DEVELOPING AND SUSTAINING CHILD HEALTH TEAMS

March 2019

OCCYSHN
Oregon Center for Children and Youth with Special Health Needs
OHSU

ABOUT THIS TOOLKIT

Child Health Teams bring together families and professionals to plan and coordinate care for children with unmet health care needs. Teams typically consist of a local physician, and representatives from education, mental health, public health, developmental disabilities, and other community services. They meet with individual families to develop clear care plans that address unmet needs. Community Connections Network (CCN) was an OCCYSHN program that adopted a Child Health Team model. These local teams served children with special health needs in rural and semi-rural Oregon for over twenty-five years. While the program ended in 2017, several teams secured funding elsewhere and continued their work.

Today, the lessons learned from the CCN program have informed OCCYSHN's shared care planning initiative in the context of standing care coordination teams for children and youth with special health care needs. An important aspect of CCN child health teams was the development of local communities of practice, defined by the National Wraparound Initiative as ***"people [who] come together out of a shared passion for a topic and a desire to achieve change, improve existing practices, and/or identify and solve problems in a specific domain of knowledge. The community of practice provides members with opportunities for collaborative reflection, dialogue, and inquiry, allowing them to share expertise and resources, learn from each other, and solve problems."***[1] Professionals on CCN child health teams learned from one another and built relationships. This helped them leverage local resources more effectively.

Included in this toolkit are resources to help community professionals build and sustain child health teams. Resources for families regarding child health teams and other topics can be found on the Oregon Family to Family Health Information Center's website at www.oregonfamilytofamily.org. For individual copies of the materials in this toolkit or for more information on child health teams, contact our center at occyshn@ohsu.edu or (503) 494-8303.

[1] Walker, J. S., Bruns, E. J., Conlan, L., & LaForce, C. (2011). The National Wraparound Initiative: A community of practice approach to building knowledge in the field of children's mental health. *Best Practices in Mental Health: An International Journal, 7*(1), 26–46.

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All OCCYSHN programs strive to meet the standards recommended by the Association of Maternal and Child Health Programs (AMCHP) in their report, *The National Standards for Systems of Care for Children and Youth with Special Health Care Needs (Version 2.0).*[2] The CCN program aimed to address these standards and inform program development using a patient- and family-centered care coordination framework first put forth in a publication of *Pediatrics*.[3]

In addition, the child health team model provided a foundation for OCCYSHN's shared care planning initiative, adapted from a report by Jeanne McAllister, BSN, MS, MHA, from the Lucile Packard Foundation for Children's Health.[4] The following pages provide an example of some talking points used to communicate the value of the CCN program as well as an overview of the broader child health team model. Although each CCN team was unique to each community it served, all teams adopted a child health team approach.

BACKGROUND

[2] Association of Maternal and Child Health Programs (2017). *Standards for Systems of Care for Children and Youth with Special Health Care Needs, Version 2.0*. Retrieved February 26, 2019, from https://www.lpfch.org/publication/standards-systems-care-children-and-youth-special-health-care-needs-version-20

[3] Turchi, R. M., Antonelli, R. C., Norwood, K. W., Adams, R. C., Brei, T. J., Burke, R. T., ... & Levy, S. E. (2014). Patient- and family-centered care coordination: A framework for integrating care for children and youth across multiple systems. *Pediatrics, 133*(5), e1451-e1460. https://doi.org/10.1542/peds.2014-0318

[4] McAllister, J. W. (2014). Lucile Packard Foundation for Children's Health. *Achieving a Shared Plan of Care with Children and Youth with Special Health Care Needs*. Retrieved from https://www.lpfch.org/sites/default/files/field/publications/achieving_a_shared_plan_of_care_full.pdf

The Child Health Team Model

Coordinating Care Across Systems for Children with Special Health Care Needs

What do child health teams do?

Child health teams bring together families and professionals to plan and coordinate care for children with unmet health care needs. Child health teams typically consist of a local physician, and representatives from education, mental health, public health, developmental disabilities, and other community services. The team meets with each family to develop a clear care plan that addresses unmet needs. The plan identifies who is agreeing to do what, by when. It can be adjusted as needed over time.

Which children benefit most from a child health team?

The children and families best served by the process are those with especially complicated circumstances. These families may face financial, cultural or other barriers to using local resources effectively. They benefit from extra support determining what services are needed, where those services are available, and how to access them. Having a team of the child's health and service providers meet with the family helps ensure a coordinated, comprehensive plan to address unmet needs.

September 2016

Community Connections Network (CCN) has used a child health team model to provide care coordination services to children and youth with special health care needs (CYSHCN) in Oregon communities for over 20 years.

Often there are multiple health and service providers working on behalf of particularly vulnerable CYSHCN and their families. Caring for these children can be especially costly for insurers if it is not well-coordinated, and if families don't get the support they need. Child health teams provide care coordination across these various systems (like education, mental health, developmental disabilities, community services, and specialty and primary health care).

Child health teams provide a forum for providers to collaborate with each other, and with the child's family. This collaboration holds the promise of delivering care more efficiently and effectively. In-kind efforts from diverse groups of local professionals demonstrates the momentum of the program, and the value these professionals find in child health teams.

Institute on Development & Disability
Oregon Center for Children and Youth with Special Health Needs
503-494-8303 occyshn@ohsu.edu www.occyshn.org
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The child health team approach aligns with Patient-Centered Primary Care Home (PCPCH) standards and measures, which in turn align with the coordinated care model being implemented by Oregon's CCOs. Child health teams support PCPCHs by linking CYSHCN to services and care coordination. PCPs are invited to participate in and inform the child health team process. Teams help families access services and support, and provide them with current and relevant resources.

Child health teams help PCPCHs meet accountability measures[1] for CYSHCN by addressing complex care coordination and care planning (5.c.2 and 5.c.3) and by implementing screening strategies for developmental conditions, and referring to local resources to address those conditions (3.c.0).The child health team approach is also grounded in the National Standards for Systems of Care for CYSHCN.[2]

Community Connections Network child health teams were supported by the Oregon Center for Children and Youth with Special Health Needs (OCCYSHN), which is Oregon's Title V Agency for CYSHCN. OCCYSHN is funded by an annual block grant from the federal Maternal and Child Health Bureau (MCHB).

With some support this time-tested model could be applied statewide to help CCOs and others meet their healthcare transformation goals. The principles and practices of child health teams can be adapted to address the needs of individual communities.

DATA SNAPSHOT

- 28% of Oregon CYSHCN live in rural or frontier areas, often far from specialty care and services.
- 49% of Oregon CYSHCN experience two or more chronic conditions.
- Spanish is the primary language spoken in the homes of nearly 5% of Oregon CYSHCN.
- The most commonly reported unmet need for CYSHCN is mental health care or counseling.
- Parents of CYSHCN in Oregon were three times more likely than other parents to report that they could have used more help coordinating their child's care.
- 64% of Oregon youth did not get the services they needed for a successful transition to adult health care.

Sources for this data can be found in OCCYSHN's 2015 Needs Assessment Report, available online at www.occyshn.org.

More information on the community/ child health team model:

- National Academy of State Health Policy
- Care Management for Medicaid Enrollees through Community Health Teams
- Supporting Iowa Rural Provider Capacity Through Community Care Coordination Teams

To learn more about sustaining a child health team in your community contact Marilyn Berardinelli at OCCYSHN: (503) 494-8303, occyshn@ohsu.edu

[1]https://www.oregon.gov/oha/pcpch/Documents/TA-Guide.pdf

[2] VanLandeghem, K., Sloyer, P., Gabor, V., & Helms, V. (2014). Standards for systems of care for children and youth with special health care needs. A product of the National Consensus Framework for Systems of Care for Children and Youth with Special Health Care Needs project. Washington, DC: Association of Maternal & Child Health Programs

The following section provides tools for team building and developing ways to work together. These materials comprise the foundation of a functioning child health team, such as a care plan template; a draft brochure with sample information and talking points about your child health team to share with families in your area; team standards; an example HIPAA/FERPA Release of Information (ROI) template; and facilitation guides. In addition, this section includes Parent Partner materials, such as guiding questions for teams regarding Parent Partners and team sustainability; the role of a Parent Partner on a child health team; and a sample Parent Partner job description.

TEAM BUILDING AND TEAM OPERATING RESOURCES

ABOUT THIS TOOL — *Care Plan Template*

Shared care planning is an approach to coordinating care for children and youth with special health care needs (CYSHCN). It is called "shared" care planning because families and professionals share the work of creating a care plan and putting it into action. OCCYSHN has adopted this approach within its CaCoon Home-Visiting program and other efforts. A shared plan of care template is included in this section to guide child health teams in care planning for CYSHCN in their communities.

For Microsoft Word or fillable PDF versions of the sample templates, contact our center at occyshn@ohsu.edu or (503) 494-8303.

Shared Plan of Care
For Children and Youth with Special Health Needs

TEAM MEETING LOCATION:	MEETING DATE:
CHILD/YOUTH NAME:	CHILD/YOUTH LIKES TO BE CALLED:
GENDER IDENTITY: ☐ M ☐ F ☐ OTHER	DATE OF BIRTH:
PARENT(S):	PARENT PHONE #:
PRIMARY CARE PROVIDER:	PRIMARY CARE PHONE #:
REFERRED BY:	NECESSARY RELEASES OBTAINED ☐ YES ☐ NO

Child/Family Strengths and Assets

Child/Family Language and Cultural

Child/Family Concerns and Goals

For today:

For the longer term:

Shared Plan of Care
For Children and Youth with Special Health Needs

Brief Medical Summary

Brief Summary of Involvement with Community-Based Services (including education)

Developed by: Oregon Center for Children and Youth with Special Health Needs (OCCSYHN), August 2016

Phone: 503-494-8303 | Email: occyshn@ohsu.edu

Includes original and adapted content from:

- Jeanne W. McAllister. May, 2014. *Achieving a Shared Plan of Care with Children and Youth with Special Health Care Needs: An Implementation Guide.* Lucile Packard Foundation for Children's Health.
- Taylor EF, Lake T, Nysenbaum J, Peterson G, Meyers D. Coordinating care in the medical neighborhood: Critical components and available mechanisms. White Paper (Prepared by Mathematica Policy Research under Contract No. HHSA29020090000191TO2). AHRQ Publication No. 11-0064. Rockville, MD: Agency for Healthcare Research and Quality. Jun 2011.
- Community Connections Network –Shared Care Plan (Community Connections Network is a program of The Oregon Center for Children and Youth with Special Health Needs)

This project 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 (#B04MC28122, in the amount of $1,859,482) and the "Enhancing the System of Services for Oregon's CYSHCN" grant (#D70MC27548, in the amount of $300,000). The project receives no nongovernmental funding. This information or content and conclusions are those of the author and should not be construed as the official position or policy of, nor should any endorsements be inferred by HRSA, HHS, or the U.S. Government.

