



Introduction to CaCoon 2016-17

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Learning Objectives

- Describe a beginning understanding of the population of children with special health care needs.
- Demonstrate a beginning understanding of CaCoon program standards.
- Identify agencies with whom CaCoon may partner in providing care to this population.
- Identify next steps in your own professional development.

Worksheet: “Questions to Consider”

Embedded in this slide presentation you will find a series of “Questions to Consider”. Those same questions are reflected in the Worksheet which you found listed in the “Introduction to CaCoon – Instructions”.

Your responses to the questions will depend on your community setting and your own experience. There are not necessarily “right answers”; think of these questions as discussion-starters.

Acronym Dictionary

- AMCHP = Association of Maternal & Child Health Programs
- ASD = Atrial Septal Defect (or Autism Spectrum Disorder...)
- CCN = Community Connections Network
- CCO = Coordinated Care Organization
- CYSHCN = Children and Youth with Special Health Care Needs
- FERPA = Family Educational Rights and Privacy Act
- HIPAA = Health Insurance Portability and Accountability Act
- LHD = Local Health Department
- OCCYSHN = Oregon Center for Children and Youth with Special Health Needs
- ORCHIDS = Oregon Child Health Information Data System
- OR F2F HIC = Oregon Family to Family Health Information Center
- Title V = Maternal and Child Health Services Block Grants to States

What is CaCoon?

CaCoon is a statewide public health program that focuses on community-based **CAre COordination** for children and youth with special health care needs (CYSHCN) through nurse home visiting.

<http://www.ohsu.edu/xd/outreach/occyshn/programs-projects/upload/CaCoon-Brochure-2014-fillable-2.pdf>



What is Care Coordination?

“Care coordination is the set of activities that occur in **the space between...** the space between providers, between visits, between hospitalizations and the space between organizations.”

Richard C. Antonelli, MD, FS, FAAP, Boston Children's Hospital



Who is eligible for CaCoon services?

- **Age eligibility:** The CaCoon program serves children birth through 20 years of age.
- **Diagnostic eligibility:** The “B Codes” of the Oregon Child Health Information Data System (ORCHIDS) outline diagnostic eligibility.
- **Financial eligibility:** The CaCoon program is open to all children regardless of child or family insurance status or income.

Note: Local CaCoon service providers may not have the capacity to serve everyone who is eligible. Priority for service will be given to the most vulnerable children and families.

Eligibility Criteria – CaCoon B Codes - ORCHIDS

Diagnosis

- B1. Heart Disease
- B2. Chronic Orthopedic Disorders
- B3. Neuromotor disorders including cerebral palsy and brachial palsy
- B4. Cleft lip and palate and other congenital defects of the head, face
- B5. Genetic disorders, e.g. cystic fibrosis, neurofibromatosis
- B6. Multiple minor anomalies
- B7. Metabolic disorders, e.g. PKU
- B8. Spina Bifida
- B9. Hydrocephalus or persistent ventriculomegaly
- B10. Microcephaly and other congenital or acquired defects of the CNS
- B12. Organic speech disorders, e.g. dysarthria/dyspraxia
- B13. Hearing Loss
- B23. Traumatic Brain Injury
- B24. Fetal Alcohol Spectrum Disorder
- B25. Autism, autism spectrum disorder, e.g. PDD, Asperger's
- B26. Behavioral or mental health disorder with developmental delay
- B28. Chromosomal disorders, e.g. Down syndrome
- B29. Positive Newborn Blood Screen
- B30. HIV, seropositive conversion
- B31. Visual Impairment

Very High Risk Medical Factors

- B16. Intraventricular hemorrhage (grade III or IV) or periventricular leukomalacia (PVL) Or chronic subdurals
- B17. Perinatal asphyxia accompanied by seizures
- B18. Seizure disorder
- B19. Oral-motor dysfunction requiring specialized feeding program e.g. Failure to Grow, Organic-Non-organic (medical diagnosis), gastrostomy, nasogastric
- B20. Chronic lung disorder, e.g. tracheostomies, ventilator
- B21. Suspect neuromuscular disorder, e.g. abnormal Neuromotor exam at NICU Discharge

Developmental Risk Factors

- B22. Developmental Delay

Other

B90. Other chronic conditions not listed

Oregon Center for Children and Youth with Special Health Needs

The Oregon Center for Children and Youth with Special Health Needs (OCCYSHN) is **Oregon's Title V** agency for this population.

