stress on families;
- Increased provider satisfaction;
- Reduced emergency room use, hospitalizations, hospital length of stay
- Others?

What care coordination model are we evaluating?

Define the essential elements of the service you are assessing and identify indicators; examples include:

- Development of a registry of CYSHCN;
- Development of a specific plan of care for each child;
- A central record or database containing all medical information about a CYSHCN;
- Family involvement in decision making and development of a care plan;
- Linkages to community family support services;
- Coordination of care provided by specialists and consultants.
- Others?

Identify key personnel involved in delivering care coordination services:

- Clinical and/or non-clinical staff
- Develop a list of providers providing the essential elements of the service; may include physicians, social workers, nurses, office staff or other administrative staff.

Document variability in implementation:

- Identify care delivery settings such as physician office practice, hospital, clinic setting, community health center
- Identify resources or infrastructure available at each site

How can we identify CYSHCN?

Choose a reliable method:

- Consult existing methods for identification used in the field
- Select a method for identifying CYSHCN
- Contact the Massachusetts General Hospital Center for Child and Adolescent Health Policy for information on use of diagnostic categories in claims data

What evaluation design should we use?

Standardize the time frame:

- Identify time frame that includes a one to two-year pre-period and similar post-period.

Establish a control group:

- Identify a comparison group that represents typical care delivery.
- Match comparison group on the basis of key characteristics such as severity or type of diagnosis.

Build collaboration for data access:

- Identify data sources using a multi-source approach
- Include:
    - Cost or utilization data
    - Parent and provider satisfaction
    - Clinician time studies
    - Parental stress surveys
    - Clinical outcome improvement data such as compliance with treatment regimens

o Develop a working relationship with representatives from the state Medicaid program