

# Taking Charge of My Health Care Toolkit: A Toolkit for People with Intellectual and Developmental Disabilities and Those Who Support Them

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## About Us

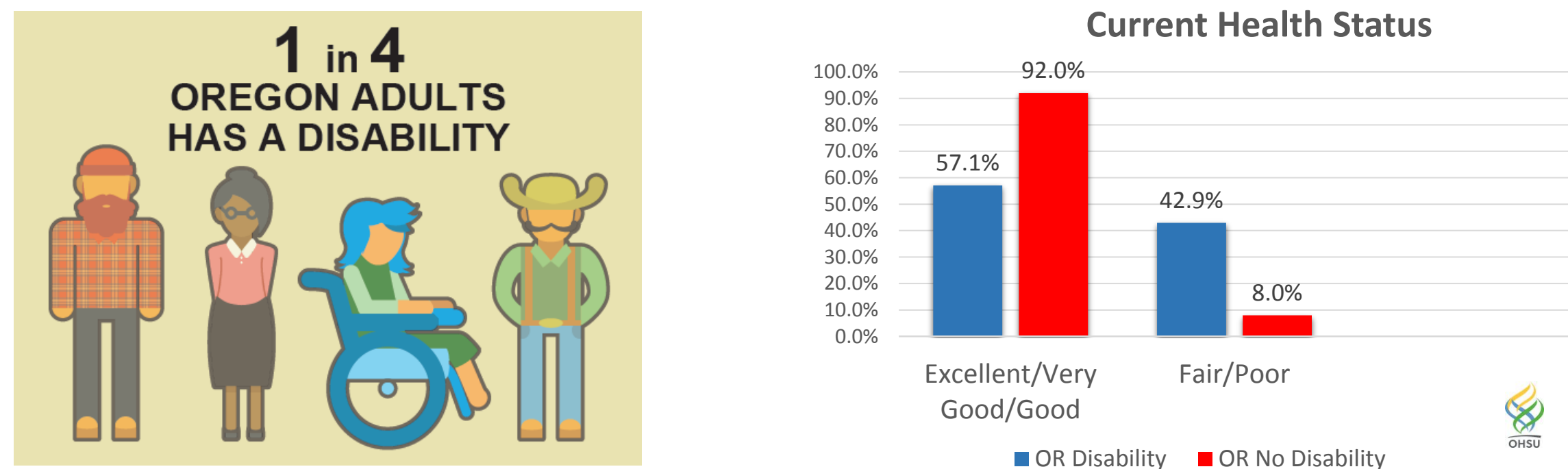
The Oregon Self Advocacy Coalition’s (OSAC) Health Care Committee is made up of people with intellectual and/or developmental disabilities (I/DD) who are passionate about the importance of advocating for one’s health and health care. OSAC is a non-profit organization whose primary funding comes from the Oregon Council on Developmental Disabilities (OCDD), an advocacy group for people with I/DD that is funded by the Administration for Community Living. Other partners in this project were the Oregon Office on Disability and Health (OODH), funded by the Centers for Disease Control and Prevention, and the OHSU UCEDD; these are both housed in the Institute on Development and Disability at Oregon Health & Science University.

## Project Vision

To create a comprehensive advocacy toolkit that provides training, education, and resources for people with I/DD so they can better advocate for their health and health care. The toolkit promotes learning in both independent and group settings for people with I/DD, and opportunities for learning alongside their parents or guardians, families, caregivers, support workers, teachers, health care providers and others.

## Health Disparities

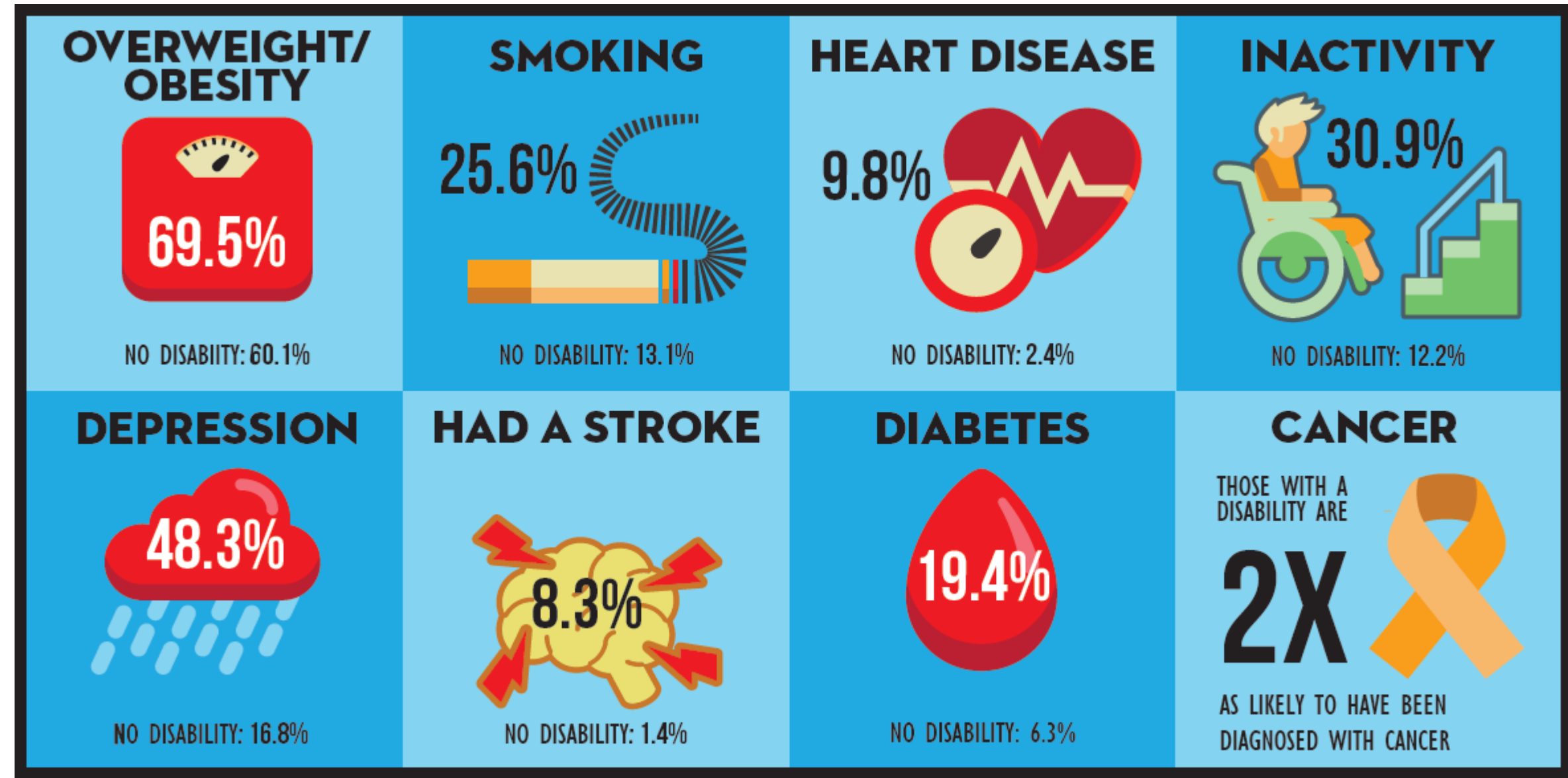
According to the 2016 Behavioral Risk Factor Surveillance System Survey



