



**2014 Oregon Youth Survey on
Health & Daily Life**

An effort to understand the issues important to youth with special health care needs between ages 12 and 26 years.

To be completed by or with a youth between the ages of 12 and 26 years who has a special health care need.

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

We are writing to ask for your help. We would like to learn about the kinds of things youth and their families need. The best way we have to learn about these needs is to survey youth and their families.

This survey asks you questions about education, health care, recreation, work, and independence. The Oregon Center for Children and Youth with Special Health Needs (OCCYSHN) is conducting this survey. OCCYSHN is part of Oregon Health and Science University (OHSU). Your answers will help us to plan services for youth with special health care needs in Oregon.

This survey should take less than 15 minutes to complete. It is your choice whether you want to complete the survey or not. Your answers are anonymous, which means that no one at OCCYSHN or OHSU will know that these are your answers. You may skip any questions that you do not want to answer. Please fill out our survey by August 21, 2014, and mail it to us using the attached postage paid envelope.

The information you provide is very important! We will raffle five \$50 iTunes gift cards to youth 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 being conducted as part of Oregon's Title V block grant needs assessment. 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_Youth_English
In Spanish: https://www.surveymonkey.com/s/OR_Juventud_Espanol***

This survey was adapted from a survey tool created by the Alabama Department of Rehabilitation Services, Children's Rehabilitation Service and the Got Transition Health Care Feedback Survey for Youth and Young Adults. Permission was obtained for modification of Alabama's CSHCN survey tool for use in the Oregon Title V Needs Assessment process.

INFORMATION ABOUT YOUR HEALTH & HEALTH CARE PROVIDER

1. What health conditions do you have? (Please check one for each condition.)

Health Condition	Yes	No	I don't know
a. Attention deficit disorder	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. Autism	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. Bleeding disorders or hemophilia	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. Blindness or visual impairment	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e. Bone or joint condition	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f. Breathing or lung condition (e.g., asthma, cystic fibrosis)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g. Cancer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
h. Cerebral palsy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
i. Deafness, hard of hearing or hearing loss	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
j. Down syndrome	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
k. Epilepsy or seizures	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
l. Genetic syndrome	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
m. Heart condition	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
n. Learning disability	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
o. Mental health	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
p. Muscular dystrophy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
q. Sickle cell disease	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
r. Speech/language disorder	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
s. Spina bifida	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
t. Stomach or intestinal conditions	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
u. Traumatic brain injury	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
v. Other, <i>please specify:</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

2. How often does your health condition(s) affect you doing things that you like or need to do on a regular day? (Please check one.)

- Every day
- Most days
- Some days
- Occasionally
- Never
-
- I don't know

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

3. A health care provider is a doctor, naturopath, nurse, physician's assistant, or surgeon. Do you have a health care provider that you go to about your health condition? (Please check one.)

- Yes
- No → Go to Question 10

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

4. During the last school year, about how many times did you go to your health care provider? (Please check one.)

- 3 or more times per month....
- 2 times per month.....
- 1 time per month.....
- Less than 1 time per month ...
- None → Go to Question 10
-
- I don't know.....

5. How often does your health care provider explain things in a way that is easy for you to understand? (Please check one.)

- Always
- Usually
- Sometimes
- Rarely
- Never
-
- I don't know

6. How often does your health care provider listen carefully to what you have to say? (Please check one.)

- Always
- Usually
- Sometimes
- Rarely
- Never
-
- I don't know

THINKING ABOUT YOUR FUTURE

7. Managing your own health and health care means knowing about things like the medications you take and their side effects, what to do in an emergency, and how to schedule appointments with your health care providers. How much help does your health care provider give you to learn how to manage your own health and health care? (Please check one.)

- A lot of help
- Some help
- A little help
- No help
-
- I don't know

8. Have you and your health care provider ever worked together to make a written plan to help you stay healthy? (Please check one.)

- Yes
- No
- I don't know

9. During the last school year, did your health care provider talk with you about how your relationship with your health care provider changes when you become a legal adult at age 18? (Please check one.)

