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 – 2023 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) through the current contract year.

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 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.*

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 gift 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 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.)*

☐ Baker	☐ Lake
☐ Benton	☐ Lane
☐ Clackamas	☐ Lincoln
☐ Clatsop	☐ Linn
☐ Columbia	☐ Malheur
☐ Coos	☐ Marion
☐ Crook	☐ Morrow
☐ Curry	☐ Multnomah
☐ Deschutes	☐ North Central (Wasco-Gilliam-Sherman)
☐ Douglas	☐ Polk
☐ Grant	☐ Tillamook
☐ Harney	☐ Umatilla
☐ Hood River	☐ Union
☐ Jackson	☐ Wallowa
☐ Jefferson	☐ Washington
☐ Josephine	☐ Wheeler
☐ Klamath	☐ 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 <u>your</u> first name?** *(Please type the name of the person entering the data in the space below.)*

_____

5. What is <u>your</u> 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.)	☐	☐	☐
b. Behavioral/mental (e.g., ADHD, anxiety, depression, substance abuse, etc.)	☐	☐	☐
c. Developmental (e.g., autism spectrum disorder, developmental delay, etc.)	☐	☐	☐
d. Social complexity (e.g., domestic violence, food insecurity, homelessness or housing instability, joblessness or underemployed, parental incarceration, parental mental health conditions, etc.)	☐	☐	☐
e. Other, *please specify:* _____	☐	☐	☐

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 49 or 69*

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.)*

If yes →

15. *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. Dental or Orthodontic Health	☐	☐	☐	☐	☐	☐	☐	☐
b. DHS Child Welfare	☐	☐	☐	☐	☐	☐	☐	☐
c. DHS Developmental Disabilities (DD) Services	☐	☐	☐	☐	☐	☐	☐	☐
d. Early Intervention/Early Childhood Special Education (EI/ECSE)	☐	☐	☐	☐	☐	☐	☐	☐
e. Preschool (e.g., Head Start, Pre-K Programs, private, etc.) or School (e.g., classroom or special education teacher, school nurse, etc.)	☐	☐	☐	☐	☐	☐	☐	☐
f. Child care provider	☐	☐	☐	☐	☐	☐	☐	☐
g. Family member(s)	☐	☐	☐	☐	☐	☐	☐	☐
h. Insurer (public, private, or both)	☐	☐	☐	☐	☐	☐	☐	☐
i. Mental/Behavioral Health	☐	☐	☐	☐	☐	☐	☐	☐
j. Primary medical care (e.g., MD, RN, care coordinator, etc.)	☐	☐	☐	☐	☐	☐	☐	☐

k. Specialty medical care	☐	☐	☐		☐	☐	☐	☐	☐
l. Occupational, physical, or speech therapist	☐	☐	☐		☐	☐	☐	☐	☐
m. Relief Nursery	☐	☐	☐		☐	☐	☐	☐	☐
n. WIC	☐	☐	☐		☐	☐	☐	☐	☐
o. Other, *please specify:*	☐	☐	☐		☐	☐	☐	☐	☐

*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	☐	☐
b.	Preschool teacher (e.g., Head Start, Pre-K Programs, private, etc.)	☐	☐
c.	DD Services staff	☐	☐
d.	Early Intervention/Early Childhood Special Education (EI/ECSE) staff	☐	☐
e.	Insurer (public or private)	☐	☐
f.	Mental/behavioral health provider	☐	☐
g.	School staff (e.g., classroom or special education teacher, school nurse, etc.)	☐	☐
h.	Primary care provider	☐	☐
i.	Hospital or tertiary care center staff	☐	☐

j. Other, *please specify:* _____ ☐ ☐

21. What were the <u>reasons</u> 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 resource family (i.e., foster care family) or in an out-of-home placement group setting? *(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 <u>the child's family</u> 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:* _____

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- ☐ 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.)*	**Yes**	**No**	**NA**	*If yes →*	**32. *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**
a.	The young adult (for whom the shared care plan is being created)	☐	☐	☐			☐	☐	☐	☐	☐
b.	Dental or Orthodontic Health	☐	☐	☐			☐	☐	☐	☐	☐
c.	DHS Child Welfare	☐	☐	☐			☐	☐	☐	☐	☐
d.	DHS Developmental Disabilities (DD) Services	☐	☐	☐			☐	☐	☐	☐	☐
e.	School (e.g., classroom or special education teacher, school nurse)	☐	☐	☐			☐	☐	☐	☐	☐
f.	Family member(s)	☐	☐	☐			☐	☐	☐	☐	☐
g.	Insurer (public, private, or both)	☐	☐	☐			☐	☐	☐	☐	☐
h.	Mental/Behavioral Health	☐	☐	☐			☐	☐	☐	☐	☐
i.	Primary medical care (e.g., MD, RN, care coordinator)	☐	☐	☐			☐	☐	☐	☐	☐
j.	Specialty medical care	☐	☐	☐			☐	☐	☐	☐	☐
k.	Occupational, physical, or speech therapist	☐	☐	☐			☐	☐	☐	☐	☐
l.	Other, *please specify:*	☐	☐	☐			☐	☐	☐	☐	☐