The Title V Maternal and Child Health Block Grant Program is the nation's oldest federal-state partnership. It aims to **improve the health and well-being of women (particularly mothers) and children.**

<http://www.ohsu.edu/xd/outreach/occyshn/>



OCCYSHN's Mission and Vision

OCCYSHN's **mission** is to improve the health, development and well-being of all of Oregon's children and youth with special health care needs.

OCCYSHN's **vision** is that all of Oregon's children and youth with special health care needs are supported by a system of care that is family-centered, community-based, coordinated, accessible, comprehensive, continuous and culturally competent.



More about OCCYSHN

- OCCYSHN is funded by the Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services (HHS) under Oregon's **Title V Maternal and Child Health Block Grant**.
- OCCYSHN **partners with the Oregon Health Authority** Maternal and Child Health Section in implementing the Title V Block Grant.
- OCCYSHN is **housed on the Marquam Hill Campus** of Oregon Health and Science University (OHSU) in Portland.
- OCCYSHN is **part of the Institute on Development and Disability (IDD)** at Oregon Health and Science University.



Who are the Children and Youth with Special Health Care Needs (CYSHCN)?

“those who have or are at **increased risk** for a chronic physical, developmental, behavioral or emotional condition AND who also require health and related services of a type or amount **beyond that required by children generally.**”

Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Bureau (MCHB)



How Common are Special Health Care Needs?

Approximately 14.6 million children ages 0–17 years in the **United States** (19.8%) have special health care needs.

Data Resource Center for Child and Adolescent Health:

http://childhealthdata.org/docs/nsch-docs/whoarecshcn_revised_07b-pdf.pdf

Approximately 133,000 CYSHN live in **Oregon**

http://www.ohsu.edu/xd/outreach/occyshn/programs-projects/upload/CaCoon-Report-2014_v05_Final.pdf



History of Services to Children with Special Health Needs

1935: Title V of the Social Security Act Enabled each state to extend and improve services for **locating** crippled children, and provided for medical, surgical, corrective and other services and facilities for **diagnosis, hospitalization and aftercare.**

Association of Maternal and Child Health Programs - About Title V:
<http://www.amchp.org/AboutTitleV/Pages/default.aspx>



History of CaCoon

In 1989 the federal government mandated a focus on **community-based systems of care** for children with special health needs .

The CaCoon program was developed over 20 years ago in response to this mandate.

Almost all counties in Oregon provide CaCoon services

Positive Indicators!

Data indicates that children served by the CaCoon program:

- Made fewer visits to the **Emergency Department**
- Had higher rates of **immunization**
- Had higher rates of annual **well child visits**
- Had higher rates of **dental care visits**

[Evidence-Based Outcomes for CSHN](#), [Medicaid Diagnosis Comparison](#), [Emergency Room Use Comparison](#)

CaCoon Standards

The CaCoon Program is based in a series of **standards which are outlined in a contract** between OCCYSHN and the local service provider, usually a Health Department.

[CaCoon Standards 2015-16](#)

Implementing a Triage System

(This is a CaCoon Standard)

The service provider establishes and maintains a **triage system** for home visiting that prioritizes the most vulnerable children with special health care needs

#1 Question to Consider:

What does “vulnerable” mean to you in this context?

Making Timely Contact with Clients

(This is a CaCoon Standard)

The service provider assures initial outreach to CaCoon referrals **within 10 business days** of receiving referral.

#2 Question to Consider:

Why is it important to contact families soon after referral?