Team Member Contact List

(Add lines as needed)

Name (Initial to note attendance at meeting)	**Role/Responsibility**	**Best way to contact**
	Family member(s):	
	Primary Care Provider(s):	
	Education:	
	Mental/Behavioral Health:	
	Public Health:	
	Health Plan/Insurance:	
	Subspecialty Provider:	
	Subspecialty Provider:	

ACTION PLAN

(Add lines as needed)

- The first goal of the team should be one that the family has identified as a priority.
- If the child/youth is aged 12 or older, include a minimum of one goal focused on the transition to adult healthcare.

SHARED GOAL	Who?	Is doing what?	By when?
Goal:	This person	Will take this action	By this date (date completed)
	This person	Will take this action	By this date (date completed)
	This person	Will take this action	By this date (date completed)
	This person	Will take this action	By this date (date completed)
	This person	Will take this action	By this date (date completed)
	This person	Will take this action	By this date (date completed)
	This person	Will take this action	By this date (date completed)
Date identified:			
Date achieved:			

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(Add lines as needed)

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	This person	Will take this action	By this date (date completed)
	This person	Will take this action	By this date (date completed)
Date identified:	This person	Will take this action	By this date (date completed)
Date achieved:			

CHILD/YOUTH NAME:	DATE OF BIRTH:	TEAM MEETING DATE:
PARENT(S):	PHONE #:	SITE:
PRIMARY CARE PROVIDER:	REFERRED BY:	

HEALTHCARE PROVIDER NOTES:

Healthcare Provider Printed Name

Healthcare Provider Signature

ABOUT THIS TOOL — *Sample Brochure*

An important aspect of sustaining a child health team is communicating its value to those it serves: families. One way to communicate value is through outreach materials, or "marketing," for your team. We included a sample brochure template as one example, with a format and talking points that teams can adapt for their own purposes.

For a Microsoft Word version of the sample template, contact our center at occyshn@ohsu.edu or (503) 494-8303.

Helping your youth with special health needs prepare for the future.

Child Health Teams serve children from birth to young adulthood (age 21).

The transition from pediatric to adult health care can be complicated. As they approach adulthood, young people with special health needs sometimes need help building the skills to manage their adult health care.

Youth and young adults with special health needs might need guidance on finding adult health care providers, making and keeping medical appointments, managing medications, and using health insurance.

A Child Health Team can help you your youth organize and prepare for adult health care.

Contact Us

Name of your organization

Address

Phone

Email

Website

NOTE: This layout is for a trifold brochure. If you print this document on both sides and fold the resulting page into thirds, this section will end up on the back of the brochure.

NOTE: This is sample brochure. Please check all text before using, and edit each section so that the information is accurate for your team. This sample brochure is not available in Spanish, because it needs to be customized for each team.

Families and professionals working together for children and youth with special health needs.

Child Health Teams in YOUR AREA HERE

Concerned about your child?

A Child Health Team can help.

Do you have concerns about your child's health or development? Have you ever wished your child's doctor knew more about what went on at school, or that the teacher knew more about your child's health? Maybe you've wished everyone had a more complete picture of the child you know and love. Your local Child Health Team can help put those pieces together.

A Child Health Team meeting brings your family together with people from health, school, and community services. You all sit together at the same table to talk about how your child is doing at home, at school, and with friends.

There might be a number of things affecting your child's health or development. The Child Health Team looks at the whole picture. If your child has unmet needs, the Child Health Team will work with you on a plan to get those needs met.

What will the Child Health Team do?

- The team doctor will evaluate your child before the team meets, or review medical records and talk with your child's doctor about any health issues.
- At the health team meeting, you and the rest of the team will talk about how your child is doing at home, in school, and in the community.
- You and the rest of the team will create a care plan to address your child's needs.
- Referrals to specialists will be made, if needed.
- You will be connected with information, resources, and support.
- You can request a follow-up meeting if needed.
- A Parent Partner (another parent of a child with special health needs) will give you information and support before, during, and after the meeting (for as long as you find it helpful).

Who can use a Child Health Team?

Any family who has a child (age 0-21) with a health concern can request a Child Health Team meeting. Those concerns can be about physical, emotional, cognitive, or behavioral issues.

How can I get a Child Health Team for my child?

You or someone who works with your child (a teacher, doctor, therapist, etc.) can call to learn more, and to make a referral. There is no cost to families for Child Health Team services.

NOTE: If insurance is billed for team services, there could be copays for families. Edit accordingly!

ABOUT THIS TOOL — *Sample Team Standards*

To serve as a reference when developing standards for your child health team, we included the contractual standards used for the CCN program. The standards document begins by laying out the mission, vision, purpose, and goals of the child health team. The document then includes sample language for defining your team's Scope of Work as well as major team roles. Finally, sample language for standard operating practices of a child health team are listed. The proceeding tool, ***Child Health Team Values & Processes***, will come in handy when developing standards.

Community Connections Network Standards

OCCYSHN Mission: The Oregon Center for Children and Youth with Special Health Needs (OCCYSHN) improves the health, development and well-being of all of Oregon's children and youth with special health care needs.

OCCYSHN Vision: All of Oregon's children and youth with special health care needs (CYSHCN) are supported by a system of care that is family centered, community-based, coordinated, accessible, comprehensive, continuous and culturally competent.

The CCN Child Health Team: Engaged families and competent professionals partner in effective teams to ensure that all children and youth with special health care needs receive the integrated and high quality health-related services they require in order to thrive.

Population Served by the CCN Child Health Team:

Children and youth, through 20 years of age, 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.

Goals:

- Implement effective Child Health Teams which center on children and youth with special health needs (CYSHCN) and their families
- Increase family knowledge, skills, and confidence in caring for their children and youth with special health care needs
- Increase the capacity of communities to meet the needs of children and youth with special health care needs
- Work across systems to ensure comprehensive and coordinated services for every child

SCOPE OF WORK

The contracting organization will:

1. Build a CCN Child Health Team and maintain its membership.

2. Convene Child Health Team meetings on a regular basis, ensuring continuity of process, including receiving new referrals, following up on open shared care plans[1], and addressing the system of care. A minimum of 8 team meetings will be conducted per contract year.
    a. The Child Health Team will follow the CCN Team Meeting Facilitation Guide in conducting monthly team meetings. The guide provides structure and topical areas to address.

3. Convene a minimum of ___ child/family visits per contract year. Visits may be for children who are newly referred or for follow-up visits.
    a. The Child Health Team will follow the CCN Child/Family Visit Facilitation Guide in conducting visits with families.
    b. The Child Health Team will create an individualized shared care plan for each child and one which collaboratively addresses the full continuum of health and health-related needs, including medical, educational and community-based service needs.

4. Convene a CCN Child Health Team meeting for a referred family within a month of accepting the referral into CCN.

5. When a referral to the Child Health Team cannot be prioritized due to lack of team capacity, the team will, at a minimum,
    a. Refer the child/family to their local PCPCH[2] or Primary Care Provider (PCP), (if PCPCH is not available) and appropriate community-based services
    b. Collaborate to link the child/family to evaluative services.
    c. Maintain regular communication with the family to determine whether needs have been resolved. At a minimum, the Parent Partner will communicate with the family every 3 weeks.
    d. Track referrals for community-based services through the Parent Partner.
    e. Convene a Child Health Team meeting at a future date, as needed.

6. Reporting:
    a. Within 1 week of meeting, two forms will be sent securely to OCCYSHN:
        i. CCN Child/Family Visit Reporting Form
        ii. CCN Team Activity Reporting Form
    b. CCN Care Plan Tracking form will be faxed to OCCYSHN when a shared care plan is closed.
    c. Updated and cumulative CCN Rosters will be faxed to OCCYSHN in January and June.
    d. In May or June of each year, the Child Health Team will review accomplishments related to the standards, record them on the CCN Child Health Team Self-Assessment Tool, and send the form to OCCYSHN.

Roles:

The CCN Child Health Team Coordinator will provide administrative support to the team. He or she will:

a. Coordinate Child Health Team meetings, including administrative tasks related to team operations, pre-meeting day logistics, meeting day activities, and post-visit follow up
b. Communicate with families of children referred to the Child Health Team to coordinate and implement child/family visits.
c. Create comprehensive files for children referred to the Child Health Team in line with Health Insurance Portability and Accountability Act (HIPAA) and Family Educational Rights and Privacy Act (FERPA) requirements. Files include records from medicine, education and community-based services.
d. Disseminate reports and shared care plans appropriately and communicate with community partners as needed to ensure effective team meetings and coordination of care.
e. Find referrals to the Child Health Team through marketing and networking.
f. Coordinate shared care plan tracking with the Parent Partner.
g. Submit program data forms to OCCYSHN and facilitate data collection, as requested by OCCYSHN, e.g. program evaluations, etc.
h. Participate in CCN Child Health Team learning opportunities provided by OCCYSHN.

The Professional Adjunct to the CCN Child Health Team will contribute his or her understanding of the local system of care to the health team process. He or she will:

a. Increase awareness in the community of Child Health Team activities.
b. Find referrals to the Child Health Team through marketing and networking.
c. Communicate with community partners as needed to ensure effective team meetings and coordination of care.
d. Support the Child Health Team Coordinator in identifying providers to attend child-specific health team meetings, in completing reports, and in problem-solving related to team operations.
e. Facilitate meetings or identify a team member to facilitate meetings.
f. Write or review shared care plans.
g. Follow up with the family, Parent Partner, the Child Health Team and the Referral Source regarding implementation of the shared care plan and success of team recommendations, as appropriate.
h. Facilitate data collection, including program data forms and program evaluations required by OCCYSHN.
i. Help to build and maintain membership on the Child Health Team.
j. Participate in Child Health Team learning opportunities provided by OCCYSHN.

CCN CHILD HEALTH TEAM STANDARDS:

1. A CCN Child Health Team is made up of, at a minimum, local health care providers, educators, a Parent Partner, and community service providers in partnership with families.

2. The local child health team develops strategies to identify CYSHCN to be referred to the child health team.

3. Referrals to the Child Health Team:
    a. The Child Health Team establishes and maintains a process for prioritizing the most vulnerable children with special health care needs. If Child Health Team capacity is a consideration, priority will be given to:
        i. Families who report their child has unidentified needs related to health and development.
        ii. Families who report difficulty accessing or coordinating their child's care and services.

4. The Child Health Team ensures contact with the family of a child referred to the team within 10 business days of receiving the referral.

5. Child Health Team members collaborate or refer to ensure unresolved needs are assessed and addressed for individual children and families.

