



The Importance of Integrated Services

A system of services is a family-centered network of community-based services that is designed to promote the health and well being of CYSHCN and their families. Ideally, community-based service systems are organized so families can use them easily. Care coordination, access to a medical home, family-centered and culturally competent services are considered key elements of coordinated services for families of CYSHCN. However, many families of CYSHCN face frustration accessing services. Eligibility requirements, policies, procedures, and multiple locations of services can leave families feeling overwhelmed. There are often gaps in services due to agencies that provide limited services or duplication in services from multiple coordinators and service plans. Families may also need to travel great distances to obtain specialized services.

The examples in the following sections, from medical home, care coordination, family-centered care, to cultural competency, as well as the common application forms found in the health information technology section, all address some piece of a coordinated system of care—although no state or community addresses all issues equally well. The following models of care often use strategies recommended by Champions for Inclusive Communities for developing coordinated services: including the use and development of interagency councils, partnerships with coalitions, supporting the development of family leadership and family-directed programs, and promoting linkages at the local and state level. For local level examples, please refer to the Star Communities on the Champions website: www.Championsinc.org.

The Importance of Integrated Services

Care Coordination

Care coordination is an integral piece of comprehensive, quality care provided within the medical home model for CYSHCN. Care coordination focuses on the broad range of services that are needed by a child with a complex medical condition. It is a process that helps ensure that the child with special health care needs and his or her family find the services they need, are linked with appropriate providers, and have help getting care when care and services are either not available in the community or do not seem to be working for the child and family with the overall goal of achieving optimal health. Recently, pediatric care coordination was defined as “a patient and family-centered, assessment-driven, team-based activity designed to meet the needs of children and youth while enhancing the caregiving capabilities of families. It addresses interrelated medical, social, developmental, behavioral, educational and financial needs to achieve optimal health and wellness outcomes” (Antonelli, R. et al. Making Care Coordination A Critical Component of the Pediatric Health System: A Multidisciplinary Framework. The Commonwealth Fund, May 2009).

States support a variety of care coordination activities, ranging from office-based care coordination, to home visiting programs, to agency-based programs. These programs are largely evaluated through family satisfaction surveys and assessments. The state programs highlighted in this section present a range of models that differ in terms of type of services provided, location of service, funding source and type of personnel used to deliver care coordination.

OREGON: CaCOON PROGRAM

Public

Emerging Practice

The Oregon Center for Children and Youth with Special Health Needs (OCCYSHN), the state Title V Program, operates the care coordination home visiting program, CaCoon. CaCoon provides funding, training and consultation to public health nurses in all 36 counties in Oregon to provide care coordination to CYSHCN from birth through age 20. Similar to California, Oregon is a West Coast state with a diverse population and, like California, the CYSHCN program is outside of the Department of Public Health, in this case in a university setting.

System of Care: In Oregon, each county has a designated CaCoon Coordinator. All of the CaCoon Coordinators are registered nurses. The CaCoon programs also support promotoras in four counties that have a high proportion of Latino families. These promotoras are community health workers who collaborate with the CaCoon Coordinator to teach families such skills as how to make an appointment, fill a prescription, or arrange transportation to an appointment. The majority of services provided are home visits, although public health nurses often may make several follow-up phone calls to support the coordination of care.

Children from 0-20 years are eligible for CaCoon services; though the majority of children seen are from birth to three years. This occurs for many reasons, including limited capacity in health departments, and the Targeted Case Management (Medic-

aid) funding that is available for children in the 0-3 year old group.

Key partners in the CaCoon program are the local public health departments. OCCSYSHN also works closely with the Oregon Office of Family Health and the Oregon County Health Leaders group, known as MCH-CLHO, that focuses on Maternal and Health issues as a vehicle for getting feedback and leadership level input into the program.

The program serves a diverse population in Oregon. Children are referred into the program regardless of ethnicity and/or language. Local health departments contract with local agencies to provide interpretation for home visits, or they use health department providers as interpreters. As noted above, CaCoon supports promotoras in four counties that have a high proportion of Spanish-speaking families.

