EVALUATION DATA COLLECTION PROCEDURES

This document describes the shared care planning evaluation procedures for local health departments (LHDs). The evaluation protocol has been approved by Oregon Health & Science University's (OHSU) Institutional Review Board (IRB) and involves three data collections:

- Shared Care Plan Information Form (SIF)
- LHD Shared Care Planning End of Year Report
- Shared Care Planning Family Survey

All data are collected through a HIPAA compliant, secure web application for online surveys, called REDCap. The following sections describe the procedures for each data collection. If you have any questions about the shared care planning evaluation, please contact OCCYSHN’s Assessment & Evaluation unit.

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Assessment & Evaluation Coordinator  
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Project Coordinator  
Assessment & Evaluation Research Associate  
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gallarde@ohsu.edu

SHARED CARE PLAN INFORMATION FORM (SIF)¹

Following the creation or re-evaluation of each shared care plan, LHD staff will complete a short form, the Shared Care Plan Information Form (SIF), online via REDCap. OCCYSHN will use these data to track the number of new care plans developed, the number of existing care plans re-evaluated, the number of care plans that serve transition-aged youth (12 years old up to their 21st birthday), the number of care plans for transition-aged youth that included transition goals, and the number of children served. The results will be used (a) for required Federal Title V Block Grant reporting, (b) to monitor LHD progress in completing their required shared care plans, and (c) to describe elements of the shared care planning process. For your reference, a copy of the SIF is attached to this document.

The procedures for completing each SIF follow.

1. Every month, OCCYSHN will send the SIF web link to all LHD shared care planning participants who are recorded in our database.
   - This web link will always be the same. The purpose for sending the link to you monthly is so that you will have easy access to the SIF.
   - If there are other LHD staff developing shared care plans, please share this web link with those staff.

¹ Note: LHDs participating in Piloting Act.md Care Coordination Teams (PACCT) will have different data collection procedures.
• A new Shared Care Plan Information Form (SIF) may be accessed any time through this web link.

2. Following the creation or re-evaluation of each shared care plan, LHD staff will click on the web link to complete the SIF.
   • LHD staff should enter the child or young adult’s initials and date of birth, the date that the shared care plan was created and/or re-evaluated, and other required information into the SIF.
   • At the end of each SIF, LHDs will be asked to enter the parent/guardian name and contact information. OCCYSHN is recruiting families to participate in the family survey. The information you provide will only be used for family survey recruitment, and will not be individually linked to SIF submissions.

3. The SIF consists of 2 pages. At the end of each page there is a submit button.
   • After completing the first page, click the first submit button.
   • Depending on your responses to the first page, you will then be taken to either questions about a new child care plan, child care plan re-evaluation, new young adult care plan, or young adult care plan re-evaluation.
   • After completing the second page, click the second submit button. The second submit button will transmit the completed SIF to us.

4. If you would like to receive an email notifying you that the SIF was successfully submitted, you can enter your email address into REDCap after you complete the entire form. A notification email will be sent to you.

5. If you would like to print out a copy of your completed SIF, you will be able to print out a copy of the SIF after completing each page. There is a “Download” button after each page of the SIF. Clicking this button will download your SIF as a PDF, which you can print out.

Other Important SIF Information:
• We will not link re-evaluations conducted in the 2017 – 2020 contract years with shared care plans initiated in the 2016-2017 contract year (year 1).
• Because we sought to avoid collecting personal health information (PHI) during 2016-2017, the SIF now collects the child/young adult’s initials and date of birth. If your data are entered accurately, it will enable us to track re-evaluations of shared care plans within and across contract year 2 (2017-2018), year 3 (2018-2019), and year 4 (2019-2020).

LHD SHARED CARE PLANNING END OF YEAR REPORT

LHD staff will complete this end of year report online via REDCap. The purpose of this report is to describe the shared care planning implementation process in detail including communication methods, service gaps and redundancies, barriers, and infrastructure developed to support shared care planning.
LHDs participating in PACCT will be asked additional questions about their experience engaging primary care and/or developing or supporting standing teams for shared care planning.

1. On September 15, 2019, OCCYSHN will email your shared care planning lead a unique web link to complete the end of year report. This is a unique web link to track responses, and should not be forwarded to others.
   - Multiple staff may provide input into the report. For example, if multiple LHD staff members are involved in the shared care planning process, these staff may discuss report questions as a group.
   - Responses may be prepared outside of the online survey (e.g., in MS Word) and then copied and pasted into REDCap for submission by the recipient of the web link. We will email a copy of the questions to your shared care planning lead.

2. The shared care planning lead will submit the LHD’s report. OCCYSHN expects the end of year report to be completed by November 5, 2019.

**SHARED CARE PLANNING FAMILY SURVEY**

OCCYSHN will collect data about family experience with the shared care planning process through an online and paper survey entitled, “Experiences Working with Your Child’s Health and Other Care Professionals.” Both the online and paper formats of the survey will be available in English and Spanish. Families will receive a $25 prepaid vendor card for participating in the survey. **OCCYSHN will be recruiting families to participate.** For your reference, a copy of the Family Survey is attached to this document and OCCYSHN’s administration procedures, follow.

1. Within 2 months following a shared care planning meeting, OCCYSHN will use the parent/guardian contact information that LHD staff entered on the SIF, to mail or email a letter to the parent asking them if they would be interested in participating in a survey about their shared care planning experience.
2. One week after the initial email or letter is mailed out, OCCYSHN will follow up with families via a telephone call.
3. Parents/guardians who report interest in participating in the survey will receive an email with a unique web link to the survey via REDCap or a paper survey via postal mail.
   - Enclosed with the paper survey will be a prepaid stamped return envelope.
4. OCCYSHN will conduct a telephone survey with parents/guardians who LHDs report are not literate on the SIF. LHDs will report whether families are literate on the SIF.

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2 Note: LHDs participating in PACCT will have different data collection procedures.
ATTACHMENTS

Copies of all data collection instruments for your reference
OCCYSHN requires that the following set of questions be completed for each shared care plan created or re-evaluated. OCCYSHN will use the results of this data collection to track local health departments’ completion for Federal grant reporting purposes and to describe elements of the shared care planning process.

If you have questions about this data collection, please contact Alison Martin, PhD, OCCYSHN Assessment & Evaluation Coordinator, 503-494-5435, martial@ohsu.edu or Sheryl Gallarde-Kim, MSc, OCCYSHN Assessment & Evaluation Research Associate, 503-494-2723, gallarde@ohsu.edu.

Thank you!