- Yes
- No
- I don't know

10. Do you have at least one adult in your life who you can trust to talk to about serious problems or issues for you?
(Please check one.)

- Yes
- No
- I don't know

11. A role model is someone that you want to be like. Do you have at least one adult in your life who you can look up to as a role model?
(Please check one.)

- Yes
- No
- I don't know

12. What do your future plans include?
(Please check all that apply.)

- Completing high school
- Completing college
- Completing graduate or professional school
- Having a paid job
- Having a boyfriend or girlfriend
- Getting married
- Having children
- Learning to drive
- Living somewhere other than your parent's home, such as alone or with roommates
- Living with family
- Traveling
- Volunteering
- Other, *please specify:* _____

- None of these apply to me
- I don't know

13. Of the things listed below, what do you want to know more about? *(Please check all that apply.)*

- My health condition
- Furthering my education
- Getting reliable transportation to places in my community
- Healthy behaviors, like exercising, eating well, etc.
- How to care for my medical needs independently, like scheduling appointments, taking medications, etc.
- How to find an adult doctor when I turn 18 years old
- How to talk to the doctor about my health care needs
- Insurance and how to pay for my health care
- Jobs or careers
- Learning about supports for young people with my health condition
- Meeting or reading about other people who have the same health condition as me
- Recreational activities or things to do for fun
- Sexuality and safe sex
- Drug and alcohol use
- Volunteering and community service
- Other, *please specify:* _____

- None of these

INFORMATION ABOUT YOU

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

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	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. Facebook	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. Google Plus	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. Instagram	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e. LinkedIn	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f. Listservs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g. Pinterest	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
h. Snapchat	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
i. Twitter	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
j. Youtube	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
k. Other, <i>please specify</i> :	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

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

- Buy or sell things
- Communicate with my health care providers
- Find out about local events
- Learn about and make connections for jobs
- Learn about college or other educational programs after high school
- Learn about and promote causes or groups that are important to me
- Learn about how I can be healthy (like how to exercise, what to eat)
- Learn about how to do or make something
- Learn about my health condition
- Meet new people in general
- Meet others who have 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

16. Who do you live with? (Please check one.)

- I live alone.
- I live with one or more roommates or housemates.
- I live with others in a group facility.
- I live with parents or other relatives.
- Other, *please specify:* _____

17. What is your sex? (Please check one.)

- Female
- Male

18. How old are you? (Please write your age in years.)

_____ years

19. Are you Hispanic or Latino? (Please check one.)

- Yes
- No

20. What is your race? (Please check one.)

- American Indian/Alaska Native
- Asian
- Black or African American
- Native Hawaiian/Pacific Islander
- White
- Other race, *Please specify:* _____

21. What is the highest level of education you completed? (Please check one.)

- 6th grade
- 7th grade
- 8th grade
- 9th grade
- 10th grade
- 11th grade
- High School Diploma or GED
- Modified Diploma
- Some college
- Vocational training after high school
- Associates degree
- Bachelors degree
- Other, *please specify:* _____

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

22. Do you have health insurance? (Please check one.)

- Yes.....
- No → *Go to Question 24*
- I don't know .. → *Go to Question 24*

23. Which of the following health insurance plans covers you? (Please check one for each.)

	Yes	No	I don't know
Oregon Health Plan (OHP)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Medicaid	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Medicare.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Private insurance (such as Blue Cross, Kaiser Permanente, or Moda Health)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Tricare	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other, <i>please specify:</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Attention: Check for a “Go to” instruction after you answer the next question.

24. Who is filling out this survey? (Please check one.)

- Youth or young adult (12-26 years old)
- Youth and parent
- Parent or guardian of youth
- Other person, *please specify:*

25. If you had help filling out this survey, how did someone help you? (Please check one.)

- Someone helped by reading the questions to me.
- Someone translated the questions into my language.
- I said the answer and someone wrote it down.
- Someone else completed the survey on my behalf.
- Other, *please specify:*_____

26. Is there anything else you would like to tell us about you, your health, or this survey? (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 iTunes 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.