Financing: CaCoon is funded through the Title V CYSHCN program as a sub-contract to each of the local public health departments in Oregon. Counties receive about \$900,000 each, though the amount is based on a formula that includes variables such as: rurality, live births, and salary levels for the area. This has been sustainable through continued funding of the Title V MCH CYSHCN program, which is an inter-agency agreement from the Department of Human Services where the larger MCH program resides.

Evaluation: The program is evaluated using several methods. Two OCCYSHN Nurse Consultants provide at least one site visit per year to each county to review program standards, discuss additional training needs, and to consult with the nurses on individual children. A chart review tool was recently developed. In addition, Oregon started using a database called ORCHIDS (Oregon Child Health Information Data System) about a year and a half ago that allows public health nurses to document their encounters. This database was developed by the Oregon Office of Family Health in collaboration with the OCCYSHN program. ORCHIDS collects demographic data as well as some limited outcome data on issues addressed by care coordinators such as nutrition, child development, parent, injury, and family knowledge of their child's

condition. The program is just beginning to analyze data from the first full year of data collection.

CaCoon is developing a desktop data system that will have the ORCHIDS data so that CaCoon consultants can easily examine data from each county on a quarterly basis. In addition, the ORCHIDS database will allow for analysis of certain segments of the population of children served by CaCoon. The program is also beginning to analyze services provided to adolescents who were seen by CaCoon nurses.

Will it Work in California: This program may be of special interest to California because it is based in all counties across the state, utilizes promotoras to reach the Latino population, and has some level of evaluation and sustainability.

Sources in addition to expert interviews: <http://www.ohsu.edu/cdrc/oscsn/community/nursing1.php>. Retrieved August 26, 2009.

ILLINOIS: LINKING CARE COORDINATORS TO MEDICAL HOMES

Public/Private

Promising Practice

Illinois, a high density state like California, has a well-developed medical home effort and is fairly advanced in terms of medical home/system integration and care coordination.

System of Care: The Division of Specialized Care for Children (DSCC) in Illinois provides care coordination to families with children who meet program medical eligibility requirements through 13 regional offices that cover the state. Care coordination is provided through two-person teams, a professional (nurse, medical social worker, speech/language pathologist/audiologist) and a paraprofessional with social service experience. Each team has a caseload of families across the range of eligible medical conditions.

Contact with families occurs in many ways, including home visits, meeting at medical appointments, phone, and mail/email. Additionally, each regional office has satellite sites in other communities where they can meet families and network with

referral sources and other community resources. The state plans to transition to an electronic case management information system (probably an electronic record) so that care coordinators can be more mobile and not tied to an office building. This would potentially facilitate connections in the communities with families and resources.

Through the state's Medical Home efforts (described in the Medical Home Section above at page 15), DSCC has encouraged primary care physicians to designate an individual in their office as a care coordinator. Those practices that have participated in a medical home quality improvement team (QIT) have had additional connection to DSCC care coordinators in their communities because the DSCC care coordinator has participated in the QIT. Primary care physicians are encouraged to contact DSCC care coordinators to get information about community resources.

Care coordination services are available at no cost to any family whose child has an eligible medical condition. This includes helping families and care providers develop a plan of care, coordinating services, linking families with other resources and programs, parent-to-parent support, information provision, helping families advocate for their child and making the best use of insurance and other payment sources. DSCC invests a lot of training in the care coordinators in the beginning to ensure the provision of high quality service coordination.

Evaluation: The program is evaluated in several ways, including a family survey conducted every five years as part of the Title V Block Grant needs assessment, which includes questions about care coordination, and through a short returnable postcard sent to families that have been part of the program for one year and those that have been in the program three years. Data from 2007 show very high satisfaction from families: 96% of families who responded indicated they were satisfied with the services they were receiving from DSCC; 99% indicated they were treated well by staff; 97% indicated their calls were returned in a timely manner; 95% indicated that DSCC assisted them in finding resources for their

child; 98% indicated that staff listen to them; and 98% indicated they got answers to their questions.

Additionally, through the Home and Community-based Services waiver program, the training and technical assistance unit contacts a sample of families with children in that program to determine satisfaction with services, including care coordination. The managers also use record reviews and other management strategies for performance appraisal annually as well as asking families about the care coordination they are receiving when they have contact.