6. When a referral to the Child Health Team results in a child/family visit, the team, in partnership with the family, develops an actionable shared care plan that speaks to the continuum of the child/family experience with healthcare and related child-serving systems. The shared care plan:
    a. Is founded in and responsive to accurate and appropriate assessment of needs.
    b. Demonstrates evidence of engagement with a Patient-centered Primary Care Home (PCPCH) or with a PCP, if there is no PCPCH.

c. Demonstrates evidence of effective coordination with the primary care physician and specialty providers, as well as the broader health care team, e.g. education, mental health, developmental disabilities, child care, housing, transportation, and financial support.
d. Demonstrates evidence of child/family centeredness, including:
    i. Strategies to increase the child/family's capacity to obtain, process, and understand health and health-related information to make informed decisions about health care and developmental needs.
    ii. Evidence of shared agenda setting and decision-making with the child/family.
e. Is culturally and linguistically appropriate.
f. Supports youth transition to adult health care, work and independence.
g. Encourages families to make a follow-up appointment with PCPCH (or PCP, if no PCPCH is available) to discuss the shared care plan.
h. If there are barriers to following up with the PCPCH (or PCP, if no PCPCH), the Child Health Team will address them.
i. Is reviewed and acted upon monthly, with the Parent Partner's input on the ongoing or changing needs of the family, as well as the input of the Child Health Team members.

7. The Child Health Team supports the child's/family's ability to implement the shared care plan, e.g. by providing health and health-related information, resources, referrals, and social supports.

8. The Child Health Team reviews the standards annually.

9. The Child Health Team demonstrates evidence of continuous quality improvement efforts in service of CYSHCN.

10. Child Health Team members collaborate to identify and solve systems-level problems for the population of CYSHCN.

[1]McAllister, JW. (2014) Achieving a Shared Plan of Care with Children and Youth with Special Health Needs. Lucile Packard Foundation for Children's Health. Retrieved 7-10-15 from http://lpfch-cshcn.org/wp-content/uploads/2014/04/Achieving-a-Shared-Plan-of-Care-Full-Report.pdf

[2]A Patient-Centered Primary Care Home is a health care clinic that has been recognized for their commitment to care that is accessible, accountable, comprehensive, continuous, coordinated and patient- and family-centered. To learn more: http://www.oregon.gov/oha/pcpch/Pages/index.aspx

ABOUT THIS TOOL — *Team Values & Processes*

Deciding on the values and processes your team will actively work to preserve is another important step when establishing a child health team. This tool was originally developed for the CCN program, but your team may decide to adapt it for their own purposes. You may also use it to spur new ideas. To guide your team's thinking, refer to this checklist for examples of values and processes.

Child Health Team Values & Processes

Which values will your child health team actively work to preserve?

Some past examples of **values** used by Community Connections Network teams to guide their work include:

- ☐ Child health team members come to the table to collaborate and ensure that families have access to needed care and services for their child. The team supports families in accessing services and resources.
- ☐ Team success depends on mutual trust and respect among all team members.
- ☐ The input of all team members is valued equally.
- ☐ The team process allows the family's needs to be heard, validated and supported in a safe, nurturing and neutral environment and in partnership with professionals.

Which processes will your child health team actively work to preserve?

Some examples of important **processes** to develop in a standing care coordination team include:

- ☐ Developing partnerships for membership on the standing care coordination team
- ☐ Establishing ground rules for discussion
- ☐ Determining leadership responsibilities for each meeting
- ☐ Determining shared care planning meeting logistics
- ☐ Setting meeting agendas
- ☐ Determining how decisions will be made
- ☐ Recording team decisions
- ☐ Establishing a set of values from which the team works
- ☐ Establishing roles or responsibilities for team members
- ☐ Establishing a facilitation process for shared care planning meetings
- ☐ Establishing a process for addressing the development and management of the team's care planning program as a whole
- ☐ Determining how a parent partner may be part of the team
- ☐ Determining the sub-population of CYSHCN who will best be served by the team process (repeated under population teamwork)
- ☐ Establishing a process to develop referrals
- ☐ Establishing a process to receive referrals
- ☐ Establishing and maintaining a triage system for referrals
- ☐ Establishing a process for reaching out to the families of CYSHCN referred to the team
- ☐ Establishing a process for assessing family readiness for care coordination
- ☐ Establishing a process for assessing family and youth goals
- ☐ Establishing communication with care team members
- ☐ Developing a process for pre-populating the shared care plan
- ☐ Identifying the child or youth's medical neighborhood
- ☐ Performing pre-visit/home visit contact with the family
- ☐ Developing your description of your role, reason for referral

Child Health Team Values & Processes

- ☐ Developing process for reviewing diagnosis, assessments, medical records
- ☐ Determining a process for preparing families to participate in the share care planning process
- ☐ Establishing a process for doing or obtaining assessments needed to address family/youth goals
- ☐ Establishing a process for the actual co-production of a shared care plan with a family
- ☐ Determining the sub-population of CYSHCN who will best be served by the team process
- ☐ Establishing a process for reviewing open care plans, including tracking actions and updating plans
- ☐ Establishing a portion of regular meetings to foster team sharing of knowledge, insights and solutions at the systems level
- ☐ Establishing process for consulting with experts
- ☐ Discussing and analyze programmatic adjustments
- ☐ Using complexity scale to describe population needs
- ☐ Establishing criteria or procedures for “discharging” a child or family from shared care planning
- ☐ Establishing a process for identifying ongoing care coordination after discharge, if needed
- ☐ Establishing a process for continuous quality improvement of the shared care planning process

ABOUT THIS TOOL — *Annual Team Self-Assessment*

The Annual Self-Assessment tool was developed help CCN Child Health Teams (CHTs) identify their strengths and opportunities for growth. This information helped teams determine areas for focus and improvement, and helped OCCYSHN identify areas to focus our technical assistance. All areas of the assessment may not apply to your child health team, but this tool can be adapted to reflect your team's standards.

The purpose of this tool is to help CCN Child Health Teams (CHT) identify their strengths and opportunities for growth. This information will help your team determine areas for focus and improvement. This information also will help OCCYSHN support you by identifying possible areas for technical assistance.

Instructions: The team should complete this form as a group. Once completed, the CCN Coordinator should return a copy of the completed form to OCCYSHN by email, fax, or post mail with attention to:

Oregon Center for Children and Youth with Special Health
Needs Institute for Development & Disability
Oregon Health & Science University
707 SW Gaines Street, Mail code: CDRC
Portland, Oregon 97239-3098
Fax: 503-494-2755
Email: occyshn@ohsu.edu

a. What is the name of your CCN Child Health Team (CHT)? *(Please write your response in the space below.)*

b. What are the names of the individuals and their role (e.g., Coordinator, public health nurse, mental health provider, medical doctor) who participated in completing this self-assessment tool? *(Please write the names in the space below.)*

c. On what date(s) was this tool completed? *(Please write your response in the space below.)*

____ ____ / ____ ____ / _____ _____
(mm / dd / yy)

____ ____ / ____ ____ / _____ _____
(mm / dd / yy)

I. CHILD HEALTH TEAM OPERATIONS

	Status		
What is the <u>current</u> status of this standard in your CHT? *(Please check one response for each standard.)*	*Achieved*	*Partially achieved*	*Not yet achieved*
1. Child Health Team (CHT) is formed with representatives from: primary care and other local health care provider(s), educators, parent partners, and community service providers. (Other representatives may be included depending on the local context and needs.)	☐	☐	☐
2. CHT has developed strategies to identify CYSHCN to be referred to the CHT.	☐	☐	☐
3. CHT has established and uses a process for prioritizing the most vulnerable children with special health care needs.	☐	☐	☐
4. Families receive contact from the CHT within 10 business days of the CHT receiving the referral.	☐	☐	☐
5. CHT members collaborate with each other and/or external entities to ensure that unresolved needs are assessed and addressed for children and families.	☐	☐	☐
10. CHT actively works together to improve existing practices, to identify and solve problems for the population of CYSHCN, and to achieve system change.	☐	☐	☐

d. For the Operations Standards that your team identified as "achieved" or "partially achieved," what approaches, processes, or strategies helped your team achieve this status? *(Please write 1 to 3 sentences in the space below.)*

e. Of the Operations Standards that your team identified as "partially achieved" or "not yet achieved," which two would your team like to prioritize for improvement next year? *(Please list the standard numbers in the space below.)*

_____ _____

f. What barriers or challenges did your team encounter in attempting to achieve the Operations Standards? *(Please write 1 to 3 sentences in the space below.)*

II. CHILD HEALTH TEAM SHARED CARE PLANS

	Status		
What is the <u>current</u> status of this standard in your CHT? *(Please check one response for each standard.)*	*Achieved*	*Partially achieved*	*Not yet achieved*
6. When a referral to the CHT results in a child/family visit, CHT partners with the family to develop a shared and actionable care plan that addresses the range of healthcare and related services and supports needed by the child and her/his family.	☐	☐	☐
6.1. CHT engages with a patient-centered primary care home (PCPCH), or a primary care provider (if no PCPCH) in developing and/or implementing a shared care plan.	☐	☐	☐
6.2. CHT coordinates effectively with the primary care physician, specialty care providers, education, mental health, and others as needed (e.g., child care, developmental disabilities, housing, transportation, SSI or other financial supports).	☐	☐	☐
6.3. CHT jointly develops shared care plans with the family and/or child.	☐	☐	☐
6.4. Shared care plans include strategies to increase the child and/or family's capacity to obtain, process, and understand health and health-related information to make informed decisions about health care and developmental needs.	☐	☐	☐
6.5 Shared care plans are culturally and linguistically appropriate.	☐	☐	☐
6.6. Shared care plans support youth transition to adult health care, work, and independence.	☐	☐	☐
6.7. CHT encourages families to make a follow up appointment with the PCPCH to discuss the shared care plan after it is developed.	☐	☐	☐
6.8. CHT addresses barriers experienced by families when attempting to follow up with the PCPCH to discuss the shared care plan.	☐	☐	☐
6.9.1. CHT reviews or monitors shared care plans on a monthly basis.	☐	☐	☐
6.9.2. The parent partner communicates the ongoing or changing needs of the family to the CHT.	☐	☐	☐
7. CHT supports the child's and/or family's ability to implement the shared care plan.	☐	☐	☐

g. For the Shared Care Plan Standards that your team identified as "achieved" or "partially achieved," what approaches, processes, or strategies helped your team achieve this status? *(Please write 1 to 3 sentences in the space below.)*

h. Of the Shared Care Plan Standards that your team identified as "partially achieved" or "not yet achieved," which two would your team like to prioritize for improvement next year? *(Please list the standard numbers in the space below.)*

_____ _____

i. What barriers or challenges did your team encounter in attempting to achieve the Shared Care Plan Standards? *(Please write 1 to 3 sentences in the space below.)*

III. CHILD HEALTH TEAM QUALITY IMPROVEMENT PRACTICE & REPORTING

	Status		
What is the <u>current</u> status of this standard in your CHT? *(Please check one response for each standard.)*	*Achieved*	*Partially Achieved*	*Not Yet Achieved*
8. The contracting organization reports to OCCYSHN on a timely basis, following the schedule in the Coordinator's scope of work.	☐	☐	☐
9. The CHT reviews the standards at least annually.	☐	☐	☐
10. CHT implements continuous quality improvement efforts to improve its work.	☐	☐	☐

j. For the Quality Improvement Practice & Reporting Standards that your team identified as "achieved" or "partially achieved," what approaches, processes, or strategies helped your team achieve this status? *(Please write 1 to 3 sentences in the space below.)*

k. Of the Quality Improvement Standards that your team identified as "partially achieved" or "not yet achieved," which two would your team like to prioritize for improvement next year? *(Please list the standard numbers in the space below.)*

_____ _____

l. What barriers or challenges did your team encounter in attempting to achieve the Quality Improvement Practice & Reporting Standards? *(Please write 1 to 3 sentences in the space below.)*

IV. CHILD HEALTH TEAM QUALITY IMPROVEMENT NEXT STEPS

m. What <u>one</u> standard, or part of a standard, will your CHT work on improving over the next 6 months? Why did your CHT select this standard? *(Please write your response in the space below.)*

ABOUT THIS TOOL — *Parent Partner Materials*

Parent Partners are an invaluable resource to have as part of a child health team. They provide support to families of children or youth participating in a child health team and model positive family-professional partnerships. Their involvement on CCN Child Health Teams led to the development of these materials.

