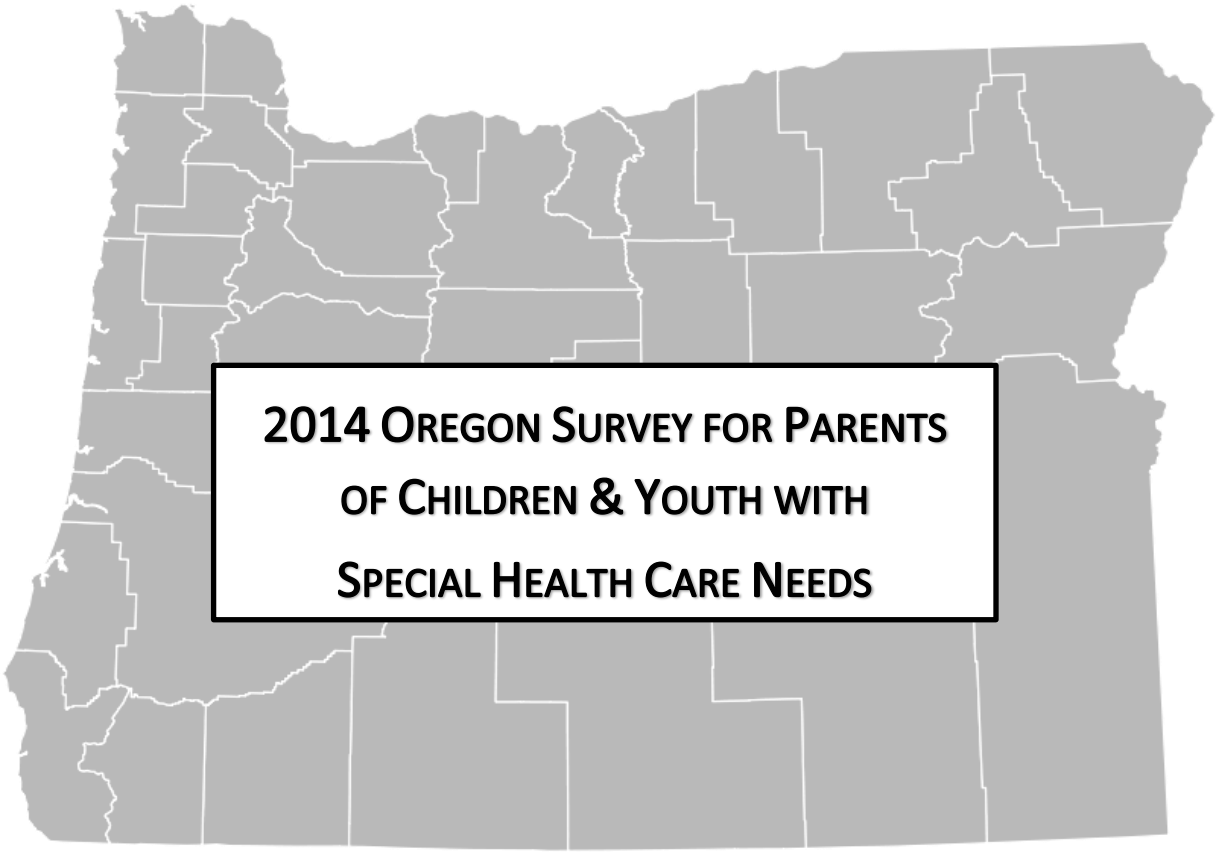

2014 Oregon Survey for Parents of Children & Youth with Special Health Care Needs

An effort to understand issues that are important to families with children between the ages of birth to 26 years who have a special health care need.

To be completed by the parent or other guardian of a child with special health needs between the ages of 0 and 26 years.

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

The Oregon Center for Children and Youth with Special Health Needs (OCCYSHN) promotes optimal health, development, and well-being of Oregon's children and youth with special health needs. *Children with special health needs are defined as those children who have, or are at increased risk for, a chronic physical, developmental, behavioral, or emotional condition.* These children need health care and other services more than children generally.

We are writing to ask for your help in understanding the needs of families with children and youth with special health needs. The best way we have of learning about these needs is to survey youth, their families, and those who provide services to them. Questions ask about your child's health, health care providers, services that your child and family need, and problems you encounter when seeking health care for your child. We will use parents' answers to identify state priorities and to plan our work for the next 5 years. We also will share the results of our survey with our partners and families across the state.

