

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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SHARED CARE PLAN INFORMATION FORM (SIF)

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.
 - 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 shared care plan creation and/or re-evaluation date, if the LHD is utilizing the [Activate Care](#) platform for the child or young adult, 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), year 4 (2019-2020), year 5 (2020 – 2021), and year 6 (2021-2022).

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. Around *September 15 of every year*, 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 of every year*.

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.
 - For parents/guardians that LHDs report as utilizing Activate Care for the child or young adult, OCCYSHN will send the Family Survey that includes specific questions about their experience utilizing the Activate Care platform.
2. One week after OCCYSHN sends out the initial email or letter, 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.

[ATTACHMENTS](#)

Copies of all data collection instruments for your reference

OCCYSHN - Local Health Department (LHD)
Revised Shared Care Plan Information Form – All Forms 8/30/2021

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 Manager, 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.)*

- | | |
|-------------------------------------|--|
| <input type="checkbox"/> Baker | <input type="checkbox"/> Lake |
| <input type="checkbox"/> Benton | <input type="checkbox"/> Lane |
| <input type="checkbox"/> Clackamas | <input type="checkbox"/> Lincoln |
| <input type="checkbox"/> Clatsop | <input type="checkbox"/> Linn |
| <input type="checkbox"/> Columbia | <input type="checkbox"/> Malheur |
| <input type="checkbox"/> Coos | <input type="checkbox"/> Marion |
| <input type="checkbox"/> Crook | <input type="checkbox"/> Morrow |
| <input type="checkbox"/> Curry | <input type="checkbox"/> Multnomah |
| <input type="checkbox"/> Deschutes | <input type="checkbox"/> North Central (Wasco-Gilliam-Sherman) |
| <input type="checkbox"/> Douglas | <input type="checkbox"/> Polk |
| <input type="checkbox"/> Grant | <input type="checkbox"/> Tillamook |
| <input type="checkbox"/> Harney | <input type="checkbox"/> Umatilla |
| <input type="checkbox"/> Hood River | <input type="checkbox"/> Union |
| <input type="checkbox"/> Jackson | <input type="checkbox"/> Wallowa |
| <input type="checkbox"/> Jefferson | <input type="checkbox"/> Washington |
| <input type="checkbox"/> Josephine | <input type="checkbox"/> Wheeler |
| <input type="checkbox"/> Klamath | <input type="checkbox"/> 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.)

Condition	Yes	No	I don't know
a. Medical (e.g., cystic fibrosis, muscular dystrophy, seizures, etc.)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. Behavioral/mental (e.g., ADHD, anxiety, depression, substance abuse, etc.)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. Developmental (e.g., autism spectrum disorder, developmental delay, etc.)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. Social complexity (e.g., domestic violence, food insecurity, homelessness or housing instability, joblessness or underemployed, parental incarceration, parental mental health conditions, etc.)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e. Other, please specify:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

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 30

11. Are you utilizing the Activate Care platform for this child or young adult? (Please check one response.)

- ☐ Yes
- ☐ No

12. 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 13
- ☐ Re-evaluation → Skip to Question 48 or 68

Child New Shared Care Plan

13. 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.)

___ / ___ / ___

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

	Yes	No	NA *
a. Dental or Orthodontic Health	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. DHS Child Welfare	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. DHS Developmental Disabilities (DD) Services	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. Early Intervention/Early Childhood Special Education (EI/ECSE)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e. Preschool (e.g., Head Start, Pre-K Programs, private, etc.) or School (e.g., classroom or special education teacher, school nurse, etc.)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f. Child care provider	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g. Family member(s)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
h. Insurer (public, private, or both)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
i. Mental/Behavioral Health	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
j. Primary medical care (e.g., MD, RN, care coordinator, etc.)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

If
yes
→

15. If yes, how did the team member participate in the shared care planning meeting? (Please check one response for each.)

In Person	By Phone	By Video	Written comment	Did not participate
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

OCCYSHN - Local Health Department (LHD)
Revised Shared Care Plan Information Form – All Forms 8/30/2021

k. Specialty medical care	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
l. Occupational, physical, or speech therapist	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
m. Relief Nursery	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
n. WIC	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
o. Other, <i>please specify</i> :	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**Sheryl, please spell out "Not Applicable" in REDCap.*

16. [Note: This question appears only if "Yes" is checked for Q14J] Did a representative from primary care help your local health department to prepare for the shared care planning meeting?