To help you develop and hire for a Parent Partner position on your child health team, included in the packet is:

(a) An FAQ about Parent Partners,
(b) A document outlining the roles and responsibilities of a Parent Partner, and
(c) A sample Parent Partner job description.

Questions for Child Health Teams about Parent Partners

What, specifically, does the Parent Partner do?
See the attached "Sample Job Description" and "Important Role" documents. Parent Partners work a minimum of 10 hours per month.

May teams use volunteers to fill the Parent Partner role?
No. Parents' expertise needs to be reimbursed.

How can our team hire a Parent Partner?
Some options are:

- A Child Health Team partner agency (such as Public Health, the Medical Home, etc) hires a Parent Partner as an hourly employee, paying their payroll taxes and covering liability insurance. (This is generally the best option for Parent Partner, as taxes are withheld and liability is covered by employer.)
- Parent Partner is an Individual Contractor (This is possible if the Parent Partner claims own taxes and assumes own liability insurance through a third party insurer.) This option may be more expensive for the team to sustain.
- Parent Partner is "shared" with another agency. For example, funding may be given to a partner agency to pay for the part of an employee's hours that are dedicated for the Child Health Team. An Interagency Agreement or Memorandum of Understanding would be required between the Child Health Team's Administrative Partner and the employer to identify details such as hours, liability coverage, etc.

Who does the Parent Partner work for, what kind of support will they need, and who is their supervisor?
Depending on the hiring arrangement (see above) the Parent Partner will most likely be supervised by a representative from the Partner Agency. The Parent Partner and the Child Health Team will work together to determine the level of support needed/desired. Close communication through a secure email will be required. If the Parent Partner is an independent contractor, they technically have no supervisor, but report back to the team as a whole. Clear communication and reporting guidelines should be established, followed, and evaluated.

What kind of training do PPs have access to?
Through the Family Involvement Network at OCCYSHN, new Parent Partners, along with key team members, may receive an initial orientation to the position reviewing purpose, goals, and guidelines. They will be invited (at no cost) to participate in monthly FIN training webinars on a variety of subjects related to CYSHN/health care, and may be invited to attend OCCYSHN's annual Parent Partner training in Portland. The Child Health Team would be responsible for covering the cost of travel and meals to the annual training, and is responsible for other on-going training as needed or desired.

What does it cost to have a Parent Partner on the team?
Teams should plan to pay a Parent Partner approximately $17 per hour for 10 hours per month. The hiring organization is responsible for paying all payroll taxes, so should plan on budgeting approximately $18 per hours. Based on 12 meetings per year, the total annual cost is approximately $2200. The team may also choose to pay related expenses such as:

- Mileage to meetings
- Conferences/trainings related to their position
- Allowance for use of phone, computer, printer, etc.

Must a Parent Partner have their own child who has special needs?
Yes. They may also be a close family member/caretaker, such as a grandparent or sibling, who has taken responsibility for learning and using the systems of support for CYSHN and who is experienced in navigating those systems.

Could a youth with special health needs also be a "Parent" Partner?
Yes. A "Youth Partner" would be appropriate to work with youth who participate in Child Health Teams. Like Parent Partners, they must be knowledgeable and experienced with using the systems of support for CYSHN and be comfortable reporting to the professionals on the team. A "Youth Partner" may not be the best choice to support families of younger children, however. Child Health Teams could have both a Youth and a Parent Partner.

Details: Whose phone do they use? Do they get mileage? What email do they use? Do they do home visits? Child care?
Each Child Health Team will determine these answers independently. In a perfect situation, the Parent Partner would have a dedicated computer, email, and phone.

- Parent Partner should have a plan that allows unlimited minutes/long distance. If they do not, arrangements for cost reimbursements will need to be made. The team and the Parent Partner should establish policies for the use of private cell phones, such as who may give out the number, who may use the phone, etc.
- PPs should use the email account belonging to the entity who pays their wages.
- Home visits are discouraged for a number of reasons, liability the primary reason. Also, home visits are time and mileage intensive.
- Parent Partners should not bring children to Child Health Team meetings, nor should they be expected to care for the children who attend the meetings. If a family brings a child that requires minding during a meeting, everyone on the team can take a turn.

Are Parent Partners mandated reporters?
Because Parent Partners are in a position to learn about abuse and neglect first-hand from families, it is recommended that they be mandated reporters in accordance with the practices of their fellow team members. The Child Health Team should work with Oregon Department of Human Services to identify procedures for child abuse reporting that all members follow.

What files do they keep? How do they protect confidential information?
A locking box or (unshared) file cabinet is sufficient as a secure place to store written records. Electronic records should not be kept on home computers that others have access to. A dedicated, unshared laptop with a unique password is recommended.

Questions may be sent to Tamara Bakewell, Family Involvement Coordinator, at occyshn@ohsu.edu; 503-494-8303

The **Parent Partner's** Important Role on a Child Health Team

Guidelines from the Oregon Center for Children and Youth with Special Health Needs
Family Involvement Program

The Job of the Parent Partner is to:

- contact the parents before the meeting to answer questions, offer guidance, and support.
- be present at the meeting, sit next to the family, provide emotional support and help the parent understand the Child Health Team process and recommendations
- share appropriate resources with families; find resources on behalf of the team
- make one or two follow-up calls to the parent after meeting to answer questions, check process, and offer further guidance
- remind parents to respond to parent satisfaction survey, if applicable
- initiate contact with the team as needed, check email regularly, and respond to email and calls in a timely manner.
- submit time card and other paperwork in a timely manner
- stay abreast of parent leadership activities offered through the Oregon Center for Children and Youth with Special Health Needs. (OCCYSHN)

The Parent Partner is:	**The Parent Partner is not expected to be:**
• a parent of a child with special health, developmental, or behavioral conditions who has knowledge of the services and systems families use • a full partner on the team • a compassionate and non-judgmental listener • good at brainstorming solutions with the team • trained in HIPAA, FERPA, and other professional standards	• a case manager • a volunteer • privy to medical records or educational records outside of the team process • the participating family's only source of help • the family's crisis manager.
The Parent Partner does:	**The Parent Partner does not:**
• help the team understand the concerns of the participating family • share their personal experiences as a parent • introduce families to community activities, events, and supports • contacts participating parents once or twice after the team meeting to check progress and offer guidance • meets participating parents in person in a public location when necessary or preferable	• provide on-going care-coordination or emotional support • make home visits • transport parents or children • volunteer their time to the team • attend IEPs • give advice to parents on which kinds of treatment, management, or educational placement to pursue

Communication tips for Parent Partners and Team Members:

- Team should provide Parent Partner with contact information of participating parent in plenty of time
- Parent Partners are expected to speak up in meetings if and when they note that the family is confused, upset, or otherwise needs an advocate.
- Team meetings should include an opportunity for Parent Partners to present observations, concerns, ask questions, etc.
- Parent Partners should be informed about all meeting logistics and have adequate notice for team meetings.

The Parent Partner's role in sensitive situations:

From time to time, situations arise when Parent Partners are privy to information from or about families that is sensitive or concerning. In those cases, and especially when child abuse or domestic violence is suspected, the Parent Partner should assume they are mandated to report the abuse. If child abuse is suspected, or if the family is experiencing crisis, the Parent Partner should immediately contact the team for consultation.

Sample Child Health Team Parent Partner Job Description

POSITION SUMMARY: The position of Parent Partner is for a family member of a child, youth, or adult who experiences special health, mental health, or developmental needs. It is a 10 hour per month position reporting to _____. The purpose is to provide support to families of children who are participating in the _____ Child Health Team, and to model positive family/professional partnerships.

KEY RESPONSIBILITIES	% Of duties
1 Participate as a full partner in monthly Child Health Team meetings. o Represent family perspectives in pre and post team meetings o Provide feedback to the team o Communicate regularly with the team coordinator	40
2 Communicate with and support families participating in the CH team. o Call or meet with family prior to the team meeting to orient and explain the process o Assist families in framing questions and issues they want to have addressed with the team o Provide support to families before and during the team process o Assist families with follow up recommendations and linkage with local resources o Conduct follow-up calls with families to determine outcome of recommendations o Track outcomes using supplied forms and report to team at monthly meetings. o Based on outcomes of tracking, make recommendations to team regarding the continuation of families in the team process.	40
3 Develop and maintain contacts of local resources that may be helpful to families and bring contact lists to each meeting	5
4 Participate in training/professional development opportunities as requested by CHT	5
5 Promote positive family-professional relationships as a member of the ___ Child Health Team	5
6 Using secure email and telephone, communicate regularly with supervisor. Submit time card on a timely basis.	5

Qualifications	**Required**
Education:	High School Diploma
Experience:	Four or more years of experience as the parent, foster parent, grandparent, or caretaker of a child or youth with special health, developmental, or behavioral needs. Experience using community systems of care for children/youth with special needs
Job Related Knowledge, Skills and Abilities (Competencies):	• Ability to use email, and computers for documentation and reports • Knowledge of pediatric disability/health-related services and supports • Positive collaboration and team-building skills • Understanding of diverse cultural, geographic, and social issues that impact families with special needs • Strong communication skills, including writing skills (Bi lingual skills preferred)
Registrations, Certifications and/or Licenses:	n/a

WORKING CONDITIONS: This position conducts its work from an offsite location and requires access to necessary telecommunications/computer to meet the demands of the position. Must have transportation to travel to community meetings and activities.

PHYSICAL DEMANDS & EQUIPMENT USAGE:
Must be able to lift up to 25 pounds, move meeting room furniture as needed.

ABOUT THIS TOOL — *Release of Information Template*

Ideally, a child health team bridges the gap in communication between education and health care for families. Due to the national Family Rights and Privacy Act (FERPA) and the Health Insurance Portability and Accountability Act (HIPAA), child health teams must have up-to-date releases of information (ROIs) from all participating organizations in order to share client data. Included in this section is a sample ROI template provided by the Oregon Department of Education that is compliant with both FERPA and HIPAA laws.