Your input matters! We need to hear from as many families across the state as possible to understand families' concerns. You received this survey because we asked our partners to send this questionnaire to parents they work with. *(If you already completed this survey, please do NOT complete it again.)*

We hope that you will spend 15-20 minutes completing our survey. Please use the postage paid envelope to return the survey to us. It is your choice whether to complete the survey, and you can choose not to answer items that you do not want to answer. The answers you provide are anonymous, which means that no one at OCCYSHN or OHSU will know whether you completed the survey or what answers you gave us. When OCCYSHN receives completed surveys, our staff will combine all of the responses into summary reports.

The information you provide is very important. We will raffle five $50 gift cards to family members who complete the survey. This is our way of saying thank you for your help. If you would like to be entered into the raffle after you complete the survey, please email your name and telephone number to Dr. Alison J. Martin (martial@ohsu.edu) by August 21, 2014. We will call you by October 3, 2014 if your name was drawn.

This survey is part of a statewide project that is conducted every 5 years as a requirement of our Federal funding. If you have any questions about this survey, you can call or email either of us.

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If you would rather take this survey online, please visit
In English: https://www.surveymonkey.com/s/OR_Family_English
In Spanish: https://www.surveymonkey.com/s/OR_Familia_Espanol

INTRODUCTION

1. Is your child older than 26 years?

Yes...☐ → *You are done! Our survey only seeks information about children who are 26 years or younger. Thank you for your* time!

No ....☐ → Please continue.

2. Does your child need or use prescription medications? *(Please check one.)*

☐ Yes
☐ No

3. Does your child have any kind of behavioral, developmental, or emotional needs that require treatment or counseling? *(Please check one.)*

☐ Yes
☐ No

4. Compared to other children your child's age, does your child need or use more educational or medical supports or services (such as specialists, mental health, occupational therapy, physical therapy, etc.)? *(Please check one.)*

☐ Yes
☐ No

5. Is your child limited in his or her ability to do the things that most children of the same age can do? *(Please check one.)*

☐ Yes
☐ No

6. Have your child's health needs existed or are they expected to last for at least 12 months? *(Please check one.)*

☐ Yes
☐ No

7. During the 2013-2014 school year, about how many days did your child miss school or work because of his or her health condition(s)? *(Please write a number in the space below.)*

_____ days

MEDICAL HOME

Attention: Remember to check for a "Go to" instruction after you answer the next question.

8. A <u>primary health care provider</u> is a health professional who knows your child well and is familiar with your child's health history. This can be a general doctor, a pediatrician, a specialist doctor, a nurse practitioner, or a physician's assistant. Do you have a health professional that you think of as your child's primary health care provider? *(Please check one.)*

Yes.....☐
No .....☐ → *Go to Question 20.*

9. What type of professional is your child's primary health care provider? *(Please check one.)*

☐ Brokerage worker
☐ Chiropractor
☐ Family practice, general practice, or internal medicine
☐ Naturopath
☐ Nurse practitioner
☐ Pediatrician or Developmental Pediatrician
☐ Physician's assistant
☐ Specialist (e.g., surgeon, heart doctor, psychiatrist, pediatric specialist)
☐ Other, *please specify:*

_____

_____

10. How do you keep in touch with your child's primary health care provider?

☐ Email
☐ Telephone
☐ Text message
☐ Other, *please specify:*

_____

_____

11. When visiting your child's primary health care provider in the last 12 months, how often did you have the following problems? *(Please one response for each problem listed.)*

Type of Problem	Always	Usually	Sometimes	Never	I don't know or Not applicable
a. We did not have insurance.	☐	☐	☐	☐	☐
b. Our health insurance plan did not cover services.	☐	☐	☐	☐	☐
c. We could not afford the service copays or insurance deductibles.	☐	☐	☐	☐	☐
d. We were unable to take time off from work for the health care appointment.	☐	☐	☐	☐	☐
e. We were unable to schedule an appointment that was convenient for our work schedule.	☐	☐	☐	☐	☐
f. We were unable to schedule an appointment as quickly as we needed one.	☐	☐	☐	☐	☐
g. We had a long wait in the waiting room before our appointment.	☐	☐	☐	☐	☐
h. We were unable to get a referral for services that my child needs.	☐	☐	☐	☐	☐
i. Our provider(s) did not speak my language.	☐	☐	☐	☐	☐
j. An interpreter was not available.	☐	☐	☐	☐	☐
k. Our provider did not understand our cultural beliefs or values.	☐	☐	☐	☐	☐
l. I was confused by what our provider told us.	☐	☐	☐	☐	☐
m. Other, *please specify:*	☐	☐	☐	☐	☐

Attention: Remember to check for a "Go to" instruction after you answer the next question.