- ☐ Yes → Continue to Question 17
- ☐ No → Skip to Question 18

17. How did the primary care representative help your local health department prepare for the shared care planning meeting? (Please enter your response in the space below.)

18. Is this child currently part of your LHD's CaCoon caseload?

- ☐ Yes
- ☐ No

19. Did someone outside of your LHD refer this child to you to receive shared care planning?

- ☐ Yes → Continue to Question 20
- ☐ No → Skip to Question 21

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

Source	Yes	No
a. Child care provider	<input type="checkbox"/>	<input type="checkbox"/>
b. Preschool teacher (e.g., Head Start, Pre-K Programs, private, etc.)	<input type="checkbox"/>	<input type="checkbox"/>
c. DD Services staff	<input type="checkbox"/>	<input type="checkbox"/>
d. Early Intervention/Early Childhood Special Education (EI/ECSE) staff	<input type="checkbox"/>	<input type="checkbox"/>
e. Insurer (public or private)	<input type="checkbox"/>	<input type="checkbox"/>
f. Mental/behavioral health provider	<input type="checkbox"/>	<input type="checkbox"/>
g. School staff (e.g., classroom or special education teacher, school nurse, etc.)	<input type="checkbox"/>	<input type="checkbox"/>
h. Primary care provider	<input type="checkbox"/>	<input type="checkbox"/>
i. Hospital or tertiary care center staff	<input type="checkbox"/>	<input type="checkbox"/>

j. Other, *please specify*:

☐☐

21. 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*: _____

22. Did the family receive a copy of the shared care plan?

- ☐ Yes
- ☐ No

23. 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

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

- ☐ Yes
- ☐ No
-
- ☐ I don't know

25. How many years old is the child? *(If the child is less than 1 year old, enter "0.")*

_____ years

26. 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.)*
- ☐ Middle Eastern/North African *(This includes Egyptian; Iranian; Iraqi; Lebanese; Moroccan; Saudi; Syrian; Tunisian; Other Middle Eastern; Other North African)*
- ☐ Native Hawaiian / Pacific Islander *(This includes Guamanian or Chamorro; Micronesian; Native Hawaiian; Samoan; Tongan; Other Pacific Islander.)*
- ☐ Other *(Please specify: _____)*
-
- ☐ I don't know

27. 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

28. What is the primary language of the child's family? *(Please check one response.)*

- ☐ Cantonese
- ☐ English
- ☐ Mandarin
- ☐ Russian
- ☐ Spanish
- ☐ Vietnamese
- ☐ Other, *please specify:* _____

29. 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

30. 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.)

____ / ____ / ____

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

If
yes
→

32. If yes, how did the team member participate in the shared care planning meeting? (Please check one response for each.)

	Yes	No	NA	In Person	By Phone	By Video	Written comment	Did not participate
a. The young adult (for whom the shared care plan is being created)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. Dental or Orthodontic Health	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. DHS Child Welfare	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. DHS Developmental Disabilities (DD) Services	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e. School (e.g., classroom or special education teacher, school nurse)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f. Family member(s)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g. Insurer (public, private, or both)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
h. Mental/Behavioral Health	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
i. Primary medical care (e.g., MD, RN, care coordinator)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
j. Specialty medical care	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
k. Occupational, physical, or speech therapist	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
l. Other, please specify:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

33. [Note: This question appears only if “Yes” is checked for Q31I] Did a representative from primary care help your local health department to prepare for the shared care planning meeting?

- ☐ Yes → Continue to Question 34
☐ No → Skip to Question 35

34. How did the primary care representative help your local health department prepare for the shared care planning meeting? (Please enter your response in the space below.)

35. Is this young adult currently part of your LHD’s CaCoon caseload?

- ☐ Yes
☐ No

36. Did someone outside of your LHD refer this young adult to you to receive shared care planning?

- ☐ Yes → Continue to Question 37
☐ No → Skip to Question 38

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

Source	Yes	No
a. DD Services staff	<input type="checkbox"/>	<input type="checkbox"/>
b. Insurer (public or private)	<input type="checkbox"/>	<input type="checkbox"/>
c. Mental/behavioral health provider	<input type="checkbox"/>	<input type="checkbox"/>
d. School staff (e.g., classroom or special education teacher, school nurse, etc.)	<input type="checkbox"/>	<input type="checkbox"/>
e. Primary or specialty provider	<input type="checkbox"/>	<input type="checkbox"/>
f. Hospital or tertiary care center staff	<input type="checkbox"/>	<input type="checkbox"/>
g. Other, please specify: _____	<input type="checkbox"/>	<input type="checkbox"/>

38. What were the reasons that your staff decided to create a shared care plan for this young adult? (Please check all that apply.)

