

## ***Oregon Care COOrdination Program (CaCoon)***

Location: Oregon  
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Category: **Promising Practice**

### **BACKGROUND**

National initiatives around developing comprehensive care and coordination in a medical home, including maternal and child health performance and outcome measures for all Title V programs, highlight the continued need for better coordination for Children and Youth with Special Health Care Needs (CYSHCN). Data from the 2005-2006 National Survey for CYSHCN confirm that Oregon families do not receive needed care coordination even though most families report having a regular source of care.

CaCoon is a community-based care coordination program for CYSHCN administered by the Oregon Center for Children and Youth with Special Health Needs (OCCYSHN) and Oregon's Title V (CYSHCN) program. OCCYSHN contracts with Oregon's local health departments (LHDs) to implement the CaCoon program statewide. Oregon's care coordination program for children with special health care needs has a network of public health nurses who work with families to determine family needs and priorities and to develop a care plan. Public Health Nurses (PHNs) promote optimal child and family outcomes through the practice of care coordination and home visiting. Strengths of the CaCoon programs include its flexibility to meet the changing needs of families and its strong links to community systems. The program was designed in partnership with LHDs and pediatric specialists. It began as a pilot project in three Oregon counties.

### **PROGRAM OBJECTIVES**

The goals of the CaCoon Program are to ensure:

- Access to health care services for CYSHCN
- Increased family confidence/competence in caring for their CYSHCN
- Coordinated care for children with special needs
- Knowledgeable and skilled public health nurses are available to implement care coordination

### **TITLE V/MCH BLOCK GRANT MEASURES ADDRESSED**

**#2:** The percent of children with special health care needs age 0 to 18 years whose families partner in decision making at all levels and are satisfied with the services they receive.

**#3:** The percent of children with special health care needs age 0 to 18 who receive coordinated, ongoing, comprehensive care within a medical home.

**#5:** The percent of children with special health care needs age 0 to 18 who receive coordinated, ongoing, comprehensive care within a medical home.

**#6:** The percentage of youth with special health care needs who received the services necessary to make transitions to all aspects of adult life, including adult health care, work, and independence.

### **TARGET POPULATION SERVED**

The CaCoon program is delivered statewide at the local level in all 36 Oregon counties. Data from the National Survey of Children with Special Health Care Needs (2005-2006), estimates approximately 117,000 children (0 to 17 years of age) in Oregon have special needs. In FY09, 1,858 Oregon children received 7,773 visits from CaCoon nurses.

### **PROGRAM ACTIVITIES**

The strength of this program is the face-to-face contact with families, and assistance with coordinating care tailored to the needs of the child and family circumstances. Providers are typically from the community which they serve and have expertise about the unique issues and challenges relating to accessing services in the local community. CaCoon providers help families navigate barriers and link them with supporting services. PHNs and/or promotoras receive a comprehensive orientation to public health, including the core functions of public health, working with maternal child populations, and working with CYSHCN and families.

**PROGRAM OUTCOMES/EVALUATION DATA**

The CaCoon program collects data about every visit. The encounter data are entered into an electronic database (the Oregon Child Health Information Data System known as ORCHIDS). These data are updated daily and made available to the program for tracking and evaluation purposes.

ORCHIDS supports the collection of key demographic data as well as outcome data on issues addressed by PHNs including nutrition, child development, parenting, injury, and family knowledge of their child’s condition. ORCHIDS data reports also support activities of quality assurance as in setting targets for increasing the percentage of children who have a nutrition screening.

OCCYSHN’s state nurse consultants conduct minimally 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. Local health department capacity and community issues are also addressed. The table below shows the program’s accomplishments from 2008-2009.

	FY2008	FY2009
Number of children served	1,363	1,669
Number of visits by nurse	5,864	7,763

**PROGRAM COST**

Local implementation costs of the CaCoon program varies county by county. This variation depends on variables such as population, density, level of need, and county capacity to contribute financial and/or personnel resources to the CaCoon program. OCCYSHN contracted with the local counties at a total annual cost of \$939,801 in FY09.

**ASSETS & CHALLENGES**

Assets

- In 1989, legislation redefined the mission of the Title V Maternal Child Health Programs to also provide care coordination services to children with special needs and their families in addition to existing programs. The CaCoon program was designed and implemented to reflect this expansion in focus.

Challenges

- Consistency of implementation while allowing flexibility to accommodate to the unique setting and issues within a local community.

- Care Coordination, including access to specialty care and therapies, is challenged by Oregon’s diverse geography, and demographics.

Overcoming Challenges

- To ensure consistency, OCCYSHN developed an Annual Onsite Monitoring Guide to assess the fidelity of implementation with program design and standards. Additionally, the development of a statewide data system has supported improved monitoring of program implementation throughout the year.
- To address the challenge of geography, CaCoon has worked toward increased web-enhanced training and technical assistance, and the center works to contribute to the development of effective models of telemedicine.

**LESSONS LEARNED**

Regular contact with PHN supervisors and prompt responses to their requests for information is necessary to maintain program credibility.

**FUTURE STEPS**

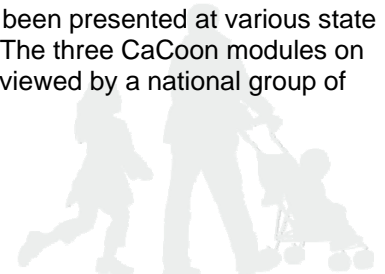
CaCoon is sustained through the continued funding of the OCCYSHN program. Special development projects of the CaCoon program have been funded through grants from private or governmental sources.

**COLLABORATIONS**

- Local public health departments and the Maternal and Child Health Committee of the Conference of Local Health Officials (MCH-CLHO) an organization of local health county department nursing supervisors focused on maternal and child health.
- Early Intervention and Early Childhood Education (Part C), Department of Education, through participation on state and local interagency coordinating councils
- Oregon Title V Maternal and Child Health Program, Oregon Department of Human Services, Division of Public Health, Office of Family Health to assure a coordinated effort around integrated data collection systems as well as maintaining shared communications regarding home visiting programs that complement one another

**PEER REVIEW & REPLICATION**

The CaCoon program has been presented at various state and national conferences. The three CaCoon modules on specific conditions were reviewed by a national group of nursing experts.



The CaCoon program was visited and/or reviewed early on by several states that have gone on to develop a state care coordination program.

### RESOURCES PROVIDED

Some resources produced by the CaCoon Program include the following:

- CaCoon Program Manual, which includes sections on:
  - Family-centered care
  - Family assessment of needs
  - Child health assessment
  - Instructions and recommendations for use of standardized screening tools
  - Information to increase cultural competency relative to disability
  - Community resources
  - Tertiary care center services around the state
- CaCoon Tier Level Assessment Tool – assessing the extent and urgency of health care needs for the child and family. The Tier Level Assessment addresses thirteen areas of evaluation including medical needs and management, parent/child interaction, coping, and housing.
- CaCoon Program Brochure
- Webinar trainings

To find out more about this program, visit:

<http://www.ohsu.edu/cdrc/oscsn/community/nursing1.php>

**Key words:** Care Coordination, CYSHCN, Medical Home, Home Visiting

***\*\*For more information about programs included in AMCHP's Innovation Station database, contact [bp@amchp.org](mailto:bp@amchp.org). Please be sure to include the title of the program in the subject heading of your email\*\****