12. A *Care Plan* is a written document that your child's health provider can give you that describes things like your child's health conditions and treatments, what to expect or do about your child's health condition, and what to do if your child has a health emergency. Does your child have a Care Plan?

Yes..... ☐
No ..... ☐ → *Go to Question 15*
-- -- -- --
I don't know... ☐ → *Go to Question 15*

13. Who helped develop your child's Care Plan? *(Please check all that apply.)*

- ☐ My child's primary health care provider
- ☐ My child
- ☐ Me
- ☐ Other family members
- ☐ Other health care providers that work with my child
- ☐ My child's teacher or child care provider
- ☐ Other, *please specify:*

  _____

14. Has your child's Care Plan been given to all of his or her health care providers?

- ☐ Yes
- ☐ No

-- -- -- --

- ☐ I don't know

YOUTH TRANSITION TO ADULT CARE

Attention: Remember to check for a "Go to" instruction after you answer the next question.

15. Is your child 14 years or older?

Yes..... ☐
No ..... ☐ → *Go to Question 20*

16. In the last 12 months, has your child's primary health care provider talked with you about how your child's care may change after he or she turns 18? *(Please check one.)*

- ☐ Yes
- ☐ No

17. How important is it to your family to have your child's primary health care provider work with your child to develop skills to manage his or her health care (such as learning about his or her medications, scheduling appointments, and what to do in an emergency)? *(Please check one.)*

- ☐ Very important
- ☐ Somewhat important
- ☐ A little important
- ☐ Not at all important

-- -- -- --

- ☐ I don't know

18. How important is it to your family to have your child's primary health care provider talk with your child about future plans (such as education or work)? *(Please check one.)*

- ☐ Very important
- ☐ Somewhat important
- ☐ A little important
- ☐ Not at all important

-- -- -- --

- ☐ I don't know

19. How important is it to your family to have your child's primary health care provider talk with your family about how your child will be insured when he or she becomes an adult? *(Please check one.)*

- ☐ Very important
- ☐ Somewhat important
- ☐ A little important
- ☐ Not at all important

-- -- -- --

- ☐ I don't know

20. Which of these types of care does your child need? *(Please check one response for each.)*	**No**	**Yes**	*If yes* →	**21. *If yes*, how easy is it for your child to get that type of care?** *(Please check one response for each.)* **Very easy**	**Somewhat easy**	**Somewhat difficult**	**Very difficult**
a. Teeth cleaning, fluoride treatments	☐	☐	*If yes* →	☐	☐	☐	☐
b. Orthodontia or other dental care	☐	☐	*If yes* →	☐	☐	☐	☐
c. Occupational therapy	☐	☐	*If yes* →	☐	☐	☐	☐
d. Physical therapy	☐	☐	*If yes* →	☐	☐	☐	☐
e. Speech therapy	☐	☐	*If yes* →	☐	☐	☐	☐
f. Behavioral/mental health services or counseling	☐	☐	*If yes* →	☐	☐	☐	☐
g. Child care	☐	☐	*If yes* →	☐	☐	☐	☐
h. Durable medical equipment	☐	☐	*If yes* →	☐	☐	☐	☐
i. Eye glasses or vision care	☐	☐	*If yes* →	☐	☐	☐	☐
j. Nutrition counseling	☐	☐	*If yes* →	☐	☐	☐	☐
k. Genetic counseling	☐	☐	*If yes* →	☐	☐	☐	☐
l. Hearing aids or hearing care	☐	☐	*If yes* →	☐	☐	☐	☐
m. Home health care	☐	☐	*If yes* →	☐	☐	☐	☐
n. Mobility aids	☐	☐	*If yes* →	☐	☐	☐	☐
o. Care to lessen symptoms (e.g., pain, fatigue, depression, inability to sleep or eat) of serious and chronic illness	☐	☐	*If yes* →	☐	☐	☐	☐
p. Prescription medications	☐	☐	*If yes* →	☐	☐	☐	☐
q. Respite care	☐	☐	*If yes* →	☐	☐	☐	☐
r. Autism specific therapies	☐	☐	*If yes* →	☐	☐	☐	☐
s. Substance abuse treatment or counseling	☐	☐	*If yes* →	☐	☐	☐	☐
t. Other, *please specify:*	☐	☐	*If yes* →	☐	☐	☐	☐