OCCYSHN - Local Health Department (LHD)
Revised Shared Care Plan Information Form – All Forms 8/30/2021

- ☐ 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: _____

39. 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 40
- ☐ No → SKIP to Question 41

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

a.
b.
c.
d.

41. Did the young adult and family receive a copy of the shared care plan?

- ☐ Yes
- ☐ No

42. 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

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

_____ years

44. 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.)*
- ☐ Middle Eastern/North African *(This includes Egyptian; Iranian; Iraqi; Lebanese; Moroccan; Saudi; Syrian; Tunisian; Other Middle Eastern; Other North African)*
- ☐ Native Hawaiian / Pacific Islander *(This includes Guamanian or Chamorro; Micronesian; Native Hawaiian; Samoan; Tongan; Other Pacific Islander.)*
- ☐ Other *(Please specify: _____)*

-- --

☐ I don't know

45. 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

46. What is the primary language of the young adult? *(Please check one response.)*

- ☐ Cantonese
- ☐ English
- ☐ Mandarin
- ☐ Russian
- ☐ Spanish
- ☐ Vietnamese

OCCYSHN - Local Health Department (LHD)
Revised Shared Care Plan Information Form – All Forms 8/30/2021

☐ Other, please specify: _____

47. 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

48. 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.)

____ / ____ / ____

49. 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.)

____ / ____ / ____

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

	Yes	No	NA
a. Dental or Orthodontic Health	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. DHS Child Welfare	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. DHS Developmental Disabilities (DD) Services	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. Early Intervention/Early Childhood Special Education (EI/ECSE)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e. Preschool (e.g., Head Start, Pre-K Programs, private, etc.) or School (e.g., classroom or special	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

If
yes
→

51. If yes, how did the team member participate in the shared care plan meeting? (Please check one response for each.)

In Person	By Phone	By Video	Written comment	Did not participate
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

OCCYSHN - Local Health Department (LHD)
Revised Shared Care Plan Information Form – All Forms 8/30/2021

education teacher, school nurse, etc.)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f. Child care provider	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g. Family member(s)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
h. Insurer (public, private, or both)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
i. Mental/Behavioral Health	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
j. Primary medical care (e.g., MD, RN, care coordinator, etc.)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
k. Specialty medical care	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
l. Occupational, physical, or speech therapist	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
m. Relief Nursery	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
n. WIC	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
o. Other, <i>please specify:</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

52. [Note: This question appears only if “Yes” is checked for Q50J] Did a representative from primary care help your local health department to prepare for the shared care planning meeting?

- ☐ Yes → Continue to Question 53
☐ No → Skip to Question 54

53. How did the primary care representative help your local health department prepare for the shared care planning meeting? (Please enter your response in the space below.)

54. Where does your local public health department store this child’s shared care plan? (Please enter your response in the space below.)

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

_____ goals

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

_____ completed goals

57. 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.)*

58. Did the child health team create new goals when this shared care plan was re-evaluated? *(Please check one response.)*

- ☐ Yes → Continue to Question 59
☐ No → Skip to Question 60

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

_____ new goals

60. Did the family receive a copy of the re-evaluated shared care plan?

- ☐ Yes
☐ No

61. 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

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

- ☐ Yes
☐ No
☐ I don't know

63. How many years old is the child? *(If the child is less than 1 year old, enter "0.")*

_____ years

64. 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.)*

OCCYSHN - Local Health Department (LHD)
Revised Shared Care Plan Information Form – All Forms 8/30/2021

- ☐ 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.)*
- ☐ Middle Eastern/North African *(This includes Egyptian; Iranian; Iraqi; Lebanese; Moroccan; Saudi; Syrian; Tunisian; Other Middle Eastern; Other North African)*
- ☐ Native Hawaiian / Pacific Islander *(This includes Guamanian or Chamorro; Micronesian; Native Hawaiian; Samoan; Tongan; Other Pacific Islander.)*
- ☐ Other *(Please specify: _____)*
-- -- --
- ☐ I don't know

65. 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

66. What is the primary language of the child's family? *(Please check one response.)*

- ☐ Cantonese
- ☐ English
- ☐ Mandarin
- ☐ Russian
- ☐ Spanish
- ☐ Vietnamese
- ☐ Other, *please specify:* _____

67. 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
- -- --

OCCYSHN - Local Health Department (LHD)
Revised Shared Care Plan Information Form – All Forms 8/30/2021

☐ I can't tell

Young Adult Re-evaluation Shared Care Plan

68. 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.)