1. **What county is your local health department located in?** *(Please check one response.)*

   - [x] Baker
   - [ ] Benton
   - [x] Clackamas
   - [ ] Clatsop
   - [x] Columbia
   - [ ] Coos
   - [x] Crook
   - [ ] Curry
   - [ ] Deschutes
   - [ ] Douglas
   - [ ] Grant
   - [ ] Harney
   - [ ] Hood River
   - [ ] Jackson
   - [ ] Jefferson
   - [ ] Josephine
   - [ ] Klamath
   - [ ] Lake
   - [x] Lane
   - [ ] Lincoln
   - [ ] Linn
   - [ ] Malheur
   - [ ] Marion
   - [ ] Morrow
   - [ ] Multnomah
   - [ ] North Central (Wasco-Gilliam-Sherman)
   - [ ] Polk
   - [ ] Tillamook
   - [ ] Umatilla
   - [ ] Union
   - [ ] Wallowa
   - [ ] Washington
   - [ ] Wheeler
   - [ ] Yamhill

2. **What are the initials of the child or young adult for whom you are reporting?** *(Please enter one letter in each space.)*

   First  Middle  Last

3. **What is the date of birth for this child or young adult?** *(Please type the date in the space below using mm/dd/yyyy format.)*

   ____ ____ / ____ ____ / ____ ____

4. **What is your first name?** *(Please type the name of the person entering the data in the space below.)*

   _____________________________
5. **What is your last name?** *(Please type the name of the person entering the data in the space below.)*

________________________

6. **Did you facilitate the shared care planning meeting?** *(Please check one response.)*

   - ☐ Yes → **SKIP to Question 9**
   - ☐ No, another LHD employee facilitated the meeting → **Continue to Question 7**
   - ☐ No, the shared care planning meeting was part of an IEP/IFSP, Wraparound, or other meeting → **SKIP to Question 9**

7. **What is the name of the local health department staff person who facilitated the shared care planning meeting?** *(Please type the person’s first and last names in the space below.)*

________________________

8. **Does the person work for your local public health department?** *(Please check one response.)*

   - ☐ Yes
   - ☐ No

9. **To the best of your knowledge, what type(s) of conditions does the child or young adult have?** *(Please check one for each.)*

<table>
<thead>
<tr>
<th>Condition</th>
<th>Yes</th>
<th>No</th>
<th>I don’t know</th>
</tr>
</thead>
<tbody>
<tr>
<td>a. Medical (e.g., cystic fibrosis, muscular dystrophy, seizures, etc.)</td>
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<tr>
<td>b. Behavioral/mental (e.g., ADHD, anxiety, depression, substance abuse, etc.)</td>
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<td>c. Developmental (e.g., autism spectrum disorder, developmental delay, etc.)</td>
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<tr>
<td>d. Social complexity (e.g., domestic violence, food insecurity, homelessness or housing instability, joblessness or underemployed, parental incarceration, parental mental health conditions, etc.)</td>
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<tr>
<td>e. Other, please specify:</td>
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</tbody>
</table>
10. Are you reporting about a shared care plan for a child or young adult? *(Please check one response.)*
   - ☐ CHILD: Less 12 years old → Continue to Question 11
   - ☐ YOUNG ADULT: 12 years old up to the child’s 21st birthday → SKIP to Question 27

11. Are you reporting the initiation of a new shared care plan or the re-evaluation of an existing shared care plan? *(Please check one response.)*
   - ☐ New → Continue to Question 12
   - ☐ Re-evaluation → Skip to Question 44
Child New Shared Care Plan

12. The following questions will ask about the child for whom the shared care plan was created. On what date was the shared care planning meeting held? (Please type the date in the space below using mm/dd/yyyy format.)

___ ___ / ___ ___ / ___ ___

13. Which of the following are members of the child’s health team? (Please check one response for each.)

<table>
<thead>
<tr>
<th>Member of the Child’s Health Team</th>
<th>Yes</th>
<th>No</th>
<th>NA</th>
</tr>
</thead>
<tbody>
<tr>
<td>a. Dental or Orthodontic Health</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
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<tr>
<td>b. DHS Child Welfare</td>
<td>☐</td>
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<tr>
<td>c. DHS Developmental Disabilities (DD) Services</td>
<td>☐</td>
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<tr>
<td>d. Early Intervention/Early Childhood Special Education (EI/ECSE)</td>
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<td>e. Preschool (e.g., Head Start, Pre-K Programs, private, etc.) or School (e.g., classroom or special education teacher, school nurse, etc.)</td>
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<tr>
<td>f. Child care provider</td>
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<tr>
<td>g. Family member(s)</td>
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<td>h. Insurer (public, private, or both)</td>
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<td>i. Mental/Behavioral Health</td>
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<td>j. Primary medical care (e.g., MD, RN, care coordinator, etc.)</td>
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<td>k. Specialty medical care</td>
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<td>l. Occupational, physical, or speech therapist</td>
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<td>m. Relief Nursery</td>
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<td>o. Other, please specify:</td>
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14. If yes, how did the team member participate in the shared care planning meeting? (Please check one response for each.)

<table>
<thead>
<tr>
<th>Participation Method</th>
<th>In Person</th>
<th>By Phone</th>
<th>By Video</th>
<th>Written comment</th>
<th>Did not participate</th>
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</thead>
<tbody>
<tr>
<td>a. Dental or Orthodontic Health</td>
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<td>f. Child care provider</td>
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<td>h. Insurer (public, private, or both)</td>
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*Sheryl, please spell out “Not Applicable” in REDCap.
15. Is this child currently part of your LHD’s CaCoon caseload?
   □ Yes
   □ No

16. Did someone outside of your LHD refer this child to you to receive shared care planning?
   □ Yes → Continue to Question 17
   □ No → Skip to Question 18

17. Who referred this child to you to receive shared care planning? (Please check all that apply)

<table>
<thead>
<tr>
<th>Source</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>a. Child care provider</td>
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<tr>
<td>b. Preschool teacher (e.g., Head Start, Pre-K Programs, private, etc.)</td>
<td></td>
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<tr>
<td>c. DD Services staff</td>
<td></td>
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</tr>
<tr>
<td>d. Early Intervention/Early Childhood Special Education (EI/ECSE) staff</td>
<td></td>
<td></td>
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<tr>
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<tr>
<td>h. Primary care provider</td>
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<tr>
<td>i. Hospital or tertiary care center staff</td>
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<td>j. Other, please specify:</td>
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<td>___________________________</td>
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18. What were the reasons that your staff decided to create a shared care plan for this child? (Please check all that apply.)
☐ 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.
☐ The child poses a particular worry or concern to the provider.
☐ The child’s family experiences difficulty getting the services or supports that they need.
☐ The child’s family has trouble making, keeping, or getting to appointments.
☐ The child’s family struggles to follow through with agreed upon actions or plans.
☐ The child has an undiagnosed condition.
☐ The family indicated that they need more help or support.
☐ Other, please specify: ____________________________________________________________

19. Did the family receive a copy of the shared care plan?
   ☐ Yes
   ☐ No
20. To the best of your recollection, has this child received care from an emergency department in the past 12 months? (Please check one response.)

- Yes
- No
- I don’t know

21. Is the child currently living with a foster care family? (Please check one response.)

- Yes
- No
- I don’t know

22. How many years old is the child? (If the child is less than 1 year old, enter “0.”)

________ years

23. To the best of your knowledge, how does the child’s family identify the child’s race or ethnicity? (Please check all that apply.)

