The Oregon Center for Children and Youth with Special Health Needs (OCCYSHN) works with partners around the state to convene shared care planning teams for children and youth with special health care needs (CYSHCN) in their communities. This handbook provides an overview of shared care planning, and context for how shared care planning fits into Oregon's public health landscape. It also describes how to implement shared care planning.

Shared Care Planning: An Overview

Shared care planning is a high-quality, comprehensive care coordination process. It is especially valuable for individual children and youth with special health care needs (CYSHCN) and their families. It brings the right people together at the right time to address a child's unmet needs. Family members and professionals meet to develop a plan, and the collaboration often leads to problem-solving breakthroughs.

Shared care planning is especially helpful for families who:

- face multiple barriers (or especially persistent barriers) to getting appropriate care and services for their children.
- have CYSHCN with complex health care needs.
- know their child has an undiagnosed condition, but don't know what services are needed, or how to get them.

Shared care planning gets its name because participants *share* the work of developing and implementing the care plan. The care planning team includes parents or caregivers of CYSCHN, and local professionals who can help families achieve their goals. Those professionals can include representatives from primary care, insurance, education, mental health, public health, or other community services.

Shared care planning improves communication and care coordination, which saves time and money for families and providers alike. The process allows families and providers to agree upon goals, and to leverage one another's expertise and resources to achieve those goals. Participants take mutual responsibility for creating and implementing the plan, which includes specific action steps. Developing the plan together helps hold participants accountable to one another.

In addition to serving individual CYSHCN, the shared care planning process strengthens local systems of care. Participants learn from one another and make professional connections. These connections can lead to better coordination across agencies and systems, which helps maximize local resources. Shared care planning helps professionals identify gaps, barriers, and redundancies in local systems of care for CYSHCN.

BENEFITS OF SHARED CARE PLANNING FOR FAMILIES	BENEFITS OF SHARED CARE PLANNING FOR PROVIDERS
Families' goals for their child are prioritized, which builds their confidence and leads to authentic partnership with the team	Provides professional networking opportunities and strengthens community connections
Saves families time, effort, and money on accessing services and support	Offers opportunity to brainstorm innovative strategies and solutions for families
Improves communication and coordination across systems	Improves understanding of cross-sector collaboration, and how to leverage it on behalf of patients or clients
Allows quick and efficient communication with a group of people who are positioned to help the child in various ways	Allows quick and efficient communication with a group of people who are positioned to help the child in various ways

Shared Care Planning and Statewide Health Improvement

Shared care planning aligns with Oregon's public health modernization framework and quality improvement efforts. It helps prevent costly complications born of poor communication across systems and builds cross-system partnerships. It also offers a strategy for addressing health equity for the CYSHCN population by improving access to care for CYSHCN. Shared care plans are tailored to individuals and developed with consideration for each family's culture and language.

Shared care planning is an established standard of care for CYSHCN according to the National Association of Maternal and Child Health Program's Standards for Systems of Care for Children and Youth with Special Health Care Needs. Shared care planning also supports the medical home model. A medical home builds partnerships with clinical specialists, families, and community resources.

In Oregon, primary care practices can earn a Patient-Centered Primary Care Home (PCPCH) designation, meaning they serve as a medical home for their patients. PCPCH

standards call for linking CYSHCN to local services and resources. A shared care plan offers families a roadmap for accessing those services.

Shared Care Planning Values

OCCSYHN has a long history of developing and supporting local shared care planning teams across the state, dating back to the early 90s with a program called Community Connections Network (CCN). In the more than thirty years of CCN's history, OCCYSHN observed that shared care planning works best when it is family-centered.

A family-centered approach is one that considers each child within the context of their family and community. It recognizes the primacy of family members as experts and caregivers. When care is family-centered, family members partner as equals with their child's health and service providers.

The following values come from OCCYSHN's Family-Centered Shared Care Planning Assessment Tool (FCSCPA). The FCSCPA is a quality-improvement tool. It is used to ensure that the core values of family-centered care are integrated into shared care planning. The tool was identified as a "cutting edge practice" by the National Association of Maternal & Child Health Programs.

Family-Centered Care
TEN CORE VALUES OF SHARED CARE PLANNING

Equity. The Shared Care Planning team actively applies an equity lens to its work, acknowledging that historically, racism has pervasively and negatively impacted health care for children and families.