Will it Work in California: The program is provided through regional offices across the state, a structure that may work in California and has a high level of family satisfaction.

Sources in addition to expert interviews: http://internet.dsc.uic.edu/dscroot/core_prog.asp. Retrieved August 26, 2009.

FLORIDA: COMPREHENSIVE CARE COORDINATION FOR CYSHCN

Public

Promising Practice

Florida's well-established Children's Medical Services (CMS) (described in detail above on page 12) has both nurses and social workers who perform care coordination activities. Care coordination activities are provided in 22 CMS area offices around the state. In addition, as part of CMS' statewide medical home initiative, there are physician practices that have CMS nurses out-posted in the physicians' office. In this medical home concept, the nurse works with the physician to identify all the children with special needs in the physician's practice, and care coordination services are provided to all these children regardless of CMS eligibility.

System of Care: Children's Medical Services assigns a nurse care coordinator to each child enrolled in the program. Nurse care coordinators work with families, the child's physicians and other providers, and other agencies (such as schools and social services programs) to ensure that children receive

needed care that is non-duplicative and comprehensive. If psychosocial issues are identified during the initial assessment, the child is also assigned a social worker care coordinator. CMS has care coordinators who have case loads of children with mixed diagnoses, as well as care coordinators whose case loads are composed of children with specific diagnosis, such as diabetes. Care coordinators may be state employees or are employees of contracted agencies.

Standards and Guidelines: In addition, CMS manages the statewide early intervention program that contracts for service coordinators who may be nurses, early interventionists, social workers, or other licensed professionals. The service coordinators follow the federal IDEA regulations governing family support planning, service authorization, etc. Children's Medical Services has a comprehensive plan to educate new employees about CMS care coordination guidelines. Currently CMS is working with two Florida universities to update the current CMS care coordination guidelines and develop disease management guidelines, an acuity determination matrix, and training methodologies for these initiatives.

CMS has outlined in the Children's Medical Services Care Coordination Guidelines criteria for medical and psychosocial assessments, care plan development, the implementation of the care plans, and the role of the care coordinator with the child's assigned primary care physician. Each child enrolled in CMS receives a comprehensive medical and psychosocial assessment; a care plan is then developed based on those assessments. These care plans are provided to each child's primary care physician. If indicated by the assessment a CMS social service referral is completed. The social worker referral form is completed by the nurse care coordinator when it has been determined that the client has needs that would best be addressed by a social worker. All assessments, care plans, care coordination tasks and activities are documented in the CMS electronic care coordination record.

Financing: This is a publically financed program through CMS.

Evaluation: Specific care coordination performance measures are incorporated in each care coordinator's performance evaluation and the employee is evaluated on the performance measures annually by their care supervisor. CMS contracts with the Institute for Child Health Policy to conduct annual family satisfaction surveys that include an evaluation of care coordination services.

Will it Work in California: Like California, Florida is a large and diverse state. Florida has a strong CYSHCN program, of particular interest to the California Title V CYSHCN program staff. The clear guidelines and standards of care as well as the annual evaluation may be helpful in attempting to replicate this program.

Source: Expert interviews.

RHODE ISLAND: A CARE COORDINATION MODEL FOR PARENT PEERS

Public/Private

Promising Practice

Although housed in the smallest state in the nation, Rhode Island's Pediatric Practice Enhancement Project is a model for all states and has been replicated. The Pediatric Practice Enhancement Project (PPEP) utilizes parents of CYSHCN within a medical practice to assist in system navigation, referral for specialty services and access to community-based resources. The PPEP was implemented in 2004 in eight pediatric primary care practices, including private practices, community health centers and hospitals. The PPEP was expanded to add three specialty sites to create an integrated service delivery system for CYSHCN in 2005. During the period 2006-2008, nine additional sites, including primary care practices, specialty practices, and urban health centers provided partial funding to participate in the project.