- American Indian / Alaska Native (This includes American Indians; Alaska Natives; Canadian Inuit, Metis, or First Nation; Indigenous Mexican, Central American, or South American.)
- African American / Black (This includes African American; African [Black]; Caribbean [Black]; Other Black.)
- Asian (This includes Asian Indian; Chinese; Filipino/a; Hmong; Japanese; Korean; Laotian; South Asian; Vietnamese; Other Asian.)
- Caucasian / White (This includes Eastern European; Slavic; Western European; Other White.)
- Hispanic or Latino/a (This includes Hispanic or Latino Central American; Hispanic or Latino Mexican; Hispanic or Latino South American; Other Hispanic or Latino.)
- Native Hawaiian / Pacific Islander (This includes Guamanian or Chamorro; Micronesian; Native Hawaiian; Samoan; Tongan; Other Pacific Islander.)
- Other (Please specify: ___________________)

- I don’t know
24. What is the gender identity of the child? *(Please check one response.)*
   - □ Female
   - □ Male
   - □ Other (e.g., gender nonconforming, transgender), please specify: _________________________
   - □ I don’t know

25. What is the primary language of the child’s family? *(Please check one response.)*
   - □ Cantonese
   - □ English
   - □ Mandarin
   - □ Russian
   - □ Spanish
   - □ Vietnamese
   - □ Other, please specify: _________________________

26. In your experience, how well does the child’s family comprehend materials written in English? *(Please check one response.)*
   - □ Very well
   - □ Well
   - □ Not well
   - □ Not at all well
   - □ I can’t tell
### Young Adult New Shared Care Plan

27. Are you reporting the initiation of a new shared care plan or the re-evaluation of an existing shared care plan? (Please check one response.)
   - [ ] New \(\rightarrow\) *Continue to Question 28*
   - [ ] Re-evaluation \(\rightarrow\) *Skip to Question 62*

28. The following questions will ask about the young adult for whom the shared care plan was created. On what date was the shared care planning meeting held? (Please type the date in the space below using mm/dd/yyyy format.)

   ___ ___ / ___ ___ / ___ ___

29. Which of following are members of the young adult’s health team? (Please check one response for each.)

<table>
<thead>
<tr>
<th></th>
<th>Yes</th>
<th>No</th>
<th>NA</th>
</tr>
</thead>
<tbody>
<tr>
<td>a. The young adult (for whom the shared care plan is being created)</td>
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<tr>
<td>b. Dental or Orthodontic Health</td>
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<td>c. DHS Child Welfare</td>
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<td>f. Family member(s)</td>
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<td>k. Occupational, physical, or speech therapist</td>
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<td>l. Other, <em>please specify:</em></td>
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30. *If yes,* how did the team member participate in the shared care planning meeting? (Please check one response for each.)

<table>
<thead>
<tr>
<th></th>
<th>In Person</th>
<th>By Phone</th>
<th>By Video</th>
<th>Written comment</th>
<th>Did not participate</th>
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OCCYSHN - Local Health Department (LHD)
Revised Shared Care Plan Information Form – All Forms 5/1/2019
31. Is this young adult currently part of your LHD’s CaCoon caseload?
   □ Yes
   □ No

32. Did someone outside of your LHD refer this young adult to you to receive shared care planning?
   □ Yes → Continue to Question 33
   □ No → Skip to Question 34

33. Who referred this young adult to you to receive shared care planning? *(Please check one for each.)*

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<tr>
<th>Source</th>
<th>Yes</th>
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<tr>
<td>a. DD Services staff</td>
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<td>b. Insurer (public or private)</td>
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<td>c. Mental/behavioral health provider</td>
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<td>d. School staff (e.g., classroom or special education teacher, school nurse, etc.)</td>
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<td>e. Primary or specialty provider</td>
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<td>f. Hospital or tertiary care center staff</td>
<td>☐</td>
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<td>g. Other, please specify: ________________________</td>
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34. What were the reasons that your staff decided to create a shared care plan for this young adult? *(Please check all that apply.)*

   □ The young adult is a CaCoon client.
   □ The young adult’s medical conditions are complex.
   □ The young adult or family has considerable unmet basic needs or environmental risks.
   □ The young adult poses a particular worry or concern to the provider.
   □ The young adult or their family experiences difficulty getting the services or supports that they need.
   □ The young adult’s family has trouble making, keeping, or getting to appointments.
   □ The young adult’s family struggles to follow through with agreed upon actions or plans.
   □ The young adult has an undiagnosed condition.
   □ The young adult is in need of support to transition from a pediatric to an adult model of health care (e.g., young adult cannot yet explain their medical needs to others; recognize symptoms of their conditions, including those indicating a medical emergency; identify an adult care provider; make their own medical appointments or arrange transportation to appointments.
   □ The family requires support to understand changes that will occur when their child transitions from a pediatric to an adult model of health care (e.g., legal changes, such as changes in decision-making,
privacy, and consent when their young adult turns 18; changes in insurance and access to care when their young adult turns 18).

☐ The family indicated that they need more help or support.

☐ Other, please specify: ____________________________________________________________

35. Do one or more of the young adult’s goals address transitioning to an adult model of health care? (Please check one response.)
   ☐ Yes → Continue to Question 36
   ☐ No → SKIP to Question 37

36. What is the transition goal(s)? (Please write the goal(s) in the space that follows.)

a. 

b. 

c. 

d. 

37. Did the young adult and family receive a copy of the shared care plan?
   ☐ Yes
   ☐ No

38. To the best of your recollection, has this young adult received care from an emergency department in the past 12 months? (Please check one response.)
   ☐ Yes
   ☐ No
   ☐ I don’t know

39. How many years old is the young adult? (Please type a number in the space below.)
   ________ years

40. To the best of your knowledge, how does the young adult identify their race or ethnicity? (Please check all that apply.)
   ☐ American Indian / Alaska Native (This includes American Indians; Alaska Natives; Canadian Inuit, Metis, or First Nation; Indigenous Mexican, Central American, or South American.)
   ☐ African American / Black (This includes African American; African [Black]; Caribbean [Black]; Other Black.)
   ☐ Asian (This includes Asian Indian; Chinese; Filipino/a; Hmong; Japanese; Korean; Laotian; South Asian; Vietnamese; Other Asian.)
☐ Caucasian / White (This includes Eastern European; Slavic; Western European; Other White.)
☐ Hispanic or Latino/a (This includes Hispanic or Latino Central American; Hispanic or Latino Mexican; Hispanic or Latino South American; Other Hispanic or Latino.)
☐ Native Hawaiian / Pacific Islander (This includes Guamanian or Chamorro; Micronesian; Native Hawaiian; Samoan; Tongan; Other Pacific Islander.)
☐ Other (Please specify: ___________________)

☐ I don’t know

41. What is the gender identity of the young adult? (Please check one response.)
☐ Female
☐ Male
☐ Other (e.g., gender nonconforming, transgender), please specify: _________________________

☐ I don’t know

42. What is the primary language of the young adult? (Please check one response.)
☐ Cantonese
☐ English
☐ Mandarin
☐ Russian
☐ Spanish
☐ Vietnamese
☐ Other, please specify: _________________________

43. In your experience, how well does the young adult comprehend materials written in English? (Please check one response.)
☐ Very well
☐ Well
☐ Not well
☐ Not at all well

☐ I can’t tell
Child Re-evaluation Shared Care Plan

44. The following questions will ask about the child for whom the shared care plan was re-evaluated. On what date was the shared care plan re-evaluated? (Please type the date in the space below using mm/dd/yyyy format.)

____ ____ / ____ ____ / ____ ____

45. On what date was this child’s shared care plan initially created? (Please type the date in the space below using mm/dd/yyyy format.)