Respectful and trusting. Shared Care Planning is dependent on mutual trust and respect among all the team members.

Transparent. The process of Shared Care Planning, and the plan itself, are continuously accessible to families and/or youth.

Responsive. The Shared Care Planning process is fluid and flexible. It responds to families' and/or youth needs and concerns. Neither process nor the participants are rushed.

Trauma-informed. The team recognizes that racism and prejudice are traumatizing. The team understands that the barriers families face can be traumatizing. The team members are aware and responsive to the possibility that others on the team may have experienced trauma.

Strengths-based. Shared care plans recognize the strengths of families, children, and youth, and builds on them to move the care plan forward.

Empowering. The Shared Care Planning process contributes to the families' and/or youths' knowledge and skills to advocate for their needs. When team members share power and offer information and choices, it can facilitate healing from trauma and prevent re-traumatization

Validating and supportive. The team values families' and/or youths' wisdom. They look for opportunities to help families and/or youth find the additional supports they want.

Efficient. The Shared Care Planning process is efficient for everyone, and families feel it is a good use of their time. The right people are invited to the table at the right time, resulting in families and/or youth coming away with a powerful tool they can use to achieve their goals.

Rewarding. Shared Care Planning is rewarding. It is collaborative, optimistic and innovative

Implementing Shared Care Planning

Identifying Candidates for Shared Care Planning

Some CYSHCN and their families benefit greatly from shared care planning, but it's not for everyone. Shared care planning can help create a comprehensive picture of what is

going on for a child. It is a good vehicle for problem-solving. This can be especially helpful when a family knows they need some support, but they aren't sure what they need or how to get it. Also consider shared care planning for children who are best served by a team-based approach, such as those encountering systemic barriers to getting appropriate care and services.

The following list describes some situations where shared care planning might help:

- The child is a CaCoon client.
- The child's medical conditions are complex.
- The child or family has considerable unmet basic needs or environmental risks.
- There are unresolved concerns that the team-based approach could help identify and address.
- The child's family experiences difficulty getting services or supports they need.
- The child's family encounters barriers to making, keeping, or getting to appointments.
- Systems do not adequately support families to complete agreed-upon plans.
- The child has an undiagnosed condition.
- The family indicated that they need more help or support.
- A youth or young adult (age 12-21) needs help planning for the transition from pediatric to adult health care.

Youth aged 12 to 21 years should be invited to participate in their own shared care planning. When a strengths-based approach is used to identify goals that *matter to the youth*, they are naturally more motivated to participate. Shared care planning benefits youth who need support to:

- Explain their medical needs to others.
- Manage their own medications.
- Recognize symptoms (including signs of a medical emergency) and know how to address them.
- Find an adult health care provider or providers.
- Make and keep health care appointments.
- Plan for potential changes in legal status (including decision-making, privacy, and consent).
- Plan for changes in insurance and access to care.

Inviting and Preparing Families

A key part of upholding family-centered values in shared care planning is preparing the family for the meeting. When a family is invited to a shared care planning meeting, they should be told the purpose of the meeting, who is calling it, and what to expect from the process. If a family agrees to participate, the following will help prepare them:

- Give the family a copy of "Shared Plans of Care: Information for Families." This document is available in five languages on OCCYSHN's shared care planning web page. Click on "Forms and Materials for Implementing Shared Care Plans" bar for the PDFs.
- Let the family know the meeting is being organized on their behalf, for their child's benefit. Be sure they understand they are not being summoned because their child is in some sort of "trouble."
- Tell the family who will be invited to participate. Welcome them to invite additional service providers, friends, or family members.
- Find a mutually agreeable time and place for the meeting.
- Ask the family to come prepared to talk about their child's strengths and needs.
- Ask the family to identify at least one specific goal for their child. Goals can relate directly to health and development, or to quality-of-life issues affected by health and development. For example: "We want to be able to go camping together as a family," or "We would like our child to have more friends."
- Youth and young adults should be prepared to talk about their own strengths, needs, and goals.
- Ask about barriers to participation and help to address them. Barriers might include access to transportation, childcare, or technology. Consider cultural differences, mobility issues, etc.
- Explain the Releases of Information. Make a plan to get them signed by a parent or legal guardian before the meeting.
- Work with the family to identify or gather pertinent records for the meeting.