\*57% of adults with disabilities in Oregon described their current health status as excellent, very good, or good compared to 92% of Oregon adults without disabilities.

\*43% of Oregon adults with disabilities stated their health was fair or poor compared to 8% of adults without disabilities.

The chart below shows health conditions and health risks among Oregon adults with disabilities with compared to Oregon adults without disabilities:



9 lead actors for Taking Charge of My Health Care videos

PRODUCTS

**Participant’s Workbook**  
For individuals or groups of people in a workshop setting. It includes all 9 modules and corresponding worksheets.

**Leader’s Guide**  
For groups of people in workshop or class setting. It includes overview summary, instructions on how to conduct a workshop, 9 modules and worksheets, and appendices with supplemental materials and resources.

**Providers’ Fact Sheets**  
For parents and service providers of people with I/DD. It includes 19 fact sheets that provide information and resources on various health topics, e.g., sexual health, mental health, and working with health care professionals.

**Online Toolkit**  
Taking charge of My Health Care Toolkit available on the Oregon Office on Disability and Health website. It includes 9 modules with corresponding videos, worksheets, and power points, and additional materials and resources.

## Modules 1-9

Module 1  
**Being A Self-Advocate**

Module 2  
**Finding a New Doctor**

Module 3  
**When I Should Visit My Doctor**

“Some people with disabilities process differently than other people without disabilities. The Toolkit being offered in both video and written formats helps get the message across to everyone,” said Phil Stone, OSAC Member.

Module 4  
**Me and My Doctor**

Module 5  
**Me and My Medications**

Module 6  
**Signs of Sickness**

“I am so excited about sharing this information with self-advocates. The toolkit encourages self-advocates to speak up for themselves. It is super person-centered. I love it!” said Sara Davis, Director of Supported Living at Living Opportunities, Inc.

Module 7  
**When My Doctor Recommends Surgery**

Module 8  
**Mental Health**

Module 9  
**Staying Healthy**

“Good health and access to good health care is very important. We always have a choice in what we eat, how much we exercise and how to be the person we want to be. Advocating for our health care is similar. We have a choice on who our doctor is and what happens to our bodies. Anything is possible when we take charge of our health. It makes us stronger,” said Eric Thompson, OSAC Member.

## Timeline for Creating the Toolkit

<b>April 2016</b>	OSAC asks OODH and UCEDD to partner to create Toolkit
<b>January 2017</b>	Australia gives permission to use their version of the Health Care Toolkit as a template
<b>Throughout 2017</b>	Project staff meets multiple times with OSAC members to obtain and incorporate their input and feedback
<b>January 2018</b>	Expert panel made up of self-advocates, health care professionals, parents, social workers, and others review toolkit
<b>March 2018</b>	Planning for production of the Toolkit videos begins with local videographers KLIK and Melissa Mullineaux Films + Photographs
<b>June 2018</b>	Video filming begins (Over 84 hours of filming) <ul style="list-style-type: none"><li>• 27 actors: 12 self-advocates, 5 OHSU nursing students, and 10 actors from OHSU staff and community members</li><li>• Over 7 locations used during filming</li></ul>
<b>September 2018</b>	Present a draft of the Toolkit at OSAC’s board meeting and revise the Toolkit to include their feedback
<b>October 2018</b>	Begin creating website to host the Toolkit
<b>October 2018</b>	Present Toolkit at Oregon Public Health Association (OPHA) annual conference
<b>November 2018</b>	Begin conducting video screenings at community listening sessions across Oregon as a way to disseminate toolkit

## Next Steps and How You Can Help

We are conducting a series of listening sessions throughout Oregon beginning November 2018 and continuing through spring of 2019 to disseminate the Toolkit and solicit feedback.

- How you can help:
- Share the free on-line Toolkit with disability services representatives
  - Conduct a Taking Charge of My Health Care workshop
  - Schedule a training with OODH, UCEDD and OSAC
  - Share the Toolkit with local public health departments