____ ____ / ____ ____ / ____ ____

46. Which of following are members of the child’s health team? (Please check one response for each.)

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<td>a. Dental or Orthodontic Health</td>
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<tr>
<td>b. DHS Child Welfare</td>
<td>□</td>
<td>□</td>
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<tr>
<td>c. DHS Developmental Disabilities (DD) Services</td>
<td>□</td>
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<tr>
<td>d. Early Intervention/Early Childhood Special Education (EI/ECSE)</td>
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<td>e. Preschool (e.g., Head Start, Pre-K Programs, private, etc.) or School (e.g., classroom or special education teacher, school nurse, etc.)</td>
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<td>f. Child care provider</td>
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<td>g. Family member(s)</td>
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<td>h. Insurer (public, private, or both)</td>
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<td>i. Mental/Behavioral Health</td>
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<td>j. Primary medical care (e.g., MD, RN, care coordinator, etc.)</td>
<td>□</td>
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<td>k. Specialty medical care</td>
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<td>l. Occupational, physical, or speech therapist</td>
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<td>m. Relief Nursery</td>
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<td>n. WIC</td>
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<td>o. Other, please specify:</td>
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If yes, how did the team member participate in the shared care plan meeting? (Please check one response for each.)

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47. If yes, how did the team member participate in the shared care plan meeting? (Please check one response for each.)
48. Where does your local public health department store this child’s shared care plan? (Please enter your response in the space below.)


49. How many goals did the initial shared care plan include? (Please enter a number in the space below.)
   _____ goals

50. Of those goals, how many were completed by the time of the re-evaluation? (Please enter a number in the space below.)
   _____ completed goals

51. When the child health team members complete their assigned actions, how did they let other team members, including the family, know of their completion? (Please enter your response in the space below.)


52. Did the child health team create new goals when this shared care plan was re-evaluated? (Please check one response.)
   □ Yes ➔ Continue to Question 53
   □ No ➔ Skip to Question 54

53. How many new goals were created? (Please enter a number in the space below.)
   _____ new goals

54. Did the family receive a copy of the re-evaluated shared care plan?
   □ Yes
   □ No

55. To the best of your recollection, has this child received care from an emergency department in the past 12 months? (Please check one response.)
   □ Yes
   □ No
   □ I don’t know
56. Is the child currently living with a foster care family? (Please check one response.)

- [ ] Yes
- [ ] No
- [ ] I don’t know

57. How many years old is the child? (If the child is less than 1 year old, enter “0.”)

__________ years

58. To the best of your knowledge, how does the child’s family identify the child’s race or ethnicity? (Please check all that apply.)

- [ ] American Indian / Alaska Native (This includes American Indians; Alaska Natives; Canadian Inuit, Metis, or First Nation; Indigenous Mexican, Central American, or South American.)
- [ ] African American / Black (This includes African American; African [Black]; Caribbean [Black]; Other Black.)
- [ ] Asian (This includes Asian Indian; Chinese; Filipino/a; Hmong; Japanese; Korean; Laotian; South Asian; Vietnamese; Other Asian.)
- [ ] Caucasian / White (This includes Eastern European; Slavic; Western European; Other White.)
- [ ] Hispanic or Latino/a (This includes Hispanic or Latino Central American; Hispanic or Latino Mexican; Hispanic or Latino South American; Other Hispanic or Latino.)
- [ ] Native Hawaiian / Pacific Islander (This includes Guamanian or Chamorro; Micronesian; Native Hawaiian; Samoan; Tongan; Other Pacific Islander.)
- [ ] Other (Please specify: ___________________)
  -- -- --
- [ ] I don’t know

59. What is the gender identity of the child? (Please check one response.)

- [ ] Female
- [ ] Male
- [ ] Other (e.g., gender nonconforming, transgender), please specify: __________________________
  -- -- --
- [ ] I don’t know
60. What is the primary language of the child’s family? *(Please check one response.)*
   - Cantonese
   - English
   - Mandarin
   - Russian
   - Spanish
   - Vietnamese
   - Other, please specify: _________________________

61. In your experience, how well does the child’s family comprehend materials written in English? *(Please check one response.)*
   - Very well
   - Well
   - Not well
   - Not at all well
   - I can’t tell
**Young Adult Re-evaluation Shared Care Plan**

62. The following questions will ask about the young adult for whom the shared care plan was re-evaluated. On what date was the shared care plan re-evaluated? *(Please type the date in the space below using mm/dd/yyyy format.)*

___ ___ / ___ ___ / ___ ___

63. On what date was this young adult’s shared care plan initially created? *(Please type the date in the space below using mm/dd/yyyy format.)*

___ ___ / ___ ___ / ___ ___

64. Which of following are members of the young adult’s health team? *(Please check one response for each.)*

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<tr>
<th></th>
<th>Yes</th>
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<td>a. The young adult (for whom the shared care plan is being created)</td>
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<td>b. Dental or Orthodontic Health</td>
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<td>c. DHS Child Welfare</td>
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<td>d. DHS Developmental Disabilities (DD) Services</td>
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<td>e. School (e.g., classroom or special education teacher, school nurse)</td>
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<td>g. Insurer (public, private, or both)</td>
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<td>h. Mental/Behavioral Health</td>
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<td>j. Specialty medical care</td>
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<td>k. Occupational, physical, or speech therapist</td>
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<td>l. Other, please specify:</td>
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65. *If yes, how did the team member participate in the shared care planning meeting?* *(Please check one response for each.)*

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<th>In Person</th>
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<th>Did not participate</th>
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66. Where does your local public health department store this young adult’s shared care plan? (Please enter your response in the space below.)

67. How many goals did the initial shared care plan include? (Please enter a number in the space below.)
   __________ goals

68. Of those goals, how many were completed by the time of the re-evaluation? (Please enter a number in the space below.)
   __________ completed goals

69. When the child health team members completed their assigned actions, how did they let other team members, including the family, know of their completion? (Please enter your response in the space below.)

70. Did the child health team create new goals when this shared care plan was re-evaluated? (Please check one response.)
   □ Yes  \rightarrow  Continue to Question 71
   □ No  \rightarrow  Skip to Question 72

71. How many new goals were created? (Please enter a number in the space below.)
   __________ new goals

72. Does one or more of the shared care plan goals address transitioning to an adult model of health care? (Please check one response.)
   □ Yes  \rightarrow  Continue to Question 73
   □ No  \rightarrow  SKIP to Question 75
73. What is the transition goal(s)? *(Please write the goal(s) in the space that follows.)*
   
a. 
   
b. 
   
c. 
   
d. 

74. Has the transition goal(s) been completed? *(Please check one response.)*
   
   - Yes, all of the transition goals have been completed.
   - Yes, some of the transition goals have been completed.
   - No, none of the transition goals have been completed.