Education Agency Logo and Information Here

Authorization to Use and/or Disclose Educational and Protected Health Information

1. I authorize the following provider(s) to use and/or disclose educational and/or protected health information regarding my child.

(Student/Child's Name) _____ (Date of Birth) _____

(Other Names Used by Student/Child) _____ (School or Program Name) _____

Name and address of health care provider authorized to:

- ❑ Send/disclose protected health information
- ❑ Receive/use educational information

_____

_____

Name and address of school/EI/ECSE program authorized to:

- ❑ Send/disclose educational information
- ❑ Receive/use protected health information

_____

_____

2. I understand that this information will be used for the following purposes (check all that apply):

- ❑ Determining eligibility for Special Education, EI/ECSE, or other services
- ❑ Determining student/child's current levels of performance
- ❑ Developing an individualized health plan
- ❑ Developing an appropriate Individualized Education Program or Individualized Family Service Plan
- ❑ Other (specify): _____

3. By marking the boxes below, I authorize the use/disclosure of the following specific medical and/or educational records:

- ❑ Physician's Eligibility Statement
- ❑ Health Assessment Statement
- ❑ History and physical exam
- ❑ Entire medical record
- ❑ Prenatal information
- ❑ Educational Information
- ❑ IFSP/IEP document
- ❑ Clinic records
- ❑ Communicable disease(s)
- ❑ Progress notes
- ❑ Psychological evaluations
- ❑ Social work reports
- ❑ Other: _____

4. By *initialing* the spaces below, I authorize the use/disclosure of the following information. Specific records requested must be listed below, e.g., assessment, treatment plan, discharge plan.

___ Drug/alcohol diagnosis, treatment or referral information requested: _____

___ HIV/AIDS related records requested: _____

___ Mental health related information requested: _____

___ Genetic testing information requested: _____

5. I understand that:

a. This authorization is voluntary and I may refuse to sign it without affecting my child's health care.

b. I have the right to request a copy of this form after I sign it as well as inspect or copy any information to be used and/or disclosed under this authorization (if allowed by state and federal law. See 45 CFR § 164.524).

c. I may revoke this authorization at any time by notifying _____ in writing. However, it will not affect any actions taken before the revocation was received or actions taken based on the previously shared information.

d. Federal privacy rules for protected health information apply only to health plans, health care clearinghouses or health care providers. If I authorize disclosure of medical information to other agencies or individuals the disclosed information may no longer be protected by federal privacy regulations.

e. Federal privacy rules for education information apply only to schools and EI/ECSE programs. If I authorize disclosure of educational information to other agencies or individuals the disclosed information may no longer be protected by federal privacy regulations.

6. I consent to the use/disclosure of the above information. I understand that the use of this information for any reasons other than the expressed reasons stated above is prohibited. This consent is subject to revocation at any time, except to the extent that action has been taken based on information that has already been disclosed.

_____

(Signature of Parent, Legal Guardian, Student/Child) (Date)

_____

(Relationship)

This authorization expires on _____ (Month/Day/Year) (not to exceed one year from date of signature above).

Form 581-1196-P (Rev. 6/07)

Authorization to Use and/or Disclose Educational and Protected Health Information

Purpose of form:

- This form was created so that educational agencies could request information from health entities that require HIPAA-compliant release forms. (HIPAA: Health Insurance Portability and Accountability Act)

- This form is used when there is a need to obtain consent from a parent, legal guardian or student/child to authorize the named agency to:
  - Send/disclose protected health information and/or educational information; and/or
  - Receive/use protected health information and/or educational information

Directions for completing form:

Box 1. Required.

- Enter the student/child's full legal name including middle name;
- Enter other names used by the child including nicknames;
- Enter child's date of birth;
- Enter the name and address of the health care provider who will send or receive requested protected health and/or educational information;
- Enter the name and address of the school district or EI/ECSE program sending or receiving the requested protected health and/or educational information; and
- Check all appropriate boxes that apply indicating which provider is authorized to send and which provider is authorized to receive protected health and/or educational information.

Box 2. Required.

- Mark all the boxes that apply regarding how the requested protected health and/or educational information will be used. For a record that is not represented in the list, check the "other" box and specify a different type of purpose.

Box 3. Required.

- Mark all the boxes that apply regarding which specific medical and/or educational records are being requested. For a record that is not represented in the list, check the "other" box and specify a different type of record.

Box 4. Required only if any of the four types of records indicated are requested. This box should be left blank if none of these four types of records are requested.

- The four types of records indicated require an additional level of protection. To request any record in Box #4, the specific type of record must be listed in the spaces provided and the parent, legal guardian or student/child must initial the space before each type of record requested. For example, for mental health information, a program might indicate "psychologist's assessment" and then the parent, guardian or student/ child would initial the space at the beginning of the mental health information line.

Box 5. Required.

- This box contains information relating to the parent's, guardian's, or child's rights in giving authorization including the right to refuse to sign, the right to request a copy after signing, the right to inspect the information to be used and/or disclosed, and the right to revoke the authorization. Information is given that clarifies that when requested information is sent, the laws that protect that information may no longer apply since the receiving agency may not be bound by the same laws as the sending agency.
- In item c., identify who will receive the potential revocation. The statement clarifies that if an action has already been taken, for example, protected health information has already been sent, then the revocation for that specific information is not valid. However, the agency may voluntarily return the information received after the revocation has been signed and submitted.

Box 6. Required.

- Parent, legal guardian, or student/child must sign for the authorization to be valid. If parent or guardian, the relationship to the child must be indicated. The date of the signature must be entered.
- The authorization is only valid for the purposes checked or stated in the form.

Box 7. Required.

- The month, day, and year that this authorization will expire must be included in the space provided. The date must not go beyond one year past the date of the signature.

Additional directions

- Place a copy of this form into the student/child's file.
- HIPAA requires that the school district/EI/ECSE program give a copy of the authorization form to individuals who sign it and request a copy. However, it is recommended practice that the school district/program automatically give the parent, guardian, or student/child a copy of the form after they have signed it, whether or not they request it, so they will have a record of the authorization.

ABOUT THIS TOOL — *Facilitation Guides*

When a child health team meeting is family-centered, parents know what to expect and are full partners at the table. The team recognizes the parents as the constant in the child or youth's life and builds on family strengths. Cultural diversity and family traditions are honored. To ensure that your team process is family-centered, consult this guide when facilitating meetings in which families are present. Assign a team member to check that each item on the list has been addressed in the meeting.

This section also includes a meeting facilitation guide for meetings in which families may not be present, where team-specific processes and improvements are discussed. Use this guide as a reference when hosting an internal meeting for your child health team. It can serve as a sample agenda for these meetings.

Child Health Teams

Family-Centered Meeting Facilitation Guide

When a meeting is family-centered, parents know what to expect and are full partners at the table. The team recognizes the parents as the constant in the child's life and builds on family strengths. Cultural diversity and family traditions are honored.

At the shared care planning meeting, assign a team member to ensure that each item on the agenda is addressed. Identify who will record the care plan. You may also want to identify a second recorder to write down a couple of recommendations each family can use to get started when they walk out the door. The first page of the care plan can fill this need, but be sure to get a copy to incorporate into the full care plan.

- ☐ Do introductions: names and roles
- ☐ Ensure the family of confidentiality, and circulate the confidentiality form
- ☐ Provide a brief review of the team process for the family or confirm that the Parent Partner has already done this
- ☐ Provide an overview of the child: name, age, parents' names, who referred and why, insurance status
- ☐ Invite the parents to share their hopes and/or concerns
- ☐ Discuss child and family strengths
- ☐ Summarize family and professional concerns, including history and current status
- ☐ Discuss recommendations for interventions that systematically address each unmet need. (Try to limit the number of recommendations you ask families to pursue on their own. If there are more than three, consider inviting the family to a second meeting.)
- ☐ Summarize the care plan out loud
- ☐ Conclude the meeting by asking questions: What questions do you have? What issues did we not address? Did we miss anything?
- ☐ Discuss next steps. Tell the family that the Parent Partner will follow up with a phone call in about three weeks to see how it's going. After that, check-ins will continue if they are still helpful.
- ☐ Families can decide when they want to finish with Child Health Team support.
- ☐ Provide copies of the plan to participants on the day of the meeting, or within one week's time.

Child Health Teams

Team Meeting Facilitation Guide

Child Health Teams are most effective when they meet monthly to reflect upon and improve their processes. When teams meet regularly, it allows their *community of practice* to grow.[1]

Every team meeting should include:

- ☐ Introductions, as needed
- ☐ Discuss new referrals
- ☐ Parent Partner(s) report on children previously seen at team meetings using a child health team tracking tool
    - ☐ Overview: child's name, age, parents' names, who referred and why
    - ☐ Status of each recommendation and where the family needs additional support
    - ☐ Team discussion of next steps
- ☐ Reflective practice: In the Child/Family Visits, what worked for families? What didn't? What changes are needed?
- ☐ Agency updates

Additional agenda items which may be included:

- ☐ Plan and/or review trainings aimed at building community capacity to care for children with special health needs
- ☐ Plan marketing and outreach efforts
- ☐ Discuss and address team staffing. Invite new members as appropriate
- ☐ Discuss community system of care, including identifying and addressing barriers to services for children with special health needs
- ☐ Identify and plan activities to meet annual team goal

[1] For a more complete definition of a *community of practice*, see the "About This Toolkit" section on Page 2.

ABOUT THIS TOOL — *Family Concerns Checklist & Health Information Questionnaire*

The last two tools in this section serve as prompts for the team to collect important or helpful information from families. The Family Concerns Checklist is to be filled out, as needed, by a team member in conversation with the family. Although the child health team likely will not be able to address all family concerns, the checklist helps the team identify areas where a family may need more resources or support.

The Health Information Questionnaire can be filled out by the family or a team member. It allows the team to identify and address health-related goals for the child or youth. It may also help the team fill gaps in the child or youth's medical history.

FAMILY CONCERNS

* Check all that apply. It may not be possible for the team to address and solve all family concerns, however it is helpful to know areas of concern.

