

BEFORE EDITING

Cover Letter: Survey of Family Experiences Working with Their Child's Care Providers.
An effort to understand families' experiences working with multiple care providers for their child. For families with a child with special health care needs.

Experiences Working with Your Child's Health and Other Care Professionals Family Survey

The Oregon Center for Children and Youth with Special Health Needs (OCCYSHN) promotes optimal health, development, and well-being of Oregon's children and youth with special health needs. OCCYSHN is trying to understand how child health teams work together to help children and youth with special health care needs get the care that they need. Members of child health teams include families, local health department staff, doctors, nurses, educators, therapists, specialty medical providers, and others. Children and youth with special health care needs either have chronic health conditions, or they are at risk for having them. Those conditions can be physical, developmental, behavioral, or emotional. These children need health care and other services more than other children. Within the last two to four months you and your child have visited with a child health team.

We sent this survey to you because you told the child health team you would be willing to complete it. The answers you give helps OCCYSHN learn what it is like for you to work with several different care providers (such as doctors, nurses, educators, specialists, therapists, and others) to care for your child. The answers that all families who fill out this survey will be used to improve care planning for children and families who work with many different providers.

Your input is confidential! OCCYSHN staff are the only people who will see your answers. When OCCYSHN receives completed surveys, our staff will combine the responses from all of the families into a summary.

Your input is important! We need to hear from as many families as possible to understand what it is like for you to work with several different care providers. We hope that you will spend about 10 minutes completing our survey but if you do not want to, you do not have to. You do not have to answer every question. You also may choose to quit the survey at any time. Although we have made every effort to protect your identity, there is a minimal risk of loss of confidentiality.

Benefits: Families who complete the survey will receive a \$25 prepaid vendor card. Your answers may help OCCYSHN learn how to benefit other children and families in the future.

Costs: It will not cost you anything to complete the survey.

Participation: This survey is being overseen by an Institutional Review Board ("IRB"). You may talk to the IRB at 503-494-7887 or irb@ohsu.edu if:

- ☐ Your questions, concerns, or complaints are not being answered by the research team.
- ☐ You want to talk to someone besides the research team.
- ☐ You have questions about your rights as a research subject.
- ☐ You want to get more information or provide input about this research.

AFTER (edited for plain language)

Your Care Planning Meeting: A Survey QUESTIONS AND ANSWERS

What is this survey about?

You met with a group of people recently to talk about care and services for your child. It may have been called a care planning meeting, or a shared plan of care meeting. It probably included doctors or nurses, people from your child's school, therapists, and others. See the attached sheet called "Shared Care Planning: Information for Families" for more details.

You said you might be willing to take a survey about your care planning meeting. Attached is the survey. You don't have to take it. You can skip questions if you want to. You can quit the survey any time. There is no cost to take the survey.

Why should I take the survey?

If you take the survey, we will give you a \$25 gift card to thank you for your time. The survey is used to learn whether shared care planning meetings help. Telling us how the shared care planning process worked for you can help make the program better.

Where is this survey coming from, and who sees my answers?

The survey comes from the Oregon Center for Children and Youth with Special Health Needs (OCCYSHN). OCCYSHN is Oregon's public health agency for children with special health needs. We support shared care planning in communities all across the state.

The people who went to your care planning meeting will not see your completed survey. OCCYSHN staff are the only ones who will see that. OCCYSHN will gather surveys from many families into one report, which will not include names. That combined report will go to public health professionals like the one who called your meeting, so they can learn from families like yours. OCCYSHN will not share your name or private details, but we can't guarantee you won't be recognized from your answers.

What if I have questions or concerns about the survey?

You can contact OCCYSHN's research team:

[REDACTED]
[REDACTED]

This project is also overseen by OHSU's Institutional Review Board (503-494-7887, irb@ohsu.edu). You can contact them if:

- Your questions, concerns, or complaints are not being answered by the research team.
- You want to talk to someone besides the research team.
- You have questions about your rights as a research subject.
- You want to get more information or provide input about this research.

Finally, you can contact OHSU's integrity hotline at any time, 24/7 (1-877-733-8313). You can make an anonymous report there if you have concerns.