

Shared Care Planning Handbook

version 4.0

Implementing Shared Plans of Care for Children and Youth with Special Health Needs



The Oregon Center for Children and Youth with Special Health Needs is Oregon's Maternal and Child Health Bureau Title V public health agency for CYSHCN, located at OHSU's Institute on Development and Disability.

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Shared care planning is a care coordination process for individual children and youth with special health care needs (CYSHCN). The care planning is “shared” because a team of family members and professionals share the work of developing and implementing the plan. Shared care planning includes family members of CYSHCN, as well as representatives from primary care, insurance, education, mental health, public health, and other community services.

The Oregon Center for Children and Youth with Special Health Needs (OCCSYHN) contracts with public health partners around the state to convene shared care planning teams for CYSHCN in their communities. This handbook provides guidance on that process, and context for how shared care planning fits into Oregon’s public health landscape.

Shared care planning is a **family-centered** process. Family-centeredness is an approach that views children within the context of their families and communities, and which recognizes the primacy of family members as experts and caregivers. When care is family-centered, family members collaborate as equal partners with their child’s health and service providers.

Family-Centered Care

CORE VALUES OF SHARED CARE PLANNING

Families are equal members of shared care planning teams. “Family” can include parents, children and youth, and others. Every team member’s contribution is valued equally.

Shared care planning depends on mutual trust and respect. Each team member’s input is valued equally.

Neither the process nor the participants are rushed. The environment is comfortable, and it allows time and space for creative problem-solving.

The team comes to the table as allies with the family. The family (and the youth, if they are able) contribute to the action plan.

Shared care planning recognizes the value of peer support to families. Teams endorse their contribution.

Shared care plans are strengths-based, and prioritize family goals. The process builds family confidence, skills, and knowledge.

Shared care planning validates and supports families. Their time and wisdom are respected.

Shared care planning is transparent. The family has access to the care plan, understands the benefits of using it, and feels comfortable proposing changes.

Shared care planning is efficient. People who are positioned to help the family achieve their goals are invited to participate.

Shared care planning aspires to equity. The team acknowledges that race and ethnicity impact power and opportunity.

[These core values are grounded on SAMHSA’s “Trauma-Informed Approach: Key Assumptions and Principles”](#)

BENEFITS OF SHARED CARE PLANNING

When a child has chronic complicated health conditions, or when their wellbeing is affected by a combination of health and other factors (e.g. social, economic, cultural differences), families often get care and services from multiple sources. Shared care planning can help the family and the various professionals involved align their efforts. Better communication and coordination can save time and money for families and providers alike.

The process allows families and providers to agree upon goals, and to leverage one another's knowledge. Participants take mutual responsibility for creating and implementing a plan. Because the plan includes specific action steps, and because participants are accountable to one another, care and services are coordinated.

In addition to serving individual CYSHCN, the process of shared care planning 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 and address gaps, barriers, and redundancies in their local systems of care for CYSHCN.

SHARED CARE PLANNING AND STATEWIDE HEALTH IMPROVEMENT

Shared care planning aligns with Oregon's current public health modernization framework. Shared care planning can improve access to care for CYSCHN. It helps prevent costly complications born of poor communication across systems. Shared care planning builds community partnerships. Plans are tailored for individuals, and are developed with consideration for each family's culture and language.

Oregon's Coordinated Care Organizations are required to provide integrated care. Shared care planning serves that goal. Additionally, in 2013 Oregon established 16 regional Early Learning Hubs aimed at coordinating local health, education, and community services to support families, and to lay a strong foundation for children to enter school ready to learn.

Shared care planning is an established standard of care for CYSHCN, and it supports the medical home model. "A medical home builds partnerships with clinical specialists, families, and community resources."¹ Shared care planning coordinates the efforts of these partners.

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. Using care plans to guide care coordination addresses PCPCH standards aimed at care planning and coordination. The process of shared care planning links CYSHCN to local services and resources. The care plan offers families a roadmap for accessing those services. PCPCH metric 5.E.3 states "PCPCH tracks

¹ American Academy of Pediatrics. Retrieved from <https://medicalhomeinfo.aap.org/overview/pages/whatisthemedicalhome.aspx>.

referrals and cooperates with community service providers outside the PCPCH, such as dental, educational, social service, foster care, public health, non-traditional health workers and pharmacy services.” (Oregon Health Authority. 2017 Recognition Criteria for Patient-Centered Primary Care Homes.)

ESSENTIAL ELEMENTS OF SHARED CARE PLANNING

Shared care planning is intentionally flexible. It is designed to serve people with a wide variety of needs, in a wide variety of contexts. The makeup of the groups convened for shared care planning vary, as do the circumstances and needs of every family served.