FINANCES	MEDICAL / HEALTH	ACCESS / ENVIRONMENT	PSYCHOSOCIAL	SCHOOL / EDUCATION	COMMUNITY RESOURCES
❑ No Concerns	❑ No Concerns	❑ No Concerns	❑ No Concerns	❑ No Concerns	❑ No Concerns
❑ SSI ❑ Disability services ❑ Health insurance coverage ❑ Medical expenses after insurance ❑ Household expenses covered ❑ Food/clothing ❑ Fuel/utilities ❑ Housing ❑ Respite expenses ❑ Other _____	❑ Access to Primary Care Physician ❑ Access to dental care ❑ Access to specialty care for condition ❑ Communication with professionals ❑ Coordination between providers ❑ Health information ❑ Medication use and side effects ❑ Growth & development ❑ Nutrition & feeding ❑ Other _____	❑ Adaptive equipment such as feeding utensils, lifts, prone stander, walker ❑ Manual wheelchair ❑ Motorized wheelchair ❑ Home modifications such as wheelchair ramps, doors ❑ Transportation ❑ Augmentative communication device ❑ Other _____	❑ Child behavior ❑ Peer interactions ❑ Emotional support ❑ Parent/family support ❑ Sibling support ❑ Other _____	❑ Early Intervention ❑ Special education ❑ Tutoring ❑ Voc. rehabilitation ❑ Physical therapy ❑ Speech therapy ❑ Occupational therapy ❑ Assistance teaching providers about health ❑ Support with IFSP/IEP Process ❑ Support for transition process ❑ Other _____	❑ Recreation / social interactions ❑ Child care ❑ Job training ❑ Legal services ❑ Summer/day camps ❑ Respite ❑ Other _____

HEALTH INFORMATION QUESTIONNAIRE

Child's Name: _____ **DOB**: _____ **County**: _____
Date Completed: _____ **Person Completing**: _____
Primary Language: _____ **Relationship to Child**: _____

1. Yes ❑ No ❑ Is your child on a special diet?
   If yes, specify _____
2. Yes ❑ No ❑ Does your child require special feeding techniques or have difficulties with feeding (such as choking, gagging, coughing, vomiting, or slow to complete a meal)?
   If yes, specify: _____
3. Yes ❑ No ❑ Does your child have a history of neurological problems (such as seizures/epilepsy, muscle weakness, hydrocephalus or cerebral palsy)?
   If yes, explain: _____
4. Yes ❑ No ❑ Does your child have an orthopedic problem (such as scoliosis, hand or foot deformity, hip dislocation)?
   If yes, specify: _____
5. Yes ❑ No ❑ Does your child have a history of chronic illness (such as diabetes, asthma or kidney problem)?
   If yes, specify: _____
6. Yes ❑ No ❑ Has your child been hospitalized, had surgery or a serious injury?
   If yes, explain: _____
7. Yes ❑ No ❑ Does your child have a hearing problem or use a hearing aid?
   If yes, explain: _____
8. Yes ❑ No ❑ Does your child have vision problems or wear glasses?
   If yes, explain: _____
9. Yes ❑ No ❑ Does your child use adaptive equipment such as wheelchair, prone stander, or braces?
   If yes, specify: _____
10. Yes ❑ No ❑ Does your child need any other health treatments daily (such as gastrostomy feedings, intermittent catheterization)?
    If yes, specify: _____
11. Yes ❑ No ❑ List the medication(s) that your child takes: _____

What else do you think the doctor needs to know about your child? _____
_____

The following section provides aspiring Child Health Teams the tools necessary for sustainability planning, such as sustainability action steps, a community presentation highlighting benefits, and Memorandum of Understanding (MOU) templates.

SUSTAINABILITY

ABOUT THIS TOOL — *Action Steps Toward Sustainability*

Planning for sustainability can be a daunting task for child health teams, especially if they are in early stages of development. Because the purpose of this checklist was to provide ideas to include in CCN teams' sustainability plans, many of the items on the list are specific to child health teams in Oregon. Regardless, this tool provides a foundation for sustainability planning processes, such as securing new funding streams, writing an action plan, and forming relationships with community leaders.

Action Items for Your Team to Consider in Building Your Sustainability Work Plan

Your team wants to work on sustainability, but where do you start? Here are some ideas:

❑ Build broad community awareness and support for the child health team. Each team member should be able to describe what the team does, the value of its work in the community, and what would be lost if the team stopped operating. Think about all the different people and organizations who would be interested in knowing more. Some of the people and organizations that know about CCN may choose to advocate for it.

❑ Build the awareness of *community leaders* and others who make decisions about whether to sustain the work of the child health team. Be able to talk about the needs that the team fills in the community and ways in which the model may be changed to meet specific community needs.

❑ *Demonstrate* the value of the child health team. This may happen through conversations, inviting new people to the table to participate, or sharing examples of ways the team has helped children and families (without sharing protected health information).

❑ Identify champions who can help garner resources for the child health team.

❑ Identify political champions to advocate for the child health team.

❑ Team members can ensure that the child health team has support from within their own organizations. Talk to administrators about the work. Talk to them about formalizing the relationships through a letters of agreement or a memorandum of understanding (MOU). Having agreements in place will help to sustain the work of the child health team over time, and they demonstrate the level of local commitment to an organization that may be considering taking the program on or funding it.

❑ Talk about the different ways your team can be sustained over time and pick one to work on. Your team might have an idea that you all want to pursue. You may want to explore the various interdisciplinary teams that are already functioning in your community and align with one of them.

❑ In the environment of health reform, **CCOs** hold promise for supporting the child health team model.

- Does the CCO have a Care Coordination group that meets regularly? If so, the child health team might join the care coordination group, effectively expanding the linkages to community-based services.
- Apply for a CCO Innovation or Health System Transformation funds. If the team can demonstrate success in improving health, increasing the quality of care and lowering or containing costs, then the CCO may choose to permanently fund the team.
- The team could be adopted within the CCO and administered through it, or the CCO could pay for another organization to administer it.

- In some communities the Community Advisory Committee (CAC) works with their Clinical Advisory Panel to determine services. Supporters of the child health team could attend and address the CAC.
- Oregon Transformation Center Innovator Agents may be a helpful resource to teams. http://www.oregon.gov/oha/healthplan/Pages/Innovator-Agents.aspx
- Consider whether there may be others within the CCO who are interested in learning about CCN.
- Having a physician champion (or several physician champions) is likely to increase CCO interest in the child health team model.

❑ Regardless of the model or funding for sustaining the child health team, ensure that the Parent Partner's role will be funded and sustained. Include the Parent Partner in all the planning and decision-making.

❑ Identify potential funders or funding streams. The Community Toolbox outlines funding strategies that might be helpful to teams: http://ctb.ku.edu/en/table-of-contents/sustain/long-term-sustainability/sustainability-strategies/main

❑ Some Early Learning Hubs fund projects. Contact your Hub to learn more. https://oregonearlylearning.com/current-early-learning-hubs/

❑ Write an action plan for sustainability. Here's an example:

Sustainability Plan				
Objective	What will we do	Person(s) Responsible	Target Date	Date Completed

ABOUT THIS TOOL — *Sample Sustainability Presentation*

This is a sample presentation your child health team may use to present to community organizations about your work. Additionally, the presentation can also help teams demonstrate value to potential sustainability partners. You may use this full template with additions of your team data to provide an informal proposal to stakeholders interested in supporting your sustainability efforts. Teams can adapt the format and talking points for their own purposes.

For a PowerPoint version of the sample template, contact our center at occyshn@ohsu.edu or (503) 494-8303.

Our Child Health Team: Planning for Sustainability

Draft to use in Community Presentations

Partnership of [INSERT NAME HERE] Child Health Team & Oregon Center for Children & Youth with Special Health Needs

Purpose

- The purpose of this template is to provide an outline for your Child Health Team to use as you prepare presentations for interested sustainability partners (CCO's, Early Learning Hubs, etc.)
- You may use this full template with additions of your team data to provide a full, over-arching Child Health Team proposal to interested stakeholders.

Agenda

- Background
- Alignment with CCO's
- Community Need/Our Health Team Model
- Evolution of our Child Health Team
- How to support our Child Health Team
- Thank you and Follow Up

Background/Who We Are

- We are a Child Health Team that brings families together with professionals to plan and coordinate care for children with unmet health care needs in our local community.
- Our team has provided services to children and families for over _____ years as part of the Community Connections Network (CCN) of the Oregon Center for Children And Youth with Special Health Needs (OCCYSHN) at OHSU.
- Funding and Technical Assistance have been provided in the past by OCCYSHN; however, our last day of funding will be…

What Our Child Health Team Does

- Our team evaluates children with chronic conditions and disabilities who have unmet health care needs, develops shared plans of care, and assists with coordination of care with the child's PCP.
- Our team is composed of:
  - Local Physician
  - Mental Health Provider
  - Educational Staff
  - Parent Partner
  - Representatives of other Community Services

Who Benefits from a Child Health Team Evaluation?

- Children with complex health conditions and their families are best served by this process.
- Families benefit from extra support in finding and accessing services.
  - Children often receive services from many different medical and educational providers.
  - Families may face financial, cultural, or other barriers to obtaining care.

What Makes Our Child Health Team Unique

- **Medical Component:**
  Team Physician who is able to support our families and teams by providing medical expertise and a detailed evaluation and who can recommend referrals and connect with the child's PCP.
- **Parent Partner:**
  Our team's family liaison. The Parent Partner is the main source of support and communication with families on the team. The Parent Partner is also skilled with navigating the health care system as they are also a parent of a child with special health needs.

History of Our Child Health Team

- Input relevant info here which could include:
  - How long your Child Health Team has been meeting with families
  - **Data:** # of children & youth seen, demographics, # of Medicaid, issues addressed, referrals made, etc.
  - Stories/quotes from families and professional partners

How Our Child Health Team Addresses the Goals and Objectives of Oregon's CCOs

- Our team is aligned with the OHA's Triple Aim of providing:
    1. High Quality Care
    2. Increased Family & Patient Satisfaction
    3. Lower Health Care Costs
- Our team provides high quality patient and family-centered, coordinated care in the family's local community.
- We address the PCPCH Core Attributes # 5 (Coordination & Integration) and #6 (Patient & Family-centered Care).