75. Did the young adult and family receive a copy of the re-evaluated shared care plan?
   
   - Yes
   - No

76. To the best of your recollection, has this young adult received care from an emergency department in the past 12 months? *(Please check one response.)*
   
   - Yes
   - No
   - I don’t know

77. How many years old is the young adult? *(Please type a number in the space below.)*
   
   ________ years

78. To the best of your knowledge, how does the young adult identify their race or ethnicity? *(Please check all that apply.)*
   
   - American Indian / Alaska Native *(This includes American Indians; Alaska Natives; Canadian Inuit, Metis, or First Nation; Indigenous Mexican, Central American, or South American.)*
   - African American / Black *(This includes African American; African [Black]; Caribbean [Black]; Other Black.)*
   - Asian *(This includes Asian Indian; Chinese; Filipino/a; Hmong; Japanese; Korean; Laotian; South Asian; Vietnamese; Other Asian.)*
   - Caucasian / White *(This includes Eastern European; Slavic; Western European; Other White.)*
   - Hispanic or Latino/a *(This includes Hispanic or Latino Central American; Hispanic or Latino Mexican; Hispanic or Latino South American; Other Hispanic or Latino.)*
   - Native Hawaiian / Pacific Islander *(This includes Guamanian or Chamorro; Micronesian; Native Hawaiian; Samoan; Tongan; Other Pacific Islander.)*
□ Other (Please specify: ___________________)  
-- -- --  
□ I don’t know  

79. What is the gender identity of the young adult? (Please check one response.)  
□ Female  
□ Male  
□ Other (e.g., gender nonconforming, transgender), please specify: ________________________________  
-- -- --  
□ I don’t know  

80. What is the primary language of the young adult? (Please check one response.)  
□ Cantonese  
□ English  
□ Mandarin  
□ Russian  
□ Spanish  
□ Vietnamese  
□ Other, please specify: ________________________________

81. In your experience, how well does the young adult comprehend materials written in English? (Please check one response.)  
□ Very well  
□ Well  
□ Not well  
□ Not at all well  
-- -- --  
□ I can’t tell  

[The following items will be placed at the end of every SIF]

OCCYSHN is recruiting families to participate in the family survey. Please report the parent/guardian’s name and contact information below. The information you provide will only be used for family survey recruitment, and will not be individually linked to SIF submissions.
Family Contact Information

I. What is the parent/guardian’s name?

___________________________________________________________

II. What is the parent/guardian’s email address (if applicable)?

_____________________________________________________________

III. What is the parent/guardian’s telephone number (if applicable)?

_____________________________________________________________

IV. What is the parent/guardian’s postal mailing address?

_____________________________________________________________

V. Is the parent/guardian able to read and write? *(OCCYSHN is asking this question to determine whether we will need to obtain consent and collect data over the telephone.)*

☐ The parent/guardian can read and write in English.

☐ The parent/guardian can read and write in Spanish.

☐ The parent/guardian cannot read or write in English or Spanish.

☐ Other, please explain: ________________________________________________________
LHD Shared Care Planning Process End of Year Survey 2018-2019
(To be administered online via REDCap)

The purpose of having local health departments (LHD) complete this end of year survey is to learn about your shared care planning process. If you have questions about this data collection, please contact Alison Martin, PhD, OCCYSHN Assessment & Evaluation Coordinator, 503-494-5435, martinal@ohsu.edu or Sheryl Gallarde-Kim, MSc, OCCYSHN Assessment & Evaluation Research Associate, 503-494-2723, gallarde@ohsu.edu.

Thank you!

1. Has your local health department completed at least one shared care plan this year?
   - Yes, we have completed one or more shared care plan.  \( \rightarrow \) Go to Question 2
   - No, we have not yet completed any shared care plan.  \( \rightarrow \) Go to Question 10

2. How does your local health department find children or youth for whom shared care plans will be created?
   (Please be specific.)

3. A child health team is the group of people who collaborate to create and maintain the shared care plan. What means of communicating among child health team members have you used in your shared care planning process? (Please check all that apply.)
   - In person meetings
   - Telephone conference calls
   - Video conference calls
   - Webinar
   - Multiple methods used simultaneously
   - Other, please specify: ______________________________________________________________________

4. After the shared care plan is created, how do families access it? (Please check all that apply.)
   - Our LHD staff hand-deliver or mail a hard copy of the plan to the families.
   - Our LHD staff email a copy of the plan to the families.
   - Families access the plan online.
   - Other, please specify: ______________________________________________________________________

5. After the shared care plan is created, how do non-family members of your child health teams access it? (Please check all that apply.)
   - Our LHD staff hand-deliver or mail a hard copy of the plan to team members.
   - Our LHD staff email a copy of the plan to team members.
   - Our LHD staff fax a copy of the plan to team members.
   - Team members access the plan online.
   - Other, please specify: ______________________________________________________________________

6. After completing their assigned actions, how does a member of the child health team let the other team members know that their action is completed? (Please be specific.)

7. What barriers have your child health teams encountered in collaborating to create shared care plans? (Please be specific and provide examples, but do not include names or other identifiable information. We’re expecting at least 3 sentences.)
8. In coordinating care using a shared care plan, what gaps in care or services for CYSHCN and their families have your child health teams encountered? (Please be specific when answering this question. Please provide an example if you are able.)

For this question, we define care or service gaps as physical, mental, or dental health care; occupational, physical, or speech therapy; educational supports or services; or social services or supports that your child health teams observe are needed for a child or family but not available to them. The care or service is not available for a variety of reasons that include, but are not limited to: geography, eligibility, cost to family, lack of insurance coverage, wait lists, and so forth.

9. In coordinating care using a shared care plan, what redundancies have your child health teams observed? (Please be specific when answering this question. Please provide an example if you are able.)

For this question, we define redundancies as health care and services that are provided to an individual child by more than one professional. For example, ASQs being done for a child by multiple providers, a child having both a DD case manager and school case manager, or a child receiving OT services from their private insurance provider and Early Intervention.

10. What has prevented your local health department from creating shared care plans? (Please be specific.)

Hide this question if respondent answers “Yes” to Question 1.

11. Has your local health department tried to find children who could benefit from shared care planning? 

Hide this question if respondent answers “Yes” to Question 1.

□ Yes → Go to Question 12
□ No → Go to Question 13

12. How does your local health department find children who could benefit from shared care planning? (Please be specific.)

Hide this question if respondent answers “Yes” to Question 1.

13. What has prevented your local health department from trying to find children who could benefit from shared care planning? (Please be specific.)

OR “Yes” to Question 11.

14. What challenges, if any, have you experienced engaging in shared care planning for transition-aged youth?

15. What existing resources have helped the members of your child health teams with shared care planning? (Please check all that apply.)

□ Communication technology (e.g., computers, conference call lines, laptops, telephones, etc.)
□ LHD staff time
□ Meeting space (location for meetings to occur)
□ Parent Partners (Parent Partners are parents or primary caregivers of CYSHCN who have received specialized training to coach and mentor other parents to effectively advocate for their own child and to be an equal partner in service delivery and policy)
□ Child health team member staff time
□ Relationships among child health team member organizations
□ Support from LHD leadership
16. Has your LHD ever decided not to do shared care planning for a child or young adult who was referred to your LHD? (Please check one response)
   □ Yes → Continue to Question 17
   □ No → Skip to Question 18
   □ I don’t know → Skip to Question 18

17. What reasons contributed to your LHD’s decision not to do shared care planning for a child or young adult? (Please be specific when answering this question)

18. In August 2018, OCCYSHN provided your LHD with an additional $10,000 to support the development of infrastructure (i.e., partnerships, processes, tools & technology, policies) for your shared care planning work. What goal(s) did you set out to accomplish with these funds? (Please be specific when answering this question)

19. As of the date that you are completing this report, has your LHD spent the all, or nearly all, of it’s $10,000 infrastructure funds?
   □ Yes → Go to Question 20
   □ No → If no, i. What progress have you made toward achieving the infrastructure goals described in the previous question? (Please be specific when answering this question and provide examples.) Respondent is then taken to Question 24.