22. How much are you concerned about the following things? *(Please check one for each.)*

		Very concerned	Somewhat concerned	A little concerned	Not at all concerned	Not applicable
a.	Bullying of your child at school	☐	☐	☐	☐	☐
b.	Finding a job	☐	☐	☐	☐	☐
c.	Finding affordable housing that is adapted for your child's health condition	☐	☐	☐	☐	☐
d.	Getting dental care for yourself	☐	☐	☐	☐	☐
e.	Getting health care for yourself	☐	☐	☐	☐	☐
f.	Getting health insurance for yourself	☐	☐	☐	☐	☐
g.	Getting information about how to provide healthy meals for your family	☐	☐	☐	☐	☐
h.	Getting information about safe sleep for infants	☐	☐	☐	☐	☐
i.	Learning about developmental changes that occur with teenagers	☐	☐	☐	☐	☐
j.	Learning about how much physical activity your family needs to stay healthy	☐	☐	☐	☐	☐
k.	Learning about how to support your child's growth and development	☐	☐	☐	☐	☐
l.	Making sure that your child is ready for kindergarten	☐	☐	☐	☐	☐
m.	Making sure that your child receives all of his or her required immunizations	☐	☐	☐	☐	☐

23. What is the furthest distance in miles that you have to travel for your child to get care from any of his or her providers? *(Please write the number of miles in the space below.)*

_____ miles

24. About how often do you have to travel that distance? *(Please check one.)*

- ☐ More than 12 times per year
- ☐ 7 to 12 times per year
- ☐ 4 to 6 times per year
- ☐ 2 or 3 times per year
- ☐ One time per year

25. Transportation costs can include public transportation or gas for your personal car or a family member's or friend's car. In a typical month, how often is it hard for you to pay for transportation so that your child can get care from any of his or her providers? *(Please check one.)*

- ☐ Always
- ☐ Usually
- ☐ Sometimes
- ☐ Never

-- -- -- --

- ☐ I'm not sure.

26. What are the 3 things that your child or family needs most but has a hard time getting? *(Please write your responses below.)*

a. _____

_____

_____

b. _____

_____

_____

c. _____

_____

CARE COORDINATION

27. How well do your child's different health care providers work together to meet your child's needs? *(Please check one.)*

- ☐ Extremely well
- ☐ Moderately well
- ☐ Slightly well
- ☐ Not at all well

-- -- -- --

- ☐ I don't know

28. Do your child's health care providers need to work with his or her school, Early Intervention Program, Special Education services, child care providers, or vocational or rehabilitation program? *(Please check one.)*

Yes..... ☐
No ..... ☐ → *Go to Question 30*
-- -- -- --
I don't know..... ☐ → *Go to Question 30*

29. How well do your child's health care providers work with your child's school, Early Intervention Program, Special Education services, child care providers, or vocational or rehabilitation program to meet your child's needs? *(Please check one.)*

- ☐ Extremely well
- ☐ Moderately well
- ☐ Slightly well
- ☐ Not at all well

-- -- -- --

- ☐ I don't know

30. In the last 12 months, how often did you get as much help as you wanted arranging or coordinating your child's care? *(Please check one.)*

- ☐ Always
- ☐ Usually
- ☐ Rarely
- ☐ Never

31. In the last 12 months, did anyone help you arrange or coordinate care for your child? *(Please check one.)*

Yes..... ☐
No ..... ☐ → *Go to Question 34*

32. Which of the following types of people helped you arrange or coordinate your child's care? *(Please check all that apply.)*

- ☐ Someone at your child's primary health care provider's office
- ☐ Family member
- ☐ Family friend
- ☐ Hospital discharge planner
- ☐ Mental health specialist (such as a counselor, psychologist, therapist, etc.)
- ☐ Oregon Health Plan representative
- ☐ Occupational, physical, or speech therapist
- ☐ Parent partner
- ☐ Peer support specialist
- ☐ Public health nurse who visits you in your home (such as CaCoon or Babies First!)
- ☐ Social worker
- ☐ Someone at your child's school
- ☐ Other, *please specify:*

_____

_____

33. In general, how sensitive to your family's values and customs are the people who help you arrange or coordinate your child's care? *(Please check one.)*

- ☐ Extremely sensitive
- ☐ Moderately sensitive
- ☐ Slightly sensitive
- ☐ Not at all sensitive

-- -- -- --

- ☐ I don't know

DEMOGRAPHIC AND HEALTH INSURANCE INFORMATION

34. What is your relationship to the child you described in this survey? *(Please check one.)*

- ☐ Parent
- ☐ Foster parent
- ☐ Grandparent
- ☐ Other legal guardian
- ☐ Other, *please specify:*