OCCYSHN contracts detail the scope of work required, including numbers and characteristics of children who receive a shared care plan. Anyone implementing OCCYSHN-supported shared care planning efforts should read the scope of work in their agency’s contract to ensure compliance.

While there is no specific formula for a successful shared care planning meeting, the following elements are essential:

- Meetings take place in real time. They may be in person or virtual. The hosting agency’s information-sharing requirements must be met.
- The process and the resulting plan are appropriate for the youth or family’s language and culture.
- The plan is guided by the family’s goals (or the youth’s goals, if the youth is old enough).
- A shared care plan template is completed for every plan developed, with every section of the template completed, including an action plan with timelines. (Templates are available in five languages on OCCYSHN’s shared care planning web page.)
- The care plan that comes out of the meeting is shared with the family.
- Team members communicate between meetings as needed to make progress on the care plan.
- Data on shared care planning meetings are reported to OCCSYHN as detailed in “Shared Care Planning Evaluation and Data Collection Procedures,” which is available on the Shared Care Planning web page.
- Representatives from the following sectors are invited to participate. The primary care provider’s perspective is especially critical:
 - (1) Family of the referred child, and youth over 12 when appropriate
 - (2) Primary care provider, or their care coordinator
 - (3) School representatives (e.g. teachers, counselors, health professionals, etc.)
 - (4) Mental/behavioral health (if applicable)
 - (5) Public health
 - (6) Health insurance plan (someone familiar with getting care and service covered)

IMPLEMENTATION

Every community is unique. Each shared care planning process is different than the next. As long as the essential elements detailed above are in place, each meeting can unfold in its own way. The following guidance is for people who are new to convening shared care planning meetings, or who are encountering implementation challenges.

Engaging Local Partners

The better people understand the process of creating and using a shared care plan, the more likely they are to participate. Outreach can be formal or informal. Take time to ask potential partners about their needs, and how shared care planning might be useful to them. If there is a local program or agency you would like to engage, ask for a few minutes to talk with them about the purpose and process of shared care planning.

The following products are available on the Shared Care Planning web page. They may be useful in outreach efforts:

- Shared Care Planning: Information for Families (available in five languages)
- Shared Care Planning for Youth and Young Adults
- Shared Care Planning: An Overview (a one-page document for professionals)
- Shared Care Planning: A PowerPoint Presentation (can be customized to your needs)

Be creative about leveraging local resources. Strong interagency relationships make shared care planning easier over time. A shared care planning meeting can be a stand-alone event, or you can coordinate with other efforts, like Mental Health Wraparound or Individual Education Plan meetings. These meetings offer valuable information-sharing and relationship-building opportunities. Simply participating in them does not constitute shared care planning. However, if such teams are willing to modify or extend their process, it may be possible to engage them in shared care planning. **To qualify as shared care planning for OCCYSHN reporting purposes, meetings must include all the “essential elements” and “family-centered care core values” detailed above.**

“Care mapping” is a valuable exercise to help identify what supports, care, and services a particular family is using. A care map can clarify community partners who can contribute to the planning process. (See OCCYSHN’s shared care planning web page for resources on care mapping.)

Identifying Good Candidates for Shared Care Planning

Consider shared care planning for children who are best served by a team-based approach, such as those who are encountering systemic barriers to getting appropriate care and services, or who:

- ...pose a particular worry or concern to a health or service provider.

- ...indicate that they need more help or support.
- ...have considerable unmet basic needs or environmental risks.
- ...have trouble making, keeping, or getting to appointments.
- ...struggle to follow through with agreed-upon plans.
- ...score high on any measure of complexity of care needs.
- ...are age 12-21 and are planning for adult health care.²

Shared Care Planning for Youth

Youth (age 12-21) with special health care needs often benefit from a team-based approach to preparing for adult health care. Youth and their family members can use the shared care planning to help them plan together for this transition. When a strengths-based approach is used to identify goals that matter to *them*, youth are naturally more motivated to participate.

Examples of youth who might benefit include those who require support to:

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

Inviting a Family to Participate in Shared Care Planning

Families will be more comfortable about participating in shared care planning if they understand what to expect. The initial conversation should cover the following:

- Explain the purpose of shared care planning and details the meeting. You can use “Shared Plans of Care: Information for Families.” It’s a nice, succinct description of the shared care planning process. You can find it on OCCYSHN’s shared care planning web page.
- Explain who you plan to invite to the meeting, and ask if there are other people who should be there.
- Prepare families to talk about some specific hopes they have for their child. Offer some examples of priorities like “We want to be able to go camping together as a family,” or “We would like our child to have more friends.”
- Work out the best time and place to meet.

² 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.