20. Did your LHD use these funds to develop partnerships to support shared care planning?
   □ Yes → If yes, i. What partnerships did your LHD develop, and what results were achieved? (Please be specific when answering this question and provide examples.)
   □ No

21. Did your LHD use these funds to develop or enhance processes to support shared care planning?
   □ Yes → If yes, i. What processes did your LHD develop, and what results were achieved? (Please be specific when answering this question and provide examples.)
   □ No

22. Did your LHD use these funds to develop or adopt tools and/or technology to support shared care planning?
   □ Yes → If yes, i. What tools or technology did you develop/adopt, and what results were achieved? (Please be specific when answering this question and provide examples.)
   □ No

23. Did your LHD use these funds to develop policies to support shared care planning?
   □ Yes → If yes, i. What policies did your LHD develop, and what results were achieved? (Please be specific when answering this question and provide examples.)
   □ No

24. What did you learn from creating shared care plans during this contract year? How did you apply the learning to improve your implementation of the process?
25. What else do you want to tell us about your experiences coordinating care using shared care plans?

IRB Note: The following questions will be asked of the 5 counties participating in the ACT.md Pilot.

26. Did your county have an existing standing care coordination team at the start of this project?
   □ Yes → Go to Question 27.
   □ No → Go to Question 30.

27. If yes to question 26, can you describe your county’s existing standing care coordination team? (Please describe its purpose and who led the team.) (After responding continue to Question 28.)

28. Which type of agencies or organizations were represented on your standing care coordination team? (Please check one for each type of agency.)

<table>
<thead>
<tr>
<th>Agency Type</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>Behavioral/mental health</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Early Intervention/Early Childhood Special Education (EI/ECSE)</td>
<td></td>
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<tr>
<td>Elementary or secondary education</td>
<td></td>
<td></td>
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<tr>
<td>Payors</td>
<td></td>
<td></td>
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<tr>
<td>Primary healthcare</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Public health nurses</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other, please specify</td>
<td></td>
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</tr>
</tbody>
</table>

If yes to Primary healthcare, answer question 28a.

28a. Has the representative of primary care attended more than half of your standing team meetings this year?
   □ Yes
   □ No

29. If yes to question 26, Did you recruit additional agencies or organizations to participate in your standing care coordination team? (After responding, participant will go to Question 32.)
   □ Yes, please specify which types of agencies or organizations ____________________________
   □ No

30. Which type of agencies or organizations did you attempt to recruit for your standing care coordination team? (Please check one for each type of agency.)

<table>
<thead>
<tr>
<th>Agency Type</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>Behavioral/mental health</td>
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<td>Public health nurses</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other, please specify</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

If yes to Primary healthcare, answer question 28a.
31. Did any of those agencies or organizations decline to participate?
   □ Yes, please specify reasons for declining _____________________________
   □ No

32. From April 1, 2019 until now, how many times has your standing care coordination team met? (Please enter a whole number in the space below.)
   __________

33. From April 2019 until now, has your team formally agreed to use any of the following group processes? By “formally,” we mean that your team discussed the process and agreed as a group to consistently use a specific approach. (Please check one for each.)

<table>
<thead>
<tr>
<th>Yes, our team agreed to an approach</th>
<th>Yes, our team discussed but has not yet agreed on an approach</th>
<th>No, our team has not yet discussed any approaches</th>
<th>I don't know</th>
</tr>
</thead>
<tbody>
<tr>
<td>a. Determining shared care planning meeting logistics</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>b. Establishing roles or responsibilities for team members</td>
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<tr>
<td>c. Determining how a parent partner may be part of the team</td>
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<tr>
<td>d. Determining the sub-population of CYSHCN who will be best served by the team process</td>
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<tr>
<td>e. Establishing a process to receive referrals</td>
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<tr>
<td>f. Establishing and maintaining a triage system for referrals</td>
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<tr>
<td>g. Establishing a process for reaching out to families of CYSHCN referred to the team</td>
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<tr>
<td>h. Determining a process for preparing families to participate in the shared care planning process</td>
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<tr>
<td>i. Establishing a process for doing or obtaining assessments needed to address family or youth goals</td>
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<tr>
<td>j. Establishing a process for the actual co-production of a shared care plan with a family</td>
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<tr>
<td>k. Establishing a process for reviewing open care plans, including tracking actions and updating plans</td>
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<tr>
<td>l. Establishing criteria or procedures for discharging a child, youth, or family from shared care planning</td>
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<tr>
<td>m. Establishing a process for continuous quality improvement of the shared care planning process</td>
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<td></td>
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</tbody>
</table>
34. Thus far, how has your LPHA, partner organizations, and/or CYSHCN and their families benefited from your organization's participation in the standing care coordination pilot using ACT.md and the ECHO learning collaborative model?

35. Thus far, what challenges have your LPHA, partner organizations, and/or CYSHCN and their families experienced from your organization's participation in the standing care coordination team pilot using ACT.md and the ECHO learning collaborative model?

36. What else would you like to tell us about your organization's participation in the standing care coordination pilot using ACT.md and the ECHO learning collaborative model?
Working with Your Child’s Health Care and Service Providers

Earn a $25 gift card for your input! The purpose of this survey is to hear from families about their experiences getting care and services for their children. This input will help us improve services and systems for all Oregon’s children and youth with special health needs.
**Survey Information**

**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 care planning meeting. It probably included doctors or nurses, people from your child’s school, therapists, and others. It may also have been part of an Individual Education Plan (IEP) or Individual Family Service Plan (IFSP) meeting. This survey is about your care planning meeting. Attached is the survey.

**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. OCCYSHN supports shared care planning in communities across the state. Your child’s public health nurse shared your contact information with OCCYSHN to invite you to take the survey.

The people who went to your care planning meeting will not see your answers. OCCYSHN staff are the only ones who will see your answers to the survey questions. OCCYSHN will gather responses from many families into one report, which will not include your name. Although OCCYSHN will make every effort to protect your identity, we can’t completely guarantee confidentiality.

**Why should I take the survey?**
- Your input will help improve shared care planning for other Oregon children and families.
- Results from all families will help us learn more about what families need, and whether shared care planning meetings help.
- You don’t have to take the survey.
- There is no cost to take the survey. You can skip questions if you want to, and you can quit the survey any time.
- If you take the survey, we will give you a $25 gift card to thank you for your time.

**What if I have questions or concerns about the survey?**
You can contact OCCYSHN’s research team:

**Sheryl Gallarde-Kim, MSc, Project Coordinator:** 503-494-2723, gallarde@ohsu.edu

**Alison J. Martin, Ph.D., Principal Investigator:** 503-494-5435, martial@ohsu.edu

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 participant.
- 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.