___ / ___ / ___

69. 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.)

___ / ___ / ___

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

If
yes
→

71. If yes, how did the team member participate in the shared care planning meeting? (Please check one response for each.)

	Yes	No	NA	In Person	By Phone	By Video	Written comment	Did not participate
a. The young adult (for whom the shared care plan is being created)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. Dental or Orthodontic Health	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. DHS Child Welfare	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. DHS Developmental Disabilities (DD) Services	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e. School (e.g., classroom or special education teacher, school nurse)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f. Family member(s)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g. Insurer (public, private, or both)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
h. Mental/Behavioral Health	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
i. Primary medical care (e.g., MD, RN, care coordinator)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
j. Specialty medical care	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
k. Occupational, physical, or speech therapist	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
l. Other, please specify:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

72. [Note: This question appears only if "Yes" is checked for Q70i] Did a representative from primary care help your local health department to prepare for the shared care planning meeting?

- ☐ Yes → Continue to Question 73
- ☐ No → Skip to Question 74

73. How did the primary care representative help your local health department prepare for the shared care planning meeting? *(Please enter your response in the space below.)*

74. Where does your local public health department store this young adult's shared care plan? *(Please enter your response in the space below.)*

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

_____ goals

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

_____ completed goals

77. 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.)*

78. Did the child health team create new goals when this shared care plan was re-evaluated? *(Please check one response.)*

☐ Yes → Continue to Question 79

☐ No → Skip to Question 80

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

_____ new goals

80. Does one or more of the shared care plan goals address transitioning to an adult model of health care? *(Please check one response.)*

☐ Yes → Continue to Question 81

☐ No → *SKIP to Question 82*

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

a.

b.

c.

d.

82. 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.

83. Did the young adult and family receive a copy of the re-evaluated shared care plan?

- ☐ Yes
- ☐ No

84. 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

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

_____ years

86. 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.)*

OCCYSHN - Local Health Department (LHD)
Revised Shared Care Plan Information Form – All Forms 8/30/2021

- ☐ Middle Eastern/North African *(This includes Egyptian; Iranian; Iraqi; Lebanese; Moroccan; Saudi; Syrian; Tunisian; Other Middle Eastern; Other North African)*
- ☐ Native Hawaiian / Pacific Islander *(This includes Guamanian or Chamorro; Micronesian; Native Hawaiian; Samoan; Tongan; Other Pacific Islander.)*
- ☐ Other *(Please specify: _____)*
-- -- --
- ☐ I don't know

87. 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

88. What is the primary language of the young adult? *(Please check one response.)*

- ☐ Cantonese
- ☐ English
- ☐ Mandarin
- ☐ Russian
- ☐ Spanish
- ☐ Vietnamese
- ☐ Other, *please specify:* _____

89. 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

(To be administered online via REDCap)

The following questions pertain to the Shared Care Planning End of Year Report. The purpose of having local health departments (LHD) complete this end of year survey is to learn about your shared care planning process.

We recognize that the COVID-19 pandemic has and continues to impact service delivery, including shared care planning, in your community. Please think of any shared care plans that your LHD and partners were able to initiate or re-evaluate in spite of COVID-19.

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 plans. → *Go to Question 2*
- ☐ No, we have not yet completed any shared care plans. → *Go to Question 11. These respondents will only answer questions 11-13, and 18.*

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 challenges, if any, have you or your child health team experienced trying to implement shared care planning for transition-aged youth?**
11. **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.**
12. **Does your LHD receive referrals from organizations or agencies outside of your local health department for shared care planning?**
- ☐ Yes → Continue to Question 13
 - ☐ No → If the respondent answers "No" to Q1 and Q12, then respondent will go to Question 18. If the respondent answers "Yes" to Q1 and "No" to Q12, then respondent will go to Q14.
13. **From which organizations or agencies, outside of your local health department, does your LHD receive referrals for shared care planning?** *(Please check all that apply.)* → **After responding, Q1=No respondents will go to Q18 and Q1=yes respondents will continue to Q14.**
- ☐ ESD and/or school district(s)
 - ☐ Mental or behavioral health providers
 - ☐ Primary care or other medical health providers
 - ☐ WIC
 - ☐ Other, please specify: _____

14. What **existing** resources have helped the members of your child health teams with shared care planning?

(Please check all that apply.)