Accurate and Appropriate Assessment

(This is a CaCoon Standard)

All nurses serving CaCoon clients **collaborate with the healthcare team** to assure that the following **assessments** are completed for each child/family on the CaCoon caseload:

- Assessment of child/family's strengths, needs, and goals.
- Assessment of child/family's health-related learning needs.
- Assessment of child's functional status and limitations, including ability to attend school and school activities.
- Early and continuous screening for special health care needs including physical, developmental, mental health, and oral health assessments as recommended by the American Academy of Pediatrics.
- Assessment of access to health care team members as well as social supports.
- Assessment of access to supportive medical and/or adaptive equipment and supplies, e.g. suction machine, wheelchair, medications, formula, feeding tube.
- Assessment of family financial burden related to care of child with special health needs.
- Assessment of housing and environmental safety.
- Assessment of emergency preparedness.
- Assessment of preparedness for youth transition to adult health care, work, and independence, if appropriate to age.
- Assessment of child/family satisfaction with services they receive.

Assessment: Questions to Consider

#3 Question to Consider:

*Which of the required assessments do you feel the **most comfortable** with and why?*

*Which of the required assessments do you feel the **least comfortable** with and why?*

#4 Question to Consider:

If the mother of a CaCoon client reports that her child has had a recent developmental screening at their local pediatrician's office, how might the CaCoon nurse demonstrate (assure) that this requirement has been met?

Partnering to Develop the Care Plan

(This is a CaCoon Standard)

In **partnership** with the child/family and the broader health care team, nurses serving CaCoon clients develop the nursing **care plan** which:

- Is based in, and responsive to accurate and appropriate assessments (see above).
- Includes goals, progress notes, and a plan for discharge from CaCoon services.
- Demonstrates evidence of nursing support to increase patient/family engagement with primary care; specifically a patient centered primary care home when available.
- Demonstrates evidence of effective coordination with the primary care physician and specialty providers as well as the broader health care team. Coordination includes:
 - Timely and appropriate referral to needed services.
 - Identification and problem-solving around barriers to referral follow-up.
 - Identification and elimination of redundancy of services.
 - Promotion of a shared and actionable plan of care that speaks to the continuum of child/family experience with healthcare and related systems.
 - Timely, informative, and concise updates that are shared with appropriate members of the health care team, including the primary care provider and the family.

Partnering to Develop the Care Plan (cont'd)

- Demonstrates evidence of patient/family centeredness, including:
- Strategies to increase the child/family's capacity to obtain, process, and understand health information to make informed decisions about health care
 - Evidence of child/family partnership in developing the plan of care
 - Evidence of interventions that increase the patient/family's capacity to implement the plan of care, e.g. caregiver support, teaching, and provision of anticipatory guidance.
 - Cultural and linguistic responsiveness
- Provides for nurse visits that are sufficient in frequency and length to achieve the goals outlined in the care plan.
- Anticipates and supports youth transition to adult health care, work, and independence.
- Is re-evaluated as required with changing circumstances, but no less frequently than every six months.

Care Plan: Questions to Consider

#5 Question to Consider:

What steps might you take to promote a shared and actionable plan of care (one which demonstrates effective coordination with the primary care physician and specialty providers, and with the broader health care team)? Be specific.

#6 Question to Consider:

How might your nursing care plan demonstrate evidence of nursing support to increase patient/family engagement with primary care?

Health Literacy

Health literacy is a foundation for **effective partnership with families.**

Health literacy is defined as the ability to obtain, process, and understand basic health information and services needed to make appropriate decisions.

#7 Question to consider:

What are two strategies described in the AHRQ Health Literacy Toolkit that you will use to increase your effectiveness in partnering with families?

<http://www.ahrq.gov/sites/default/files/wysiwyg/professionals/quality-patient-safety/quality-resources/tools/literacy-toolkit/healthlittoolkit2.pdf>

Who's on Your Team?