**OHSU IRB No. STUDY00016550**

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**FOR YOUR REFERENCE - PLEASE DO NOT DISSEMINATE TO FAMILIES**
A doctor, nurse, or someone from your child's school gave you this survey. Please think about your child who works with that professional while you answer the questions in this survey.

1. In the last 6 months, did your child receive all needed routine preventive care, such as a physical examination, a well-child check up, or vaccinations? (Please check one response.)
   - Yes
   - No
   - My child did not need routine preventive care in the last 6 months.

2. In the last 6 months, did your child receive all needed care from a specialty doctor (such as a cardiologist, developmental pediatrician, geneticist, neurologist, etc.)? (Please check one response.)
   - Yes
   - No
   - My child did not need care from a specialty doctor in the last 6 months.

3. In the last 6 months, did your child receive all needed mental health care or counseling? (Please check one response.)
   - Yes
   - No
   - My child did not need mental health care or counseling in the last 6 months.

4. In the last 6 months, did your child receive all needed dental care (such as preventive checkups, cleanings, and emergency dental care)? (Please check one response.)
   - Yes
   - No
   - My child did not need dental care in the last 6 months.

5. In the last 6 months, did your child receive all needed prescription medication? (Please check one response.)
   - Yes
   - No
   - My child did not need prescription medication in the last 6 months.

6. In the last 6 months, did your child receive all needed physical, occupational, or speech therapy? (Please check one response.)
   - Yes
   - No
   - My child did not need physical, occupational, or speech therapy in the last 6 months.

7. In the last 6 months, did your child receive all needed professional home health care? ("Home health care" is provided in the home by healthcare professionals who help with your child's daily needs and activities.) (Please check one response.)
   - Yes
   - No
   - My child did not need professional home health care in the last 6 months.

8. In the last 6 months, did you receive all needed counseling on nutrition or diet for your child? (Please check one response.)
   - Yes
   - No
   - I did not need counseling on nutrition or diet for my child in the last 6 months.

9. In the last 6 months, did your child receive all needed interventions such as ABA (Applied Behavioral Analysis) or play therapy? (Please check one response.)
   - Yes
   - No
   - My child did not need ABA or play therapy in the last 6 months.

10. In the last 6 months, did you receive all needed help finding a good preschool, daycare, or school for your child? (Please check one response.)
    - Yes
    - No
    - I did not need help finding a good preschool, daycare, or school for my child in the last 6 months.

11. In the last 6 months, did you receive all needed help communicating with preschool, daycare, or school for your child? (Please check one response.)
    - Yes
    - No
    - I did not need help communicating with preschool, daycare, or school for my child in the last 6 months.
12. In the last 6 months, did you receive all needed help getting transportation? (Please check one response.)
   □ Yes
   □ No
   □ I did not need help getting transportation in the last 6 months.

13. In the last 6 months, did you receive all needed help buying healthy food? (Please check one response.)
   □ Yes
   □ No
   □ I did not need help buying healthy food in the last 6 months.

14. In the last 6 months, did you receive all needed help finding or keeping housing? (Please check one response.)
   □ Yes
   □ No
   □ I did not need help finding or keeping housing in the last 6 months.

15. In the last 6 months, did you receive all needed help getting or keeping health insurance? (Please check one response.)
   □ Yes
   □ No
   □ I did not need help getting or keeping health insurance in the last 6 months.

16. In the last 6 months, did you receive all needed help keeping your child safe? (Please check one response.)
   □ Yes
   □ No
   □ I did not need help keeping my child safe in the last 6 months.

17. In the last 6 months, did you receive all needed help communicating with doctors, nurses, or other health care providers? (Please check one response.)
   □ Yes
   □ No
   □ I did not need help communicating with doctors, nurses, or other health care providers in the last 6 months.

18. During the last 6 months, how often were you frustrated in your efforts to get services for your child? (Please check one response.)
   □ Never
   □ Sometimes
   □ Usually
   □ Always

---

**Family Skills and Confidence**

For the next set of questions, think about yourself, not other people who may be involved in caring for and making decisions about your child. Please check one response for each question.

19. I feel that I have a right to approve all services my child receives. (Please check one response.)
   □ Never
   □ Seldom
   □ Sometimes
   □ Often
   □ Very Often
   --
   □ Not applicable

20. When problems arise with my child, I handle them pretty well. (Please check one response.)
   □ Never
   □ Seldom
   □ Sometimes
   □ Often
   □ Very Often
   --
   □ Not applicable

21. I feel confident in my ability to help my child grow and develop. (Please check one response.)
   □ Never
   □ Seldom
   □ Sometimes
   □ Often
   □ Very Often
   --
   □ Not applicable
22. I know the steps to take when I am concerned my child is receiving poor services. *(Please check one response.)*
- Never
- Seldom
- Sometimes
- Often
- Very Often
- Not applicable

23. I make sure that professionals understand my opinions about what services my child needs. *(Please check one response.)*
- Never
- Seldom
- Sometimes
- Often
- Very Often
- Not applicable

24. I know what to do when problems arise with my child. *(Please check one response.)*
- Never
- Seldom
- Sometimes
- Often
- Very Often
- Not applicable

25. I feel like my family life is under control. *(Please check one response.)*
- Never
- Seldom
- Sometimes
- Often
- Very Often
- Not applicable

26. I am able to make good decisions about what services my child needs. *(Please check one response.)*
- Never
- Seldom
- Sometimes
- Often
- Very Often
- Not applicable

27. I am able to work with agencies and professionals to decide what services my child needs. *(Please check one response.)*
- Never
- Seldom
- Sometimes
- Often
- Very Often
- Not applicable

28. I make sure I stay in regular contact with professionals who are providing services to my child. *(Please check one response.)*
- Never
- Seldom
- Sometimes
- Often
- Very Often
- Not applicable

29. I am able to get information to help me better understand my child. *(Please check one response.)*
- Never
- Seldom
- Sometimes
- Often
- Very Often
- Not applicable

30. My opinion is just as important as professionals’ opinions in deciding what services my child needs. *(Please check one response.)*
- Never
- Seldom
- Sometimes
- Often
- Very Often
- Not applicable

31. I tell professionals what I think about services being provided to my child. *(Please check one response.)*
- Never
- Seldom
- Sometimes
- Often
- Very Often
- Not applicable
32. I believe I can solve problems with my child when they happen. *(Please check one response.)*
☐ Never
☐ Seldom
☐ Sometimes
☐ Often
☐ Very Often
☐ Not applicable

33. I know what services my child needs. *(Please check one response.)*
☐ Never
☐ Seldom
☐ Sometimes
☐ Often
☐ Very Often
☐ Not applicable

34. When I need help with problems in my family, I am able to ask for help from others. *(Please check one response.)*
☐ Never
☐ Seldom
☐ Sometimes
☐ Often
☐ Very Often
☐ Not applicable

35. I make efforts to learn new ways to help my child grow and develop. *(Please check one response.)*
☐ Never
☐ Seldom
☐ Sometimes
☐ Often
☐ Very Often
☐ Not applicable

36. When necessary, I take the initiative in looking for services for my child and family. *(Please check one response.)*
☐ Never
☐ Seldom
☐ Sometimes
☐ Often
☐ Very Often
☐ Not applicable

37. When dealing with my child, I focus on the good things as well as the problems. *(Please check one response.)*
☐ Never
☐ Seldom
☐ Sometimes
☐ Often
☐ Very Often
☐ Not applicable