- ☐ Child health team member staff time
- ☐ Communication technology (e.g., computers, conference call lines, laptops, smart phones, telephones, etc.)
- ☐ Communication platforms (e.g., Zoom, Webex, FaceTime, Activate Care, 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)
- ☐ Relationships among child health team member organizations
- ☐ Support from LHD leadership
- ☐ Support from child health team member organization leadership
- ☐ Other, please specify: _____

15. 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. As of the date that you are completing this report, has your LHD spent the remainder of its \$10,000 infrastructure funds? → **This question will only be asked to LHDs who reported not spending all of their infrastructure funds in last year's End of Year Report.**

- ☐ Yes → How did your LHD spend the infrastructure funds? (Please be specific)
- ☐ Not yet → How does your LHD intend to spend the remainder of the infrastructure funds? (Please be specific)

16. 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?

17. What else do you want to tell us about your experiences coordinating care using shared care plans?

18. How has the COVID-19 pandemic changed the way you implement shared care planning?

[IRB Note: The following questions will be asked of the 10 counties participating in the Activate Care Pilot.]

Piloting Activate Care for Care Coordination Teams (PACCT).

The final set of questions ask about your county's experience piloting Activate Care.

19. Did your county have an existing standing care coordination team at the start of this project?

- ☐ Yes → Go to Question 20.
- ☐ No → Go to Question 23.

20. **If yes to question 19, 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 21.)**

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

	Yes	No
Behavioral/mental health	<input type="checkbox"/>	<input type="checkbox"/>
Early Intervention/Early Childhood Special Education (EI/ECSE)	<input type="checkbox"/>	<input type="checkbox"/>
Elementary or secondary education	<input type="checkbox"/>	<input type="checkbox"/>
Payors	<input type="checkbox"/>	<input type="checkbox"/>
Primary healthcare	<input type="checkbox"/>	<input type="checkbox"/>
Public health nurses	<input type="checkbox"/>	<input type="checkbox"/>
Other, please specify: _____	<input type="checkbox"/>	<input type="checkbox"/>

If yes to Primary healthcare, answer question 21a.

- 21a. Has the representative of primary care attended more than half of your standing team meetings this year?

- ☐ Yes
☐ No

22. If yes to question 19, did you recruit additional agencies or organizations to participate in your standing care coordination team? (After responding, participants who answered "yes" to Question 19 will go to Question 24.)

- ☐ Yes, please specify which types of agencies or organizations _____
☐ No

23. 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.)

	Yes	No
Behavioral/mental health	<input type="checkbox"/>	<input type="checkbox"/>
Early Intervention/Early Childhood Special Education (EI/ECSE)	<input type="checkbox"/>	<input type="checkbox"/>
Elementary or secondary education	<input type="checkbox"/>	<input type="checkbox"/>
Payors	<input type="checkbox"/>	<input type="checkbox"/>
Primary healthcare	<input type="checkbox"/>	<input type="checkbox"/>
Public health nurses	<input type="checkbox"/>	<input type="checkbox"/>
Other, please specify: _____	<input type="checkbox"/>	<input type="checkbox"/>

24. Did any of those agencies or organizations decline to participate?

- ☐ Yes, please specify reasons for declining _____
☐ No

25. Your LHD received \$3,000 to increase primary care participation in shared care planning. Which of the following activities were supported by these funds? (Please check one response for each.).

	Yes	No	I don't know/recall
a. Local health department staff time to develop a relationship(s) with primary			

	Yes	No	I don't know/recall
care clinic providers or clinic staff (e.g., care coordinator, clinic nurse)			
b. Local health department staff time to develop processes for collaboration with primary care clinic providers or clinic staff			
c. Local health department staff time to develop tools to support collaboration with primary care clinic providers or clinic staff			
d. Payment to the primary care clinic for the clinic provider or clinic staff's time to participate in a shared care planning meeting <u>in person</u>			
e. Payment to the primary care clinic for the clinic provider or clinic staff's time to participate in shared care planning meeting <u>by phone or video</u>			
f. Other, <i>please specify and check "yes"</i> :			

26. What changed in your shared care planning work as a result of your investment in the activities a, b, c, d, e, or f in the previous question? (Please provide a detailed response.)→ This question will appear if the respondent marks "yes" to any of the items in the previous question)

27. 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.)