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	☐	☐
b. Insurer (public or private)	☐	☐
c. Mental/behavioral health provider	☐	☐
d. School staff (e.g., classroom or special education teacher, school nurse, etc.)	☐	☐
e. Primary or specialty provider	☐	☐
f. Hospital or tertiary care center staff	☐	☐
g. Other, *please specify:* _____	☐	☐

38. What were the <u>reasons</u> 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:* _____

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. Is the young adult currently living with a resource family (i.e., foster care family) or in an out-of-home placement group setting? *(Please check one response.)*

☐ Yes
☐ No

-- -- --

☐ I don't know

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

_____ years

45. 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: _____)*

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☐ I don't know

46. 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

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

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

48. 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

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- ☐ I can't tell

Child Re-evaluation Shared Care Plan

49. 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.)*

____ ____ / ____ ____ / ____ ____

50. 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.)*

____ ____ / ____ ____ / ____ ____

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

If yes →

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

	Yes	No	NA	In Person	By Phone	By Video	Written comment	Did not participate
a. Dental or Orthodontic Health	☐	☐	☐	☐	☐	☐	☐	☐
b. DHS Child Welfare	☐	☐	☐	☐	☐	☐	☐	☐

c.	DHS Developmental Disabilities (DD) Services	☐	☐	☐	☐	☐	☐	☐	☐
d.	Early Intervention/Early Childhood Special Education (EI/ECSE)	☐	☐	☐	☐	☐	☐	☐	☐
e.	Preschool (e.g., Head Start, Pre-K Programs, private, etc.) or School (e.g., classroom or special education teacher, school nurse, etc.)	☐	☐	☐	☐	☐	☐	☐	☐
f.	Child care provider	☐	☐	☐	☐	☐	☐	☐	☐
g.	Family member(s)	☐	☐	☐	☐	☐	☐	☐	☐
h.	Insurer (public, private, or both)	☐	☐	☐	☐	☐	☐	☐	☐
i.	Mental/Behavioral Health	☐	☐	☐	☐	☐	☐	☐	☐
j.	Primary medical care (e.g., MD, RN, care coordinator, etc.)	☐	☐	☐	☐	☐	☐	☐	☐
k.	Specialty medical care	☐	☐	☐	☐	☐	☐	☐	☐
l.	Occupational, physical, or speech therapist	☐	☐	☐	☐	☐	☐	☐	☐
m.	Relief Nursery	☐	☐	☐	☐	☐	☐	☐	☐
n.	WIC	☐	☐	☐	☐	☐	☐	☐	☐
o.	Other, *please specify:*	☐	☐	☐	☐	☐	☐	☐	☐

53. [Note: This question appears only if "Yes" is checked for Q51J] Did a representative from primary care help your local health department to prepare for the shared care planning meeting?

- ☐ Yes → Continue to Question 54
- ☐ No → Skip to Question 55

54. 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.)*

_____

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

_____

_____

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

_____ goals

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

_____ completed goals

58. 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.)*

_____

_____

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

- ☐ Yes → *Continue to Question 60*
- ☐ No → *Skip to Question 61*

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

_____ new goals

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

- ☐ Yes
- ☐ No

62. 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

63. Is the child currently living with a resource family (i.e., foster care family) or in an out-of-home placement group setting? *(Please check one response.)*

- ☐ Yes
- ☐ No

-- -- --

- ☐ I don't know

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

_____ years

65. 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

66. 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

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

- ☐ Cantonese

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

68. 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

69. 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.)*

____ ____ / ____ ____ / ____ ____

70. 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.)*

____ ____ / ____ ____ / ____ ____

71. Which of following are members of the young adult's health team? *(Please check one response for each.)*	**Yes**	**No**	**NA**	*If yes* →	**72. *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**
a. The young adult (for whom the shared care plan is being created)	☐	☐	☐			☐	☐	☐	☐	☐
b. Dental or Orthodontic Health	☐	☐	☐			☐	☐	☐	☐	☐
c. DHS Child Welfare	☐	☐	☐			☐	☐	☐	☐	☐
d. DHS Developmental Disabilities (DD) Services	☐	☐	☐			☐	☐	☐	☐	☐
e. School (e.g., classroom or special education teacher, school nurse)	☐	☐	☐			☐	☐	☐	☐	☐
f. Family member(s)	☐	☐	☐			☐	☐	☐	☐	☐
g. Insurer (public, private, or both)	☐	☐	☐			☐	☐	☐	☐	☐
h. Mental/Behavioral Health	☐	☐	☐			☐	☐	☐	☐	☐
i. Primary medical care (e.g., MD, RN, care coordinator)	☐	☐	☐			☐	☐	☐	☐	☐
j. Specialty medical care	☐	☐	☐			☐	☐	☐	☐	☐
k. Occupational, physical, or speech therapist	☐	☐	☐			☐	☐	☐	☐	☐
l. Other, *please specify:*	☐	☐	☐			☐	☐	☐	☐	☐

73. [Note: This question appears only if "Yes" is checked for Q71l] Did a representative from primary care help your local health department to prepare for the shared care planning meeting?