38. I have a good understanding of the service system that my child is involved in. *(Please check one response.)*
☐ Never
☐ Seldom
☐ Sometimes
☐ Often
☐ Very Often
☐ Not applicable

39. When faced with a problem involving my child, I decide what to do and then do it. *(Please check one response.)*
☐ Never
☐ Seldom
☐ Sometimes
☐ Often
☐ Very Often
☐ Not applicable

40. Professionals should ask me what services I want for my child. *(Please check one response.)*
☐ Never
☐ Seldom
☐ Sometimes
☐ Often
☐ Very Often
☐ Not applicable

41. I have a good understanding of my child's disorder.
☐ Never
☐ Seldom
☐ Sometimes
☐ Often
☐ Very Often
☐ Not applicable
42. I feel I am a good parent.
   □ Never
   □ Seldom
   □ Sometimes
   □ Often
   □ Very Often
   □ Not applicable

43. A “care coordinator” is a go-to person to help coordinate your child’s care. The person could be from your child’s physician’s office, a public health nurse, someone from your child’s insurance company, or elsewhere. Do you have a care coordinator to help you coordinate your child’s care? (Please check one response.)
   □ No, but I do not need a care coordinator
   □ No, but I do need a care coordinator
   □ I am not sure
   □ Yes, I have a care coordinator
   □ Yes, I have many care coordinators

44. In the past 6 months, has anyone worked with you to create a written care plan for your child? (Please check one response.)
   □ Yes → Continue to Question 45
   □ No → Go to Question 50
   □ I don’t know → Go to Question 50

45. Do you have a copy of the written care plan? (Please check one response.)
   □ Yes
   □ No
   □ I don’t know

46. Does the plan contain goals that you or your child wanted? (Please check one response.)
   □ Yes, the goals in the plan are ones that we wanted.
   □ Yes, but there were other goals that were more important to us that were not selected.
   □ No, the goals in the plan are not the ones that we wanted.

47. Does this written care plan work well with your family’s values and culture? (Please check one response.)
   □ Yes, definitely
   □ Yes, somewhat
   □ No

48. Was your involvement in creating or using the care plan a good use of your time? (Please check one response.)
   □ Yes, definitely
   □ Yes, somewhat
   □ No

49. Will you explain your response to Question 48 (why was the care plan a good use or not a good use of your time)? (Please use the space below to write your response.)

   _______________________________________________________
   _______________________________________________________

Healthcare Transition

50. Is your child...
   □ Under the age of 12 years → Go to Question 53
   □ 12 up to 21 years old → Continue to Question 51

51. In the past 6 months, have any of your child’s healthcare providers given you information about transferring your child to adult healthcare? (Please check one response.)
   □ Yes
   □ No

52. In the past 12 months, have any of your child’s healthcare providers talked with you about necessary steps to prepare your child to transfer to adult healthcare? (Please check one response.)
   □ Yes
   □ No
53. How stressful is it for you to manage your child’s health care? (Please check one response.)
   □ Very stressful
   □ Somewhat stressful
   □ A little stressful
   □ Not at all stressful

54. During the past 12 months, about how many days did your child miss school because of her or his health condition(s)? (Please check one response.)
   □ My child does not attend school
   □ No missed school days
   □ 1-3 days
   □ 4-6 days
   □ 7-10 days
   □ 11 or more days

55. How many years old is your child? (Please enter the number in the space below. If your child is less than 1 year old, enter “00.”)
   ______________________

56. What is your child’s gender identity? (Please check one response.)
   □ Female
   □ Male
   □ Other, please specify: ______________
   □ Decline to answer

57. What is your child’s race or ethnicity? (Please check all that apply.)
   □ American Indian / Alaska Native (This includes American Indians; Alaska Natives; Canadian Inuit, Metis, or First Nation; Indigenous Mexican, Central American, or South American.)
   □ African American / Black (This includes African American; African [Black]; Caribbean [Black]; Other Black.)
   □ Asian (This includes Asian Indian; Chinese; Filipino/a; Hmong; Japanese; Korean; Laotian; South Asian; Vietnamese; Other Asian.)
   □ Caucasian / White (This includes Eastern or Western European; Slavic; Other White.)
   □ Hispanic or Latino/a (This includes Hispanic or Latino Central American; Hispanic or Latino Mexican; Hispanic or Latino South American; Other Hispanic or Latino.)
   □ Native Hawaiian / Pacific Islander (This includes Guamanian or Chamorro; Micronesian; Native Hawaiian; Samoan; Tongan; Other Pacific Islander.)
   □ Other (Please specify: __________________)
       -- -- --
   □ I don't know
   □ Decline to answer

58. How are you related to your child? (Please check one response.)
   □ Mom or Dad
   □ Foster Mom or Dad
   □ Grandparent
   □ Aunt or Uncle
   □ Brother or Sister
   □ Other legal guardian
   □ Other, please specify: ______________

59. What is your age? (Please check one response.)
   □ Under 18 years
   □ 18 to 24 years
   □ 25 to 34 years
   □ 35 to 44 years
   □ 45 to 54 years
   □ 55 to 64 years
   □ 65 to 74 years
   □ 75 years or older

60. What is your race or ethnicity? (Please check all that apply.)
   □ American Indian / Alaska Native (This includes American Indians; Alaska Natives; Canadian Inuit, Metis, or First Nation; Indigenous Mexican, Central American, or South American.)
   □ African American / Black (This includes African American; African [Black]; Caribbean [Black]; Other Black.)
   □ Asian (This includes Asian Indian; Chinese; Filipino/a; Hmong; Japanese; Korean; Laotian; South Asian; Vietnamese; Other Asian.)
   □ Caucasian / White (This includes Eastern or Western European; Slavic; Other White.)
   □ Hispanic or Latino/a (This includes Hispanic or Latino Central American; Hispanic or Latino Mexican; Hispanic or Latino South American; Other Hispanic or Latino.)
   □ Native Hawaiian / Pacific Islander (This includes Guamanian or Chamorro; Micronesian; Native Hawaiian; Samoan; Tongan; Other Pacific Islander.)
   □ Other (Please specify: __________________)
       -- -- --
   □ I don't know
   □ Decline to answer
61. What is the highest grade or level of school that you have completed? (Please check one response.)
   - □ 8th grade or less
   - □ Some high school, but did not graduate
   - □ High school graduate or GED
   - □ Some college or 2-year degree
   - □ 4-year college graduate, or
   - □ More than 4-year college degree

62. What language do you most often speak at home? (Please check one response.)
   - □ Cantonese
   - □ English
   - □ Japanese
   - □ Korean
   - □ Mandarin
   - □ Russian
   - □ Spanish
   - □ Vietnamese
   - □ Other, please specify: ________________

63. What is your zipcode? (Please enter your response in the space below.)

   ______________________

64. We will send you a $25 gift card for completing this survey. Which one of the following stores would you like a gift card from? (Please check one response.)
   - □ Amazon (online vendor)
   - □ iTunes
   - □ Shell Gas Stations
   - □ Subway (sandwich chain)
   - □ Walmart

Thank you!

We are very grateful for your feedback and time.

Please return your survey in the attached stamped envelope.