28. 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.)

	Yes, our team agreed to an approach.	Yes, our team discussed but has not yet agreed on an approach.	No, our team has not yet discussed any approaches.	I don't know
a. Determining shared care planning meeting logistics				
b. Establishing roles or responsibilities for team members				
c. Determining how a parent partner may be part of the team				
d. Determining the sub-population of CYSHCN who will be best served by the team process				

	Yes, our team agreed to an approach.	Yes, our team discussed but has not yet agreed on an approach.	No, our team has not yet discussed any approaches.	I don't know
e. Establishing a process to receive referrals				
f. Establishing and maintaining a triage system for referrals				
g. Establishing a process for reaching out to families of CYSHCN referred to the team				
h. Determining a process for preparing families to participate in the shared care planning process				
i. Establishing a process for doing or obtaining assessments needed to address family or youth goals				
j. Establishing a process for the actual co-production of a shared care plan with a family				
k. Establishing a process for reviewing open care plans, including tracking actions and updating plans				
l. Establishing criteria or procedures for discharging a child, youth, or family from shared care planning				
m. Establishing a process for continuous quality improvement of the shared care planning process				
n. Other, please specify:				

29. Thus far, how has your LPHA, partner organizations, and/or CYSHCN and their families benefitted from your organization's participation in the standing care coordination pilot using Activate Care and the ECHO learning collaborative model?
30. 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 Activate Care and the ECHO learning collaborative model?
31. What else would you like to tell us about your organization's participation in the standing care coordination pilot using Activate Care and the ECHO learning collaborative model?
32. How has the COVID-19 pandemic changed the way you implement PACCT?

Working with Your Child's Health Care and Service Providers

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OHSU IRB No. STUDY00016550

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 - ☐ No
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 - ☐ My child did not need dental care in the last 6 months.
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 - ☐ 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?
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- ☐ 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?

- ☐ 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?

- ☐ 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?

- ☐ Yes
- ☐ No
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- ☐ Yes
- ☐ No
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17. In the last 6 months, did you receive all needed help communicating with doctors, nurses, or other health care providers?

- ☐ 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?

- ☐ 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.

19. I feel that I have a right to approve all services my child receives. (Please check one answer.)

- ☐ Never
- ☐ Seldom
- ☐ Sometimes
- ☐ Often
- ☐ Very Often
-
- ☐ Not applicable

20. When problems arise with my child, I handle them pretty well.

- ☐ Never
- ☐ Seldom
- ☐ Sometimes
- ☐ Often
- ☐ Very Often
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- ☐ Not applicable

21. I feel confident in my ability to help my child grow and develop.

- ☐ 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.

- ☐ Never
- ☐ Seldom
- ☐ Sometimes
- ☐ Often
- ☐ Very Often
-
- ☐ Not applicable

23. I make sure that professionals understand my opinions about what services my child needs.

- ☐ Never
- ☐ Seldom
- ☐ Sometimes
- ☐ Often
- ☐ Very Often
-
- ☐ Not applicable

24. I know what to do when problems arise with my child. (Please check one answer for each question.)

- ☐ Never
- ☐ Seldom
- ☐ Sometimes
- ☐ Often
- ☐ Very Often
-
- ☐ Not applicable

25. I feel like my family life is under control. (Please check one answer for each question.)

- ☐ 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 answer for each question.)

- ☐ 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 answer for each question.)

- ☐ 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 answer for each question.)

- ☐ 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 answer for each question.)

- ☐ 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 answer for each question.)

- ☐ 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 answer for each question.)

- ☐ Never
- ☐ Seldom
- ☐ Sometimes
- ☐ Often
- ☐ Very Often
-
- ☐ Not applicable

32. I believe I can solve problems with my child when they happen. (Please check one answer for each question.)

- ☐ Never
- ☐ Seldom
- ☐ Sometimes
- ☐ Often
- ☐ Very Often
-
- ☐ Not applicable

33. I know what services my child needs. (Please check one answer for each question.)

- ☐ 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 answer for each question.)