☐ Yes → Continue to Question 74
☐ No → Skip to Question 75

74. 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.)*

_____

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

_____

_____

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

_____ goals

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

_____ completed goals

78. 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.)*

_____

_____

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

- ☐ Yes → *Continue to Question 80*
- ☐ No → *Skip to Question 81*

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

_____ new goals

81. 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 82*

☐ No → *SKIP to Question 83*

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

a. _____

b. _____

c. _____

d. _____

83. 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.

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

☐ **Yes**
☐ **No**

85. 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

86. Is the young adult currently living with a resource family (i.e., foster care family) or in an out-of-home placement group setting? *(Please check one response.)*

☐ Yes
☐ No

-- -- --

☐ I don't know

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

_____ years

88. 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

89. 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

90. What is the <u>primary</u> language of the young adult? *(Please check one response.)*

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

91. 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

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

Family Contact Information

Caregiver experience with the shared care planning process is important for understanding how the process is implemented and how it can be improved. OCCYSHN learns about their experiences by collecting survey data from the caregiver who participated. Provide the contact information for the parent, resource (foster) parent or guardian, or other caregiver or guardian below.

[Note: The following questions will appear if the LHD reports "No" for the resource family item, Q24, Q43, Q63, or Q86]

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:* _____

[Note: The following questions will appear if the LHD reports "Yes" or "I don't know" for the resource family item, Q24, Q43, Q63, or Q86]

Caregiver experience with the shared care planning process is important for understanding how the process is implemented and how it can be improved. OCCYSHN learns about their experiences by collecting survey data from the caregiver who participated. Provide the contact information for the parent, resource (foster) parent or guardian, or other caregiver or guardian below.

If a child or young adult is living with a resource (foster) family, or in an out-of-home placement group setting, we want to collect information from the adult caregiver who is involved in shared care planning and in making decisions about the child/youth's health care or services.

I. **Which of the following adult caregiver(s) participated in the shared care planning meeting for this child or young adult?** *(Please choose as many responses as applicable.)*
   - ☐ Biological parent
   - ☐ Foster parent / guardian
   - ☐ Grandparent or other relative
   - ☐ Child welfare case manager
   - ☐ Other *(please specify)*:_____

II. ***If more than one adult caregiver participated,*** **Which caregiver will be <u>most knowledgeable</u> about the shared care planning process for this child/youth, the child/youth's health care and service needs, and working with health care and other providers to meet the child/young adult's needs?** *(Please choose one response.)*
   - ☐ Biological parent
   - ☐ Foster parent / guardian
   - ☐ Grandparent or other relative
   - ☐ Child welfare case manager
   - ☐ Other *(please specify)*:_____

III. **What is the name of the adult caregiver described in Question II?**

_____

IV. **What is the adult caregiver's email address (if applicable)?**

_____

V. **What is the adult caregiver's telephone number (if applicable)?**

_____

VI. **What is the adult caregiver's postal mailing address?**

_____

VII. **Is the adult caregiver 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.)*
   a. The parent/guardian can read and write in English.
   b. The parent/guardian can read and write in Spanish.
   c. The parent/guardian cannot read or write in English or Spanish.

d. 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 in your community. Please complete this report to the best of your ability and share any shared care planning work that your LHD and partners were able conduct in spite of COVID-19.

Thank you!

1. **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.)*

2. **The foundation of shared care planning is identifying and meeting family goals by eliminating gaps, barriers, and redundancies in care. How has your LHD accomplished this through the shared care planning process? (***Please provide at least two examples.)*

3. Has your child health team implemented shared care planning for a transition-aged youth (i.e. youth aged 12 years or older) this year?

- ☐ Yes → Answer Question 3a
- ☐ No → Answer 3b

3a. If yes, what has been your child health team's experience implementing shared care planning for transition-aged youth (i.e. youth aged 12 years or older)? *(Please be specific and provide examples, such as resources that helped your team serve youth and/or challenges that your team experienced serving youth).*

3b. If no, how is your child health team thinking about implementing shared care planning for transition-aged youth (i.e. youth aged 12 years or older)?