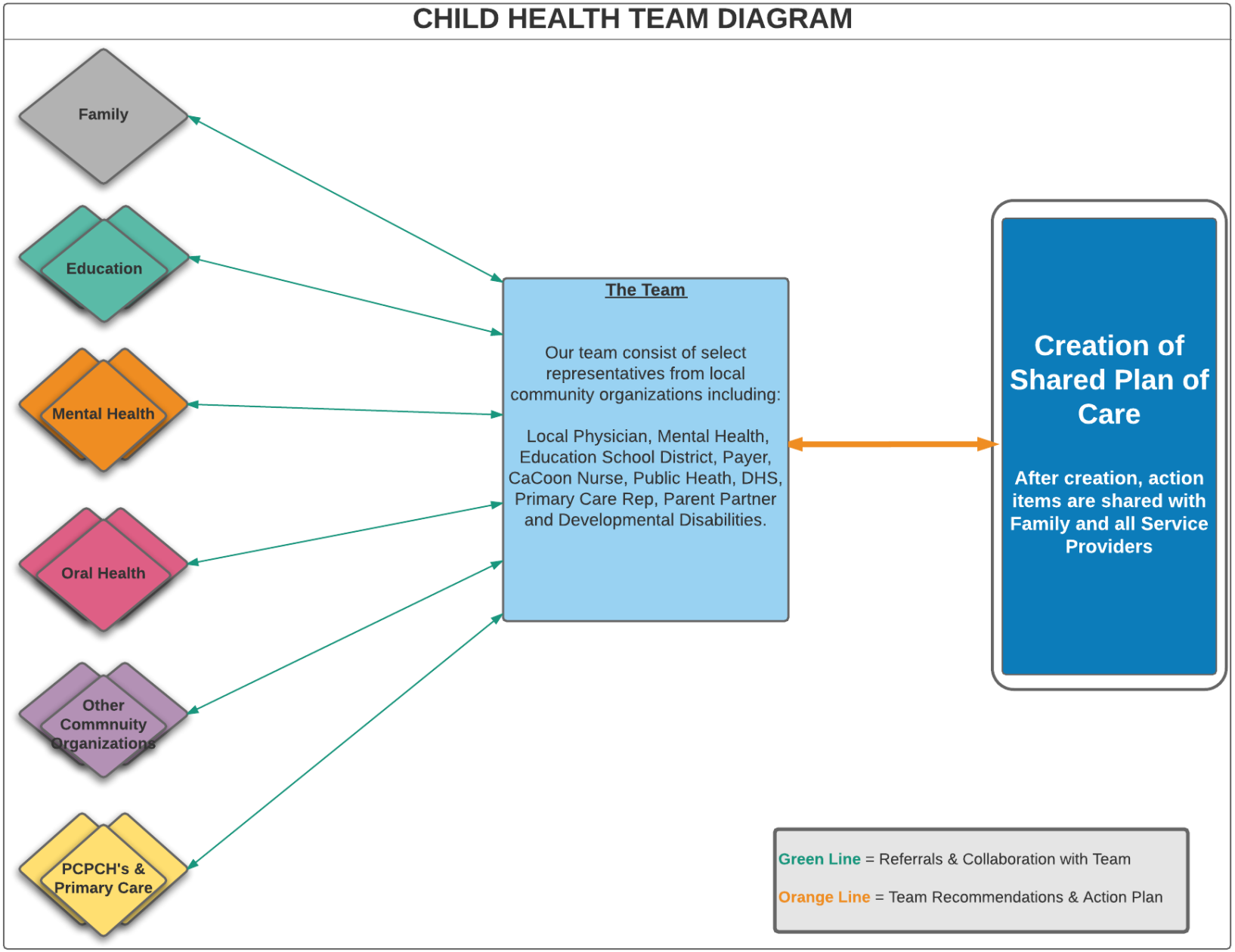
Child Health Teams Can Assist with:

- Complex Care Coordination and Specialty Care Coordination through our team evaluations (PCPCH Standards 5.C: Complex Care Coordination, & 5.E: Referral & Specialty Care Coordination)
  - We create a Shared Plan of Care and provide additional care coordination supports through the team's Parent Partner

Why Our Child Health Team Is Needed in Our Community

- Need specific info from each team here
- Include both formal & informal data
- Collection of family stories
- Collection of community professional stories (What do other professionals have to say about CCN?)

Our Child Health Team Diagram



Flexibility of Our Child Health Team to Meet the Needs of Our Community

- Talk about how your Child Health Team members can vary based on the needs of individual children and families. (Give specific examples here)
- Ask questions of your audience here!

How You Can Help Sustain Our Child Health Team

- Attend and participate in a planning meeting
- Help spread the word
- Assist with fund raising or identifying potential funding streams
- Other types of support (shared positions, donating meeting space, etc.)

Our Budget Needs

- As mentioned earlier, our funding from OCCYSHN only extends through…
- The OHSU phone consult line will continue to be available for support of the pediatrician on our team. Calls are made as needed for consultation with OHSU/CDRC Developmental Pediatricians.
- On-going funding is required for:
  - Administrative support (scheduling, requesting records, communications, convening the team etc.)
  - Medical and Mental Health Professionals (can bill as consultants for some of their services)
  - Parent Partner

Summary/Aligning Community Efforts

- Slide focused on highlighting the similarities and common goals between teams and interested parties.
- **Ex:** Our team's work closely aligned with the OHA's Triple Aim of providing:
  1. High Quality Care
  2. Increased Family & Patient Satisfaction
  3. Lower Health Care Costs
- **Ex:** Our team's work is also closely aligned with Early Learning Council Goals of:
  1. All children are kindergarten ready.
  2. Families have the information and support they need to nurture and prepare their children for school.
  3. Early Learning Services are coordinated and aligned.

Thank You

- Thank group for their time and consideration. (Should include a follow up as to when they would like to hear back from the group.)
- **Ex:** “Thank you so much for your consideration and we hope a collaborate with you further. We invite you to participate in our upcoming planning meeting on XX date.”

Thank you for your support of [INSERT NAME HERE] Child Health Team as we continue to offer services to all families of children & youth with special health needs in our community!

ABOUT THIS TOOL — *Final Sustainability Plan*

The Final Sustainability Plan document was originally developed for CCN teams that successfully secured funding to continue operating. Broadly, this tool may serve as a concrete plan for operating a child health team after a major funding opportunity ends. To think through how your team will sustain operations going forward, refer to the guiding questions in conversation with your team.

Final Sustainability Plan

Name of team:_____
Prepared by:_____
Date:_____

The Sustainability Plan is a concrete plan for operating the child health team after a major funding opportunity ends.

As a team, please answer the following questions about the plan for ongoing operations.

Describe the model of your program. Please be sure to address each bullet point.

- Who are leaders in the program?
- What organizations are committed to supporting the program? How have these relationships been formalized?
- Who, specifically, will the team serve and how will referrals be routed?
- How often will the team meet
- What will the team do, specifically? Will the team function in exactly the same way as CCN, providing evaluation of need, consultation and cross-systems care coordination through the development of a shared plan of care; Or is the new model different? If there are differences, please describe them.
- How has the model been documented and shared among partners of the "new" program?

Describe how the team will operate.
What is the administrative structure?

- Where are administrative functions located?
- How have administrative functions been formalized within an organization?
- What are the administrative functions? Examples: Requesting records, coordinating meetings, paying Parent Partner, etc.

What is the funding source?

- Is another organization "absorbing" the costs?
- Is there a new funding source? Describe how the money will flow.

What is the plan for family involvement?

- Will the team have a Parent Partner, and how will the Parent Partner be paid?

With funding and administrative support in place, what kind of additional ongoing support will your team need to continue operations? Please describe.

ABOUT THIS TOOL — *MOU & MOU Addendum Templates*

To promote sustainability, CCN teams were encouraged to formalize the relationships between team member organizations through letters of agreement or memoranda of understanding (MOUs). Having agreements in place demonstrates a level of local commitment to potential partner organizations who may adopt or fund the child health team. These MOU templates are taken from prior CCN team MOUs and are to be used as an example for informational purposes.

The last three items included in this toolkit are:

(a) A sample MOU template,
(b) An addendum to MOU to include Child Health Team standards, and
(c) An addendum to MOU to include major Child Health Team roles and responsibilities.

Memorandum of Understanding

Among

[Name of Partner Organization (acronym)]
[Name of Partner Organization (acronym)]
[Name of Partner Organization]
[Name of Partner Organization]
[Name of Partner Organization]

For the Provision of Services and Referrals Related to the
_____ Child Health Team

BACKGROUND AND MISSION

Our Child Health Team was established by the Oregon Center for Children and Youth with Special Health Needs (OCCYSHN) at OHSU as part of its Community Connections Network (CCN). The overall goal of CCN was to increase local capacity for community-based evaluation, care coordination and support of children and youth with special health care needs (CYSHCN) and their families, particularly children and families with unmet health care needs. This continues to be the goal and mission of our Child Health Team. Our team has engaged providers from different community agencies and organizations and has facilitated improved inter-agency and provider communication and community planning on health issues.

Values of our team:

- Our Child Health Team members come to the table to collaborate and ensure that families have access to needed care and services for their child.
- Our team's success depends on mutual trust and respect among all team members.
- The input of all members on our team is valued equally.
- Our team process allows the family's needs to be heard, validated and supported in a safe, nurturing and neutral environment and in partnership with professionals.
- The family and child are at the center of our team's work.
- Our Child Health Team serves all children and their families regardless of insurance type or insurance status.

PURPOSE OF THIS MEMORANDUM OF UNDERSTANDING

This Memorandum of Understanding ("MOU") is made and entered into by and among [list partners and acronyms].

This MOU is to serve as the operating agreement among the parties for the purpose of providing services and referrals related to children with special health care needs and related support to their families. The parties agree that this MOU is intended to ensure the parties' agreement and common understanding of how to work together and how to maintain the teams in the future.

CHILDREN AND YOUTH WITH SPECIAL HEALTH CARE NEEDS

Any child or youth with special health needs [aged 0-21 years of age] may be served by our Child Health Team. "Children with special health needs are those who have or are at risk for a chronic physical, developmental, behavioral or emotional conditions and who also require health and related services of a type or amount beyond that required by children generally." (McPherson, et al., 1998, p. 138).

Children with complex health conditions are *best* served by our Child Health Team. These children often have multiple service providers, and the families benefit from additional information, resources and support.

INTENDED RESULTS

Our partners share a commitment to improving access of CYSHCN and their families to comprehensive evaluation and care management services. Intended outcomes of system delivery include the following:

1. Improved access to, and quality of evaluation and care management services for CYSHCN and their families.
2. More efficient use of resources;
3. Stronger linkages to community partners;
4. Team accountability to the national standards for the system of care for CYSHCN. *Standards for Systems of Care for Children and Youth with Special Health Care Needs.* Association of Maternal Child Health Programs and Lucile Packard Foundation for Children's Health, March, 2014. (Addendum 1)
5. Mutual accountability and effective, efficient communication among partners; and
6. Sustainability of services.

GENERAL TERMS AND CONDITIONS / INDEMNIFICATION

This MOU sets the framework for coordinated policies in the following areas:

1. The underlying values and methodologies the partners will abide by in conducting the work outlined herein, as well as the competencies required.
2. Roles and responsibilities of each partner in terms of service provision to the children and families.
3. Roles and responsibilities of each partner in terms of the administrative aspects of the team.
4. The partners' agreements as to how they will work together as a team.
5. How team members are financially compensated for their work related to this partnership.
6. Where evaluations and services will be provided and where meetings will be held.
7. How to manage the exchange and disclosure of client information, subject to legal constraints of privacy and safeguards.
8. Team member attrition and identification new team members.

Each party shall defend, indemnify and hold harmless the other for its negligent acts or omission and those of its officers, employees, agents, or clients, howsoever caused.

METHODOLOGY

1. Our team ensures the roles of Team Coordinator, Parent Partner, and Professional Consultant to the team are filled per the attached document, "Roles and Responsibilities of Partners" (Addendum #2)
2. Evaluations are conducted by an interdisciplinary team of community service providers including, at a minimum, a primary care provider, a mental health provider, educational representative and our team's Parent Partner.
3. The evaluation, including which team members participate, is tailored to the needs of each child and family. Additional providers are invited as necessary to address unmet needs.
4. A shared plan of care is developed with action items for the family and services providers.
5. Reports and the shared plan of care are sent to the child's primary care provider, the family and other involved community service providers.
6. The Parent Partner supports the family in implementation of the shared plan of care.