- ☐ Never
- ☐ Seldom
- ☐ Sometimes
- ☐ Often
- ☐ Very Often
-
- ☐ Not applicable

35. I make efforts to learn new ways to help my child grow and develop.

- ☐ 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 answer for each question.)

- ☐ 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 answer for each question.)

- ☐ 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 answer for each question.)

- ☐ 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 answer for each question.)

- ☐ Never
- ☐ Seldom
- ☐ Sometimes
- ☐ Often
- ☐ Very Often
-
- ☐ Not applicable

40. Professionals should ask me what services I want for my child. (Please check one answer for each question.)

- ☐ Never
- ☐ Seldom
- ☐ Sometimes
- ☐ Often
- ☐ Very Often
-
- ☐ Not applicable

41. I have a good understanding of my child's disorder. (Please check one answer for each question.)

- ☐ Never
- ☐ Seldom
- ☐ Sometimes
- ☐ Often
- ☐ Very Often

--

- ☐ Not applicable

42. I feel I am a good parent. (Please check one answer for each question.)

- ☐ Never
- ☐ Seldom
- ☐ Sometimes
- ☐ Often
- ☐ Very Often

--

- ☐ Not applicable

Goal Setting for Your Child's Health

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?

- ☐ 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?

- ☐ 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?

- ☐ Yes
- ☐ No
- ☐ I don't know

46. Does the plan contain goals that you or your child wanted?

- ☐ 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?

- ☐ 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?

- ☐ 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?

- ☐ Yes
- ☐ No

Your Family

53. How stressful is it for you to manage your child's health care?

- ☐ 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)?

- ☐ 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
- ☐ Transgender
- ☐ Gender nonconforming/Genderqueer
- ☐ Gender fluid/not exclusively male or female
- ☐ Something else fits better, please specify:

- ☐ I am not sure of my child's gender identity
- ☐ I do not know what this question is asking

- ☐ 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.)
- ☐ Middle Eastern/North African (This includes Egyptian; Iranian; Iraqi; Lebanese; Moroccan; Saudi; Syrian; Tunisian; Other Middle Eastern; Other North African)
- ☐ 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.)*

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- ☐ 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
- ☐ Walmart

65. Do you prefer to receive the gift card through email or postal mail? *(Please check one response.)*

- ☐ Email the gift card → What is your email address?

- ☐ Post mail the gift card → The gift card will take up to 4 – 6 weeks to be mailed to your home. What is your mailing address?

Thank you!

We are very grateful for your feedback and time.

Please return your survey in the attached stamped envelope

(This survey version includes questions specific to family experience utilizing Activate Care)

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 - ☐ Yes
 - ☐ No
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- ☐ Never
- ☐ Sometimes
- ☐ Usually
- ☐ Always

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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.

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- ☐ Never
- ☐ Seldom
- ☐ Sometimes
- ☐ Often
- ☐ Very Often
-
- ☐ Not applicable

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- ☐ Very Often
-
- ☐ Not applicable

24. I know what to do when problems arise with my child. (Please check one answer for each question.)

- ☐ Never
- ☐ Seldom
- ☐ Sometimes
- ☐ Often
- ☐ Very Often
-
- ☐ Not applicable

25. I feel like my family life is under control. (Please check one answer for each question.)

- ☐ 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 answer for each question.)

- ☐ 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 answer for each question.)

- ☐ 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 answer for each question.)

- ☐ 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 answer for each question.)

- ☐ 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 answer for each question.)

- ☐ 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 answer for each question.)

- ☐ Never
- ☐ Seldom
- ☐ Sometimes
- ☐ Often
- ☐ Very Often
-
- ☐ Not applicable

32. I believe I can solve problems with my child when they happen. (Please check one answer for each question.)

- ☐ Never
- ☐ Seldom
- ☐ Sometimes
- ☐ Often
- ☐ Very Often
-
- ☐ Not applicable

33. I know what services my child needs. (Please check one answer for each question.)

- ☐ 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 answer for each question.)

- ☐ Never
- ☐ Seldom
- ☐ Sometimes
- ☐ Often
- ☐ Very Often
-
- ☐ Not applicable

35. I make efforts to learn new ways to help my child grow and develop.

- ☐ 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 answer for each question.)

- ☐ 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 answer for each question.)

- ☐ 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 answer for each question.)

- ☐ 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 answer for each question.)