System of Care: The key innovation of the project is the parent peer model and its ability to affect the lives of individual families, healthcare delivery providers and an integrated system of care. The parent peer model is quite different from professional case management. The PPEP model has similarities

to the “patient navigator” role for chronic conditions and to the community health worker role in low-income/immigrant groups, in that parent consultants provide a peer/consumer approach to managing services and supports.

From its inception, the PEPP has been a partnership that included the Rhode Island Department of Health, Department of Human Services, Rhode Island American Academy of Pediatrics (RI AAP), Neighborhood Health Plan of RI (NHPRI) (the state’s largest Medicaid Managed Care Insurer), Family Voices and the Rhode Island Parent Information Network.

Financing: The PPEP was initially funded primarily by the Rhode Island Department of Health through a three-year grant from the New Freedom Initiative, which ran from May 2006 to April 2009. Other funding sources included the Title V Block Grant, State Medicaid Agency, and a grant from NHPRI, and participating sites. At the completion of the grant funding cycle, all participating sites have agreed to continue to fund the project to varying degrees to suit their individual site needs. True sustainability of the model requires RI health plans to differentially recognize and fund enhanced medical home practices without credentialing and other constraints that exclude the PPEP. The Rhode Island Department of Health has had the most success working with NHPRI to implement utilization reviews and cost analysis that have resulted in positive outcomes in support of the project. The PPEP has a program manager, data manager, and 24 parent partners who were hired, trained and supervised through the Rhode Island Department of Health’s subcontractor, the Rhode Island Parent Information Network. The PPEP annual operating budget is approximately \$835,000, consisting primarily of the salaries of the parent partners.

Evaluation: The Department of Health has studied and documented the effects of parent partners on policy, service delivery, and consumer education, including cost savings due to a decrease in overall health care costs. In addition, the PPEP has been measured at the individual, practice and systems level. At the individual level, the PPEP was responsible for many improvements in public programs,

health plan benefits, and provider practices. The most important achievement was that CYSHCN received more effective, complete and appropriate referrals, evaluations and interventions. Through addressing family’s concerns in education, behavioral health, specialty services, health insurance, parenting, childcare, basic needs and equipment, the PPEP has resolved 75% of the problems identified. During September 2006, the Department of Health worked with NHPRI to evaluate PPEP outcome data from the participating PPEP practices.

NHPRI conducted a utilization review to compare the healthcare costs for 70 CYSHCN a year before and a year after incorporating the PPEP. The utilization analysis showed a decrease in overall health care costs, specifically a decrease in institutional level care and an increase in community-based services. In early 2009, a cost-benefit comparative analysis was conducted to evaluate healthcare utilization and costs between PPEP and non-PPEP CYSHCN. Outcome data resulting from program enrollment showed that for PPEP participants: (1) the average number of health care encounters per CYSHCN was 21% higher, (2) the average inpatient utilization was 38% lower, and (3) the annual healthcare costs were 15% lower.

Will it Work in California: The program has a strong evaluation component, is a public-private partnership and has sustainable funding. It could be replicated initially as a county-based pilot with plans to go statewide.

Sources in addition to expert interviews: <http://www.health.ri.gov/family/specialneeds/pppep.php>. Retrieved August 24, 2009 and submission to AM-CHP’s Best Practices program.

OHIO: HOSPITAL-BASED CARE COORDINATION

Public

Emerging Practice

The Ohio Department of Health’s care coordination program, operated through the Bureau for Children with Medical Handicaps (BCMh), the state CYSHCN program, uses hospital-based team service

care coordination offered at tertiary care centers within the six metro areas of Ohio.

BCMh offers service coordination in the following areas: medical home, technology dependent conditions and palliative care. Service coordination is provided for the following conditions: myelodysplasia, craniofacial, hemophilia and clotting disorders, cystic fibrosis, oncology, and cerebral palsy. Additional requirements to be eligible for service coordination include age (birth to 21) and residency (resident of the State of Ohio). Services authorized by BCMh include the service coordinator and the BCMh public health nurse.