(Community Partners)

- *Coordinated Care Organizations*
<http://www.oregon.gov/oha/OHPB/Pages/health-reform/certification/index.aspx>
- *Oregon - Patient-Centered Primary Care Home:*
<http://www.oregon.gov/oha/pcpch/Pages/index.aspx>
- *Early Intervention (EI/ECSE)*
http://www.ode.state.or.us/gradelevel/pre_k/eiecse/dyhcfinalenglish.pdf
- *Women, Infants and Children Special Supplemental Nutrition Program (WIC):*
<http://public.health.oregon.gov/HealthyPeopleFamilies/wic/Pages/index.aspx>
- *Early Hearing Detection and Intervention (EHDI)*
<http://public.health.oregon.gov/PHD/Directory/Pages/program.aspx?pid=81>

Team (cont'd)

- *Developmental Disabilities (DD):*

<http://www.oregon.gov/dhs/DD/Pages/index.aspx>

- *Social Security Income (SSI):*

<http://www.socialsecurity.gov/pubs/EN-05-10026.pdf>

- *Children's Mental Health System – Oregon*

<http://www.oregon.gov/oha/amh/Pages/children-mental-health.aspx>

- *Oregon - Early Learning Hubs:* <http://oregonearlylearning.com/other-priorities/community-based-coordinators-of-early-learning-services-hubs/current-early-learning-hubs/>

#8 Questions to Consider:

Do you understand the roles of your partner agencies?

Do you know how to contact/refer to them?

What other agencies, if any, might you expect to partner with?

Using Data for Quality Improvement

(This is a CaCoon Standard)

The service provider works with partners, at both the state and local level, to **collect data** to inform system-level quality improvement efforts and achieve optimal health outcomes for CYSHCN.

#9 Question to consider:

What methods does your agency use to track data?

Documentation and Forms

The CaCoon Toolbox contains a number of documents and forms that may be helpful to you:

<http://www.ohsu.edu/xd/outreach/occys/hn/programs-projects/introduction.cfm>

However, with the exception of the Tier Tool **specific forms are not required.**

The CaCoon program does require your charting to demonstrate that you are meeting:

- CaCoon **contract standards**
- Oregon State Board of Nursing **(OSBN) standards of practice**

CaCoon Manuals

CaCoon Manual (2012)

http://www.ohsu.edu/xd/outreach/occyshn/programs-projects/upload/Reduced-Size-Manual_CaCoonProgram_2012_0216.pdf

CaCoon Manual for ORCHIDS:

https://public.health.oregon.gov/HealthyPeopleFamilies/DataReports/ORCHIDS/Documents/orchids_manual_cacoon.pdf

OCCYSHN Resources

- [Shared Plan of Care \(SPoC\)](#): Some CaCoon clients may be well served by a shared plan of care. A SPoC promotes cross-system, family-centered care for those children and youth with special health needs who are best served by a team-based approach.
- [Community Connections Network \(CCN\)](#)
Multidisciplinary teams that meet across the state to serve specific children and to address community needs
- Coffee Time Consultations: Short webinars providing medically-focused information related to the care of CYSHN.
<http://www.ohsu.edu/xd/outreach/occyshn/training-education/index.cfm>
- [Family Involvement Network](#)
 - [Oregon Family-to-Family Health Information Center](#)
 - [Family Voices](#)
- [Community-based ASD Identification](#)
Supporting the building of local medical-education ASD identification teams.

#10 Question to Consider:

What is one important thing you learned about resources related to family involvement? Why do you find this important?



Clinical Resources

- American Academy of Pediatrics – Bright Futures: [http://brightfutures.aap.org/tool and resource kit.html](http://brightfutures.aap.org/tool_and_resource_kit.html)
- Improving the transition from pediatric to adult health care <http://www.gottransition.org>
- Ages & Stages Questionnaires (ASQ): <http://agesandstages.com/>
- Swindells Care Notebook and Organizer: <http://oregon.providence.org/our-services/s/swindells-resource-center/forms-and-information/swindells-care-notebook-and-organizer>
- Growth charts – Centers for Disease Control: <http://www.cdc.gov/growthcharts/>
- Implementation of a Shared Plan of Care for CYSHCN: <http://lpfch-cshcn.org/wp-content/uploads/2014/04/Achieving-a-Shared-Plan-of-Care-Implementation-Guide.pdf>

Let's Practice!

Case Study (1/5 slides)

Your office receives a referral for a baby girl who was born in the local hospital on New Year's Day at 35 weeks gestation. The referral states that the baby, her parents' first child, is diagnosed with Down syndrome, an atrial-septal defect (ASD), and gastro-esophageal reflux disorder (GERD). She was discharged from the hospital on January 15th and your office received the referral on January 16th. She lives in a part of the county that you are not very familiar with.