- ☐ Never
- ☐ Seldom
- ☐ Sometimes
- ☐ Often
- ☐ Very Often
-
- ☐ Not applicable

40. Professionals should ask me what services I want for my child. (Please check one answer for each question.)

- ☐ Never
- ☐ Seldom
- ☐ Sometimes
- ☐ Often
- ☐ Very Often
-
- ☐ Not applicable

41. I have a good understanding of my child's disorder. (Please check one answer for each question.)

- ☐ Never
- ☐ Seldom
- ☐ Sometimes
- ☐ Often
- ☐ Very Often

--

- ☐ Not applicable

42. I feel I am a good parent. (Please check one answer for each question.)

- ☐ Never
- ☐ Seldom
- ☐ Sometimes
- ☐ Often
- ☐ Very Often

--

- ☐ Not applicable

Goal Setting for Your Child's Health

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?

- ☐ 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?

- ☐ 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?

- ☐ Yes
- ☐ No
- ☐ I don't know

46. Does the plan contain goals that you or your child wanted?

- ☐ 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?

- ☐ 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?

- ☐ 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?

- ☐ Yes
- ☐ No

Use of Activate Care

- i. **Have you used Activate Care?**
- ☐ Yes → *Go to Question ii*
 - ☐ No → *Go to Question vii*
 - ☐ I don't remember → *Go to Question vii*
- ii. **Did someone do a good job of explaining to you the different things that Activate Care can do?**
- ☐ Yes, they did a very good job
 - ☐ Yes, they did a good job
 - ☐ Yes, they did an ok job
 - ☐ No, they did poor job
-
- ☐ I don't remember
- iii. **How easy is it for you to use Activate Care on your phone?**
- ☐ It is very easy
 - ☐ It is easy
 - ☐ It is hard
 - ☐ It is very hard
-
- ☐ I don't use Activate Care on my phone
- iv. **How easy is it for you to use Activate Care on your computer?**
- ☐ It is very easy
 - ☐ It is easy
 - ☐ It is hard
 - ☐ It is very hard
-
- ☐ I don't use Activate Care on my computer
- v. **Has Activate Care helped you communicate with all of the people who care for your child?**
- ☐ Yes, it has been very helpful for communicating
 - ☐ Yes, it has been helpful for communicating
 - ☐ Yes, it has been a little bit helpful for communicating
 - ☐ No, it has not been helpful for communicating
-
- ☐ I don't know

- vi. **How often do you use Activate Care?**
- ☐ Every day → *Go to Question 53*
 - ☐ Once a week → *Go to Question 53*
 - ☐ Once every 2 to 3 weeks → *Go to Question 53*
 - ☐ Once a month → *Go to Question 53*
 - ☐ Once every couple of months → *Go to Question 53*
-
- ☐ I don't know → *Go to Question 53*
- vii. **What has kept you from using Activate Care?**
- ☐ I don't remember how to use it
 - ☐ I don't like using technology
 - ☐ I don't have access to a computer, smart phone, or the internet
 - ☐ It doesn't seem helpful
 - ☐ It doesn't have information that I need
 - ☐ It was hard to use
 - ☐ Other reason

Your Family

53. **How stressful is it for you to manage your child's health care?**
- ☐ 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)?**
- ☐ 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
- ☐ Transgender
- ☐ Gender nonconforming/Genderqueer
- ☐ Gender fluid/not exclusively male or female
- ☐ Something else fits better, please specify: _____
- ☐ I am not sure of my child's gender identity
- ☐ I do not know what this question is asking

- ☐ 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.)*
- ☐ Middle Eastern/North African *(This includes Egyptian; Iranian; Iraqi; Lebanese; Moroccan; Saudi; Syrian; Tunisian; Other Middle Eastern; Other North African)*
- ☐ 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.)
- ☐ Middle Eastern/North African (This includes Egyptian; Iranian; Iraqi; Lebanese; Moroccan; Saudi; Syrian; Tunisian; Other Middle Eastern; Other North African)
- ☐ 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
- ☐ Walmart

65. Do you prefer to receive the gift card through email or postal mail? (Please check one response.)

- ☐ Email the gift card → What is your email address?

- ☐ Post mail the gift card → The gift card will take up to 4 – 6 weeks to be mailed to your home. What is your mailing address?

Thank you!

**We are very grateful for your
feedback and time.**

***Please return your survey in the
attached stamped envelope***