_____

35. How old is your child? *(Please write the number of years in the space below.)*

_____ years

36. Currently, how do you pay for your child's health care? *(Please check all that apply.)*

- ☐ Friends or relatives
- ☐ Indian Health Services
- ☐ Out of pocket
- ☐ Medicaid, Healthy Kids, Oregon Health Plan (OHP)
- ☐ Medicare
- ☐ Private health insurance
- ☐ Tricare (Military health insurance)
- ☐ Other, *please specify:*

_____

- ☐ I don't know

37. At any time in the last 12 months has your child been uninsured? *(Please check one.)*

- ☐ Yes
- ☐ No
- ☐ I don't know

38. How many people (adults, children, and youth) are in your household? *(Please write your response in the space below.)*

_____ people

39. What is your highest level of education? *(Please check one.)*

- ☐ Less than high school
- ☐ High school diploma or GED
- ☐ Associate or vocational degree
- ☐ Bachelors degree
- ☐ Masters or doctoral degree

40. In the last 12 months, have <u>you</u> gone without any of the following because of the cost? *(Please check all that apply.)*

- ☐ Health insurance
- ☐ Medical treatment
- ☐ Mental health care
- ☐ Prescriptions
- ☐ Other, *please specify:*_____

  _____
- ☐ None of the above

41. In the last 12 months, have you been late or unable to pay any bill because of your child's medical costs? *(Please check one.)*

- ☐ Yes
- ☐ No
- ☐ I don't know

42. Approximately how much are your monthly out-of-pocket medical expenses for your child? *(Please check one.)*

- ☐ Less than $100
- ☐ $100 - $250
- ☐ $251 - $500
- ☐ $501 - $1,000

43. Approximately how much is your annual household income before taxes? *(Please check one.)*

- ☐ Less than $14,000
- ☐ $14,000 - $21,000
- ☐ $21,001 - $25,000
- ☐ $25,001 - $39,220
- ☐ $39,221 - $55,000
- ☐ $55,001 - $65,000
- ☐ More than $65,000

44. Is your child Hispanic or Latino? *(Please check one.)*

- ☐ Yes
- ☐ No

45. What is your child's race? *(Please check one.)*

- ☐ American Indian or Alaska Native
- ☐ Asian
- ☐ Black or African American
- ☐ Native Hawaiian or Pacific Islander
- ☐ White
- ☐ Other, please specify:_____

46. What county are you living in now? *(Please check one.)*

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

47. About how often do you use the following types of internet media? *(Please check one for each.)*

Social Media Type	At least once per day	A few times per week	One to three times per month	A few times per year	Never
a. Blogs	☐	☐	☐	☐	☐
b. Facebook	☐	☐	☐	☐	☐
c. Google Plus	☐	☐	☐	☐	☐
d. Instagram	☐	☐	☐	☐	☐
e. LinkedIn	☐	☐	☐	☐	☐
f. Listservs	☐	☐	☐	☐	☐
g. Pinterest	☐	☐	☐	☐	☐
h. Snapchat	☐	☐	☐	☐	☐
i. Twitter	☐	☐	☐	☐	☐
j. Youtube	☐	☐	☐	☐	☐
k. Other, *please specify:*	☐	☐	☐	☐	☐

48. What kinds of things do you do when you use internet media? *(Please check all that apply.)*

☐ Buy or sell things
☐ Communicate with my child's health care providers
☐ Find out about local events
☐ Learn about and make connections for jobs for myself
☐ Learn about and make connections for jobs for my child
☐ Learn about college or other educational programs for my child
☐ Learn about and promote causes or groups that are important to me
☐ Learn about how my family can be healthy (like how to exercise, what to eat)
☐ Learn about how to make or do something
☐ Learn about my child's health condition
☐ Meet new people in general
☐ Meet others who have children with health conditions like mine
☐ Read the news
☐ Share my thoughts and feelings
☐ Stay in touch with friends and family
☐ Use online support groups or pages to help me deal with problems in my life
☐ View photos, web pages, and videos for fun
☐ Other, *please specify:*_____
-- -- -- --
☐ None of these things

49. Is there anything else about your child's health, health care needs, or this survey that you would like to share with us? *(Please write your response in the space below.)*

Thank you for completing our survey. The information you provided is very important to us!

After completing the survey, if you would like to participate in our raffle to receive one of five $50 gift cards, please email your name and phone number to Dr. Alison J. Martin (martial@ohsu.edu) by August 21. If your name is selected we will call you by October 3.