Running a Shared Care Planning Meeting

Preparation

Before the meeting, prepare by:

- Arranging to meet the family's language interpretation or literacy needs.
- Taking measures to ensure culturally responsive care.

- Educating yourself and other participants about taking a trauma-informed approach to the meeting.
- Building ample time into the agenda to discuss goals or issues that arise.

Facilitation

During the meeting, ensure the following are addressed:

- **Introductions:** Everyone should know who is at the table. Reiterate that developing and implementing the care plan is a team effort.
- **Confidentiality:** Remind the team that this meeting is confidential.
- **Plain language:** Acronyms and jargon that seem familiar or obvious to the professionals at the table may not be to family members, who are often reluctant to ask. Use words familiar to most people.
- **Family Strengths and Assets:** As a team, recognize what's working well for families and use their strengths and assets as a foundation for the plan.
- **Goals:** Help the team identify a goal or goals for the child or youth, ensuring that the family's expressed needs and concerns are primary.
- **Engagement:** Ask probing questions of the team members to foster participation and encourage creative problem-solving.
- **Action Steps:** Help the team identify tangible action steps that move the child or youth toward the goals. Make clear **who** is responsible for **what**, by **when**.
- **Support:** Make sure families have the support they need to accomplish any actions they agree to pursue.
- **Reflecting Back:** Read the goals and the action plan aloud at the end. Invite people to speak up if any part of the plan doesn't reflect what they thought they heard.
- **Communication:** Establish a plan for communicating and ensuring accountability. The team should all be clear about what happens next.
- **Wrap-Up:** Ask families "What questions do you have?" This implies that any reasonable person would have questions, which differs importantly from "Do you have any questions?"
- **Written Record:** Everyone at the meeting should leave with a copy of the shared care plan. Families can use it to inform their child's health and service providers. It also serves to remind the care planning team who agreed to do what, which supports accountability. If completing and printing the plan is not possible in the moment, end the meeting by explaining how and when the completed plan will be sent to every participant.

Identifying and addressing barriers to health and well-being is a process of discovery. New information, ideas, and solutions may emerge in the course of the conversation. Effective meeting facilitation is nuanced. It allows the conversation to flow, while still keeping care planning on track.

OCCYSHN created a shared care planning template to help organize and document the meeting. The template is available on OCCYSHN's shared care planning web page. (Click on "Forms and Materials for Implementing Shared Care Plans" bar for the template. It is available in five languages.) The template can guide discussion, but it's also fine if the conversation evolves organically and does not align precisely with the template. The priority is to encourage engagement and creative problem-solving.

Shared Care Planning in External Meetings

Shared care planning can take place in the context of meetings convened for other purposes ("external meetings"). Examples include education's Individualized Education Program (IEP) and 504 meetings, Early Childhood Special Education (ECSE) Individual Family Service Plans (IFSPs) meetings, Developmental Disabilities' Individual Service Plans (ISPs) meetings, or Behavioral Health's Wraparound meetings.

Participation in external meetings may be reported to OCCYSHN as shared care planning meetings **only when the following conditions are met:**

- A written shared care plan must be developed and shared with everyone, including the family. It may look different from a shared care plan developed using the OCCYSHN template, but it must include a specific action plan. Note that it takes special attention and effort to integrate this important element of shared care planning into a meeting led by another provider, which has its own structure and process.
- The process must be family-centered, as described earlier in this handbook. Families must be prepared to participate. The plan must address goals and priorities identified by them, and the family must leave the meeting knowing what happens next. During the meeting, promote family-centered shared care planning values by modeling them, or by asking questions that incorporate them. The Family-Centered Shared Care Planning Assessment tool can help determine whether an external meeting is family-centered.

Reporting Shared Care Planning to OCCYSHN

Reporting requirements are explained in the Shared Care Planning Evaluation and Data Collection Procedures. To receive payment, a Shared Care Planning Information Form (SIF) must be submitted to OCCYSHN within 30 days of the meeting, whether it's internal or external.

OCCYSHN's shared care planning webpage provides the forms, templates, resources and information needed to implement shared care planning: https://www.ohsu.edu/occyshn/shared-care-planning