Hospital-Based Team Service coordination is a team approach with the service coordinator, client and family, and the BCMh public health nurse. The service coordinator is able to assist the client and family to navigate the child's care within the health care systems (which is often complex and involves multiple providers) which also includes assisting with enrollment of BCMh diagnostic and treatment programs. BCMh public health nurses also assist the clients and families in rural areas. A team-based service coordinator from the specialty team will work with the child and family when the child visits the team. The team service coordinator will communicate with the public health nurse (PHN) in the child's local community. These service coordinators will work together with the family to follow the child's progress and help the child receive necessary team and community services.

The service coordinator completes a comprehensive service plan in conjunction with the client/family and the public health nurse. This plan is able to be used as a tool to identify and prioritize needs, identification of available resources to meet needs, identification of barriers, identification of reasonable, attainable, and measurable goals (short and long-term). The plan can be utilized as a compact medical record to assist in hospital admission databases if admitted.

Funding: Service coordinators are able to bill for comprehensive service planning up to two times

a year when the plans are submitted. Public health nurses can bill for their service in 15 minute units.

Evaluation: The program uses six outcome standards to measure effectiveness and uses a bi-annual family survey to measure family satisfaction.

Will it Work in California: This program utilizes children's hospitals and other tertiary care centers in large metropolitan areas to deliver services across the state.

Source: Expert interviews.

NEW HAMPSHIRE PARTNERS IN HEALTH PROGRAM: PROVIDING FAMILY SUPPORT SERVICES

*Public/Private
Emerging Practice*

In New Hampshire, like California, CYSHCN operates outside of the public health agency. While New Hampshire is unlike California in terms of size and diversity of the population, this program has a unique funding source and focus, is a public-private partnership and has been sustainable.

System of Care: The Partners in Health Program complements the New Hampshire Department of Health and Human Services medical care coordination program by providing supports for families of CYSHCN for services not typically covered through care coordination and other state-funded programs. Partners in Health works to help families advocate, access resources, navigate systems and build capacity to manage their child's chronic health condition. The program primarily supports services that are traditionally difficult to fund but that are necessary for the overall health and well-being of the family, such as respite care, support for auto repairs so that a family can go to medical appointments, and even recreation support for siblings of CYSHCN.

There are 13 contracted community-based sites across the state, covering the whole state. Family support coordinators at each site work with families to find and access services and resources, arrange for special needs during hospitalization and after

discharge, help with school planning, and provide recreational and respite opportunities. Many of the family support coordinators are parents of CYSHCN. Each site has a Family Council that plans interventions and programs.

To be eligible for the program children must have a chronic medical condition that impacts daily life and is certified by a medical provider. The program does not cover children who have a developmental disability as the primary diagnosis because there are other programs that provide care coordination and case management services for that population.

Financing: The program is administered by the Children with Special Health Care Needs program of the New Hampshire Department of Health and Human Services, which is located in the Division of Community-based Care Services, and thus organizationally sits outside of the Title V Program. A unique feature of this program is that it is funded through the Social Services Block Grant with other funds from Medicaid targeted case management.

The Partners in Health program has been operating for approximately 15 years. It began through a pilot program funded through the Robert Wood Johnson Foundation through a grant to the Hood Center at Dartmouth University. The program was very well received and expanded quickly. As the grant funding was ending the program approached the state to assist with sustainability. The state was able to leverage the Social Services Block Grant, which has proven to be a flexible source of funding, and use Medicaid case management billing to support the program. The program was administered by the Hood Center but recently moved into the health department because it can administer the program at a significant cost savings. The program is contracted out to 13 community-based sites across the state. The budget for the program includes approximately \$750,000 from the Social Services Block Grant and approximately \$509,000 in Medicaid billing, which includes the state match.

Evaluation: Partners in Health has an annual family satisfaction survey that has had consistently

high results. Families overwhelmingly report finding value in the services provided and report that they would refer other families to the program.

Will it Work in California: The CYSHCN program is located organizationally outside of the Title V program in the Division of Community-based Direct Services along with mental health and developmental disabilities. The program is a partnership between an academic site, the health department and communities. The program has been sustainable using the Social Services Block Grant and Medicaid targeted case management.

Sources in addition to expert interviews: <http://nhpih.dartmouth.edu>. Retrieved August 24, 2009.

(Note: This program also has relevance for the Respite Care section.)

Additional Care Coordination Sources

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