4. Does your LHD plan to continue implementing shared care planning during 2023-2024?

- ☐ Yes → *Continue to Question 5*
- ☐ No → *Go to Question 4a*

4a. How does your team plan to move forward with shared care planning during 2023-2024? *(Please describe specific examples of your plans.)*

5. **Now that your LHD has implemented shared care planning for several years, what reflections, insights, or lessons do you have about the process?**

6. **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 counties participating in the Activate Care Pilot.]

Piloting Activate Care for Care Coordination Teams (PACCT).

PACCT ends September 2023, the final set of questions ask about your county's experience piloting Activate Care.

1. **Since the start of PACCT in 2019, how has your LHD, partner organizations, and/or CYSHCN and their families benefitted from your organization's participation in the care coordination pilot using the Activate Care platform?**

2. **Since the start of PACCT in 2019, what challenges have your LHD, partner organizations, and/or CYSHCN and their families experienced from your organization's participation in the care coordination pilot using the Activate Care platform?**

3. **Moving forward after PACCT ends, how does your LHD plan to leverage what you learned from participating in the care coordination pilot?**

4. **What else would you like to tell us about your organization's participation in the care coordination pilot using the Activate Care platform?**

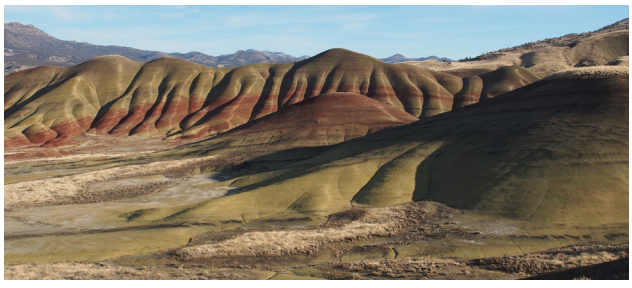
Working with Your Child's Health Care and Service Providers

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.









Oregon Center for Children and Youth with Special Health Needs
Institute on Development and Disability
Oregon Health and Science University
Portland, Oregon

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:

Raúl Vega, B.S., *Research Assistant and Primary Contact*: 503-995-4893, vegajuar@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

Start Here

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?**
   - ☐ 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.)?**
   - ☐ 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?**
   - ☐ 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)?**
   - ☐ 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?**
   - ☐ 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?**
   - ☐ 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 need 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.)**
   - ☐ 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?**
   - ☐ 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?**
   - ☐ 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?**
    - ☐ 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?**
    - ☐ 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?**

- ☐ 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
- ☐ I did not need help finding 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?**

- ☐ 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?**

- ☐ 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
- --
- ☐ 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 coordinator 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 <u>child's</u> 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 <u>your</u> 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 <u>most</u> <u>often</u> 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 <u>one</u> response.)*

- ☐ Amazon (online vendor)
- ☐ iTunes
- ☐ Walmart

65. **Do you prefer to receive the gift card through email or postal mail?** *(Please check <u>one</u> 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

OREGON CENTER FOR CHILDREN AND YOUTH WITH SPECIAL HEALTH NEEDS

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

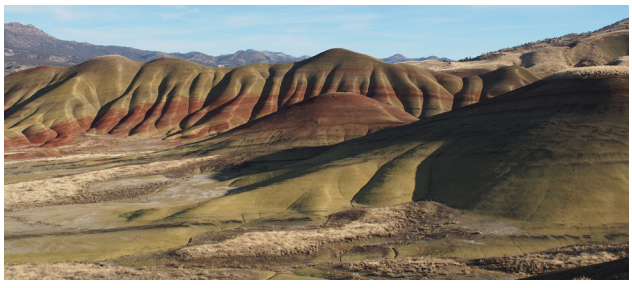
Working with Your Child's Health Care and Service Providers

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.









Oregon Center for Children and Youth with Special Health Needs
Institute on Development and Disability
Oregon Health and Science University
Portland, Oregon

FOR YOUR REFERENCE - PLEASE DO NOT DISSEMINATE TO FAMILIES

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:

Raúl Vega, B.S., *Research Assistant and Primary Contact*: 503-995-4893, vegajuar@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

Start Here

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?**
   - ☐ 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.)?**
   - ☐ 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?**
   - ☐ 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)?**
   - ☐ 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?**
   - ☐ 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?**
   - ☐ 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 need 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.)**
   - ☐ 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?**
   - ☐ 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?**
   - ☐ 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?**
    - ☐ 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?**
    - ☐ 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?**

- ☐ 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
- ☐ I did not need help finding 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?**

- ☐ 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?**

- ☐ 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
- --
- ☐ 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 coordinator 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 <u>child's</u> 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 <u>your</u> 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 <u>most</u> <u>often</u> 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 <u>one</u> response.)*

- ☐ Amazon (online vendor)
- ☐ iTunes
- ☐ Walmart

65. **Do you prefer to receive the gift card through email or postal mail?** *(Please check <u>one</u> 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