RESPONSIBILITIES OF THE PARTIES

[Partners] agree upon the following roles and responsibilities:

[Partner 1]
[Partner 1] agrees to the following:

1. Provide administrative support to the team, including organizing meetings; securing meeting locations; drafting and disseminating meeting agenda and other documents such as community outreach materials; manage communication among team members, facilitating team meetings; [additional details to be filled in by each team]. See Addendum #2.
2. Administer payment to and liability insurance for the Parent Partner. [This will likely be a different individual/agency for different teams.] The Parent Partner is the caregiver (or has been the caregiver) of a child with special health care needs and is familiar with resources for children and families and experienced in navigating services.

[Partner 2]
[Partner 2] agrees to the following:

1. Convene and facilitate team meetings on regular basis [to be determined by the team] with support from the administrative coordinator

[Partner 3]
[Partner 3] agrees to the following:

1. Utilize their expertise on the system of services for children and youth to construct and record the shared plan of care at our Child Health Team meetings

[Partner 4]
[Parent Partner] agrees to the following

1. Supports the family in implementing the shared plan of care
2. Represents the family's perspective at meetings, as needed

[Partner 5]
[Partner 4] agrees to the following:

All Partners

All partners agree to the following:

1. Determine where team and client meetings will be held.

2. Meet regularly to discuss team issues. Make the meetings a priority; show up; and participate fully.
3. Agree on whether or not team members should send representatives if they are not able to attend a meeting, and if so, who those representatives will be.
4. Meet briefly as a group to discuss evaluation results and potential recommendations or ideas before discussing the information and developing a shared plan of care with the family.
5. Conduct regular marketing and community outreach activities to ensure the local community is aware of these services and how to access them.
6. Agree to procedures for following HIPAA and FERPA regulations in exchanging protected information.
7. Contribute expertise to developing a comprehensive picture of strengths and needs for each child and their family in conference with the family and the child's other service providers.
8. Work within their organization and with their community partners to support families served by the child health team in accessing services.

GROUP AGREEMENTS FOR WORKING TOGETHER AS A TEAM

1. Partners agree to be accountable and hold each other accountable for aligning the work with the agreed upon values, stated herein. [If the section above is deleted, then fill in a few select values, such as "child- and family-centered," "collaborative," etc.]

2. The parties agree to jointly maintain the coordination of medical, educational and other community services.

3. The parties agree to collect key data for program evaluation and, in doing so, to develop and implement formal data-sharing mechanisms that safeguard client confidentiality. Using such safeguards, partners agree to collect the following information:

    a. Number and type of referral concerns and source of referral
    b. Number of children seen, sex, age at evaluation and insurance coverage
    c. Diagnoses established and referrals made
    d. Any barriers to accessing needed services
    e. Family satisfaction

FINANCIAL COMPENSATION

[Identify compensation needs and determine how those needs will met. For example, compensation for the Parent Partner, billing for physician and mental health provider time]

SPACE, FACILITIES, AND SERVICES

The parties will come to agreement about where the work will take place. The location or locations of evaluations and meetings may be subject to change. If the locations of service provision are perceived by any team member and family to inhibit the delivery of specified services, any team member may ask to have this issue formally addressed at a regular team meeting, or, if agreeable to the other team members, at a specially scheduled meeting.

EXCHANGE OF CLIENT INFORMATION AND PRIVACY CONSIDERATIONS

Federal and State Regulatory Guidance

The Health Insurance Portability and Accountability Act (HIPAA) and regulations under Oregon laws guide management and protection of personal health information and medical records kept by doctors and school-based health centers. [List partners] in this MOU are HIPAA covered entities.

The Family Educational Rights and Privacy Act (FERPA) guides management and protection of personal information in educational settings.

Responsibilities of Partners

Partners will not use or disclose clients' personal health information in a manner that would violate the requirements of the HIPAA privacy rule, FERPA, or Oregon state regulations.

TEAM MEMBER ATTRITION AND IDENTIFICATION OF NEW TEAM MEMBERS

The parties agree to the following process for identification of new members as needed. _____.

EXECUTION OF MEMORANDUM OF UNDERSTANDING

The parties agree to the following:

1. This MOU is expressly subject to and shall not become effective or binding on any party hereto until it has been fully executed by all parties.
2. The MOU shall be binding on all parties, their successors, and assigns.
3. All parties shall review terms and conditions of the MOU during the fall quarter of each academic school year. Amendments to the MOU negotiated during the spring quarter affect terms, conditions, and binding agreements for the following school year.

4. The MOU reflects the entire MOU between the parties with respect to the subject matter hereof and supersedes all other prior oral or written statements, understandings, or correspondence.
5. The persons signing and executing the MOU have been fully authorized to execute this agreement and to validly and legally bind the partners to all the terms, performances, and provisions herein set forth.
6. The term of this MOU shall commence on [date], and shall continue for a period of one year. Thereafter, this MOU shall continue unless otherwise terminated pursuant to this paragraph. This MOU may be terminated by any partner upon 90 days written notice.

IN WITNESS WHEREOF, the parties have caused this Memorandum of Understanding to be executed.

FOR [PARTNER 1]:

_____ _____
Name Date
Title

FOR [PARTNER 2]:

_____ _____
Name Date
Title

FOR [PARTNER 3]:

_____ _____
Name Date
Title

FOR [PARTNER 4]:

_____ _____
Name Date
Title

FOR [PARTNER 5]:

_____ _____
Name Date
Title

Addendum to Memorandum of Understanding
_____Child Health Team

Our Child Health Team Standards:*

1. Our Child Health Team is made up of local health care providers, educators, mental health providers, a Parent Partner, and other community service providers in partnership with families.

2. Referrals to our Child Health Team:

    a. Any provider serving a child/youth who can benefit from a team approach to coordinated care may refer to the Child Health Team.

    b. Our Child Health Team establishes and maintains a process for prioritizing the most vulnerable children with special health care needs. If capacity is a consideration, priority will be given to:
        i. Families who report their child has unidentified needs related to health and development.
        ii. Families who report difficulty accessing or coordinating their child's care and services.

3. Our Child Health Team ensures contact with the family of a child referred to the team within 10 business days of receiving the referral.

4. Our Child Health Team reviews preliminary information and determines the team members who need to be involved and the issues to address during the evaluation pending further discussion with the family.

5. When a child is evaluated by our Child Health Team, the team in partnership with the family develops an actionable shared care plan that speaks to the continuum of the child/family experience with healthcare and related child-serving systems. The shared care plan:
    a. Is founded in and responsive to accurate and appropriate assessment of needs.
    b. Demonstrates evidence of collaboration with the child's Patient-centered Primary Care Home (PCPCH) or with primary or specialty care providers (PCP), if there is no medical home.

c. Demonstrates evidence of effective coordination with the primary care physician and specialty providers, as well as with other community services, e.g. education, mental health, developmental disabilities, child care, housing, transportation, and financial support.
d. Demonstrates evidence of child/family centeredness, including:
    i. Strategies to increase the child/family's capacity to obtain, process, and understand health and health-related information and to make informed decisions about the child's health care and developmental needs.
    ii. Evidence of shared agenda setting and decision-making with the child/family.
e. Is culturally and linguistically appropriate.
f. Supports youth transition to adult health care, work and independence.
g. Encourages families to make a follow-up appointment with the child's PCPCH (or other PCP, if no PCPCH is available) to discuss the shared care plan.
h. If there are barriers to following up with the PCPCH (or PCP), our Child Health Team will address them.
i. Is reviewed monthly. The Parent Partner's input on the ongoing or changing needs of the family is obtained, as well as the input of Child Health Team members as needed.

6. Our Child Health Team supports the child's/family's ability to implement the shared care plan, e.g. by providing health and health-related information, resources, referrals, and social supports.

7. Our Child Health Team demonstrates evidence of continuous quality improvement efforts in service of CYSHCN.

8. Child Health Team members collaborate to identify and solve systems-level problems for the population of CYSHCN.

*Our Child Health Team Standards were developed in alignment with:

Standards for Systems of Care for Children and Youth with Special Health Care Needs. Association of Maternal Child Health Programs and Lucile Packard Foundation for Children's Health, March, 2014.

Addendum to Memorandum of Understanding

_____Child Health Team

Roles and Responsibilities

A team member will serve as our **Child Health Team Coordinator**. He or she will provide administrative support to the team and will:

a. Coordinate Child Health Team meetings, including administrative tasks related to team operations, pre-meeting day logistics, meeting day activities, and post-visit follow up
b. Communicate with families of children referred to the Child Health Team to coordinate and implement child/family visits.
c. Create comprehensive files for children referred to our Child Health Team in line with Health Insurance Portability and Accountability Act (HIPAA) and Family Educational Rights and Privacy Act (FERPA) requirements. Files include records from medicine, education and community-based services.
d. Disseminate reports and shared care plans and communicate with community partners as needed to ensure effective team meetings and coordination of care.
e. Notify community service providers about the services of the Child Health Team and how to make referrals.
f. Coordinate the tracking of the child's shared care plan with the Parent Partner.

A Professional will serve as **Consultant** to our Child Health Team. He or she will contribute his or her understanding of the local system of care to the health team process. He or she will:

a. Increase awareness in the community of Child Health Team activities.
b. Notify community service providers about the services of the Child Health Team and how to make referrals.
c. Communicate with community partners as needed to ensure effective team meetings and coordination of care.
d. Support the Child Health Team Coordinator in identifying providers to attend child-specific health team meetings, in completing reports, and in problem-solving related to team operations.
e. Facilitate meetings or identify a team member to facilitate meetings.
f. Write or review shared care plans.
g. Follow up with the family, Parent Partner, the Child Health Team and the Referral Source regarding successful implementation of the shared care plan as appropriate.

h. Facilitate data collection, including program data and quality improvement data
i. Help to build and maintain membership on our Child Health Team.

A **Parent Partner** will support families through our Child Health Team process. The Parent Partner is or has previously been the caregiver of a child with special health care needs. The Parent Partner will:

a. Contact the parents before the meeting to answer questions and offer guidance and support
b. Attend the Child Health Team meeting, sit next to the family, provide emotional support and help the parent understand our Child Health Team process and recommendations.
c. Share appropriate resources with families and find resources on behalf of the team.
d. Make follow-up calls to the parent after the meeting to answer questions, check on implementation of the shared plan of care, and offer further guidance
e. Communicate information from the child and family needs assessment, including the child's unmet needs, back to our Child Health Team
f. Initiate contact with the team as needed, check email regularly and respond to email and calls in a timely manner.
g. Remind parents to respond to the family satisfaction survey, if applicable.

OCCYSHN

Oregon Center for Children and
Youth with Special Health Needs

Institute on Development and Disability
Department of Pediatrics
Oregon Health & Science University

707 S.W. Gaines St.
Portland, OR 97239
(503) 494-8303
www.occyshn.org

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