- Assess and address potential barriers to participation. Barriers might include transportation or childcare issues, cultural differences, access to technology, mobility issues, etc.
- Explain Releases of Information, and make a plan to get them signed.

The Shared Care Planning Family Survey

Ensuring that family voices are heard is essential to OCCSYHN’s effectiveness. We must hear from families about their experience in order to improve shared care planning. OCCYSHN invites families to complete the survey using contact information that you provide when you submit a Shared care plan Information Form (SIF). Details about the survey are available in the *Shared Care Planning Evaluation and Data Collection Procedures*.

Please encourage families to complete the survey. Some important things to mention:

- **\$25 INCENTIVE:** This can make the difference in their decision to participate.
- **PURPOSE:** Help other families by helping improve the process.
- **PRIVACY:** Participants in their child’s care planning meeting won’t see their answers.
- **CHOICE:** Families can complete the survey over the phone, online, or with paper and pencil. The survey is available in English or Spanish.
- **NO PRESSURE:** It’s completely optional.

RUNNING A SHARED CARE PLANNING MEETING

Running a successful care planning meeting is nuanced. Identifying and addressing issues is a process of discovery. You can use the shared care planning template to guide the discussion, but you may find that the conversation evolves organically and does not align precisely with the template. This is fine and appropriate, as long as every section in the template is addressed in the course of the meeting.

Effective meeting facilitators allow the conversation to flow while still keeping it on track to address every section of the template. They also encourage quieter people to talk by asking them their opinions, so that everyone is heard. Make every effort to make family members feel comfortable. They are members of the team, on equal footing with professionals.

The following elements are part of every shared care planning meeting:

- **Introductions:** Everyone should know who is at the table. Reiterate that developing the care plan is a team effort.
- **Confidentiality:** Remind the team that this meeting is confidential.
- **Family Strengths and Assets:** Start on a positive note.
- **Goals:** Help the team identify a primary goal or goals for the child or youth, ensuring that the family’s needs and concerns are reflected in the goal(s)
- **Action Steps:** Help the team identify tangible action steps that move the child towards the goals. The action plan includes **who** is responsible for **what**, by **when**.

- 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 about the plan moving forward and ensuring accountability. The team should all be clear about what happens next.
- Wrap-Up: Ask families "What questions do you have?" This open-ended question differs importantly from "Do you have any questions?" It implies that any reasonable person would have questions.

HEALTH LITERACY: Use health literacy "universal precautions"³ throughout the shared care planning process. The concept is modelled on universal precautions for handling blood. One can't tell by looking whose blood is potentially infectious, so ALL blood is handled as if it were infectious. Similarly, one can't tell by looking who understands complex health information, so ALWAYS use plain language. Shared care plans are written in plain language. Use short words and sentences. Avoid jargon and acronyms. Everyone benefits from clear communication. (See "Resources" on the SHARED CARE PLANNING web page for more information on health literacy universal precautions.)

Sample Language for Template Sections

Child/Family Strengths and Assets - EXAMPLES

- Maria does not object to taking her medications, and even reminds her parents when it is time to take them.
- Maria has a large extended family in town who are all willing to help where they can.

Child/Family Language and Culture – SAMPLE QUESTIONS

- In what ways do friends or extended family members play a part in your child's life?
- How do community groups play a part in your family life (church, sports team, neighbor friends, etc.)?
- What should the team know about your child or family to create a plan that fits with your values and beliefs?

Child/Family Goals – QUESTIONS TO HELP IDENTIFY GOALS

- What is going well at school for your child, and what would you like to see change?
- In what ways is your child succeeding or struggling with friendships?

³ <https://www.ahrq.gov/professionals/quality-patient-safety/quality-resources/tools/literacy-toolkit/healthlittoolkit2.html>

- Are there activities your child wants to do that she can't do now? If yes, what is keeping her from those things?
- Can you talk about past efforts to support your child (from you or from others), and how they worked or didn't work?

Transition Goals for Youth and Young Adults (age 12-21) – SAMPLE GOALS

- Get a driver's license.
- Register for classes at the community college.
- Learn to take medications independently, and to get timely refills.

Brief Medical Summary

- Do you agree with this overview of your child's health right now? Are there changes you would make to the medical summary?

Brief Summary of Community and Educational Services

- What are your child's needs during the school day?
- What services does your child get outside of school? (Examples: dentist, counseling, developmental disabilities, child care, etc.)

RESOURCES

OCCYSHN's shared care planning web page has:

- Forms and Materials for Implementation
- Evaluation and Data Collection Procedures
- Selected Resources on Relevant Topics
- Literature Informing the Shared Care Planning Process

<https://www.ohsu.edu/occyshn/shared-care-planning>

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