#12a Question to Consider:

Does this child qualify for CaCoon? Why or why not?

#12b Question to Consider:

What are the first things you need to do to follow up on this referral and prepare yourself to visit?

Case Study (2/5 slides)

You go out to the home for your first visit with this family.

When you pull up in the driveway you see a single wide mobile home, various vehicles and a very large dog. After a few minutes a man comes out of the home and calls the dog in and waves to you. You get out of your car, gather your scale and other needed supplies for the home visit, and head for the door. The man introduces himself as John Jones, the baby's dad, and welcomes you into the home.

When you enter the mobile home you immediately notice it is warm and well-furnished with lots of baby equipment around. John shows you where to sit and lets you know his wife Shirley and the baby, Mandy, will be out in a few minutes. While you are waiting you notice the pictures on the walls, of what looks like a big extended family and lots of vacation photos.

Case Study (3/5 slides)

Shirley and the baby enter the living room from the back hallway. Shirley looks tired but is smiling and seems happy to see you. She explains that they are still adjusting to their routine, not sleeping much at night and sleeping more during the day. She explains she is up often to feed baby. She is pumping and fortifying her breast milk as the baby does not latch well and is slow to gain weight. Mandy is awake but drowsy and Shirley reports she just fed her two ounces of breast milk with formula added to make it 24 kcal/oz.

John goes back outside “to finish some chores”. You and Shirley complete the necessary nursing assessments to check weight, length and head circumference and you plot this on a growth chart so Shirley can see how Mandy is doing. You educate Shirley on how to adjust for Mandy’s prematurity and explain that you are using a special growth curve for children with Down syndrome. You talk to her about feeding, fortifying formula, Mandy’s bowel movements and ask if she has any concerns. Shirley states that Mandy does spit up a lot after feeding especially if she lays her down right after feeding. She tells you “the doctor thinks she might have some stomach reflex and he might give us some medicine if it does not get better”.

Case Study (4/5 slides)

As you continue your assessment, you ask what Shirley knows about Down Syndrome and how she is doing with that information. Shirley reports that “the people at the hospital were great and I read most of the information they gave me, but I still have a lot of questions. My aunt told me that babies with Down Syndrome are generally very cheerful, and Mandy seems to be a happy baby. But I feel like she might be more fragile than other babies; maybe she will catch cold more easily? I just don’t know. Are there other kids with Down Syndrome in our town? Could I talk with their moms? Also, people are using lots of words I haven’t heard before, like ASD and GERD. And I get so confused about all the different kinds of doctors! Heart doctors and stomach doctors, and what is a gastroenterologist? Who is going to keep track of all this? Also, we are getting worried about how much everything is going to cost. We are on the Oregon Health Plan and they tell me that there is some organization that coordinates care. What does that mean? I just want to take care of my baby!”

Case Study (5/5 slides)

John comes in to sit with you and Shirley and the two of them tell you that they had not had a prenatal diagnosis of Down Syndrome. It was a shock when the doctors took Mandy away for additional testing after she struggled to breathe shortly after birth. They understand she will have developmental delays and they want to do everything they can for their daughter to give her the best possible future. Shirley would like help getting connected to resources and being sure that they are not forgetting any areas to watch. The family does not have a lot of money and they anticipate lots of copays, deductibles and extra gas expenses for her many appointments.

John and Shirley would like to know how you are going to help them and their baby.

Questions to Consider

#12c Question to Consider:

What do you know for sure about this situation?

#12d Question to Consider:

What else do you need to know and how will you get the information you need?

#12e Question to Consider:

What will be your beginning priorities in working with this child/family?

The End!

Remember to:

- **Complete the accompanying document, “Introduction to CaCoon - Worksheet”**
- Review your answers with your supervisor.
- Send the completed document to me via email.
- Suggest a minimum of three options for a date/time that you AND your supervisor can be available for a 30-60 minute follow-up phone conference with me.

I look forward to talking with you and your supervisor very soon!

Caroline

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