



Taking Charge of My Health Care

A toolkit by and for self advocates

Oregon Self Advocacy Coalition

Oregon Office on Disability and Health

University Center for Excellence in Developmental Disabilities at OHSU

AUCD Webinar, June 11 2019

Presented by Lindsay Sauv , MPH, Erin Taylor, and Michael Steen

Welcome!

Today's presenters:

Lindsay Sauv , MPH
Program & Evaluation Manager, UCEDD

Michael Steen
Member, OSAC

Erin Taylor
Health Promotion & Outreach Coordinator, OODH
& UCEDD

Today's agenda

- Learn the history of the Taking Charge of My Health Care Toolkit
- Learn about the importance of advocating for one's health care
- View the toolkit and learn about the different tools that are available
- Share ideas for how you can utilize the toolkit in different settings

Project History

April 2016	OSAC asks OODH and UCEDD to partner to create Toolkit
January 2017	Australia gives permission to use their version of the Health Care Toolkit as a template
Throughout 2017	Project staff meets multiple times with OSAC members to obtain and incorporate their input and feedback
January 2018	Toolkit reviewed by expert panel made up of self-advocates, health care professionals, parents, social workers, and others
March 2018	Planning for production of the Toolkit videos begins with local videographers KLIK and Melissa Mullineaux Films + Photographs

Project History

June 2018	Video filming begins (Over 84 hours of filming) <ul style="list-style-type: none">• 27 actors: 12 self-advocates, 5 OHSU nursing students, and 10 actors from OHSU staff and community members• Over 7 locations used during filming
September 2018	Present a draft of the Toolkit at OSAC's board meeting and revise the Toolkit to include their feedback
October 2018	Create website to host the Toolkit
October 2018	Present Toolkit at Oregon Public Health Association (OPHA) annual conference
November 2018	Begin conducting video screenings at community listening sessions across Oregon as a way to disseminate toolkit

The Importance of Advocating for One's Own Health Care

1) Encourages individual ownership for healthcare decisions and actions

> It develops “buy-in” from the patient so that he/she will develop a better sense of understanding for their role

2) The PCP will be more well informed of the unique physical and possible mental health issues impacting the patient

> Through understanding the influencing factors affecting the patient's health, the PCP will have a holistic understanding for how to best meet the needs of the patient

> It is essential for developing trust between the PCP and the patient

>> The patient is more likely to speak-up when a component of their health care is not working right and the PCP is more likely to truly listen. And the patient is more likely to put into practice the doctor's directions

The Importance of Healthy Lifestyle Choices

It is well known that personal lifestyle choices affect human health outcomes. For people experiencing I/DD, the impact of one's lifestyle is magnified vs. the population as a whole

1) My diet emphasizes plant based whole foods, being careful to consume sufficient protein and essential nutrients, is essential to my well-being

2) Building in opportunities for exercise as part of daily living, as well as scheduling dedicated times for physical recreation

3) Maintaining social interactions, community involvement and “alone time” for meditation / self reflection

>> While Healthy Lifestyle Choices may seem obvious on paper, it requires a supportive team effort from Family Members, Service Providers and Health Care Professionals to foster the decisions into action over the long term

Taking Charge of My Health Care Toolkit

Module 1: Self-Advocacy



In this module, you can find information about advocacy:
 1. What is advocacy?
 2. When and when to be a self-advocate?
 3. Why would you need to be a self-advocate?
 4. How to be a self-advocate?
 5. What are the benefits of self-advocacy?
 6. What are the challenges of self-advocacy?

Module 2: Finding a New Doctor



In this module, you can find information about:
 1. Choosing a new doctor
 2. How to find a new doctor
 3. What are the signs of a good doctor?
 4. What do I need?

Module 3: When I should Visit My Doctor



In this module, you can find information about:
 1. Checkups
 2. Preventive care
 3. When to visit your doctor
 4. What do I need?

Module 4: Me and My Doctor



In this module, you can find information about:
 1. How to prepare for my doctor appointment
 2. What to expect during my doctor appointment
 3. How to talk to my doctor
 4. What do I need?

Module 5: Me and My Medications



In this module, you can find the following information:
 1. Understanding my medications
 2. Knowing when my prescription may be running out
 3. Understanding medication safety
 4. What do I need to know about my medications?
 5. What do I need to know about my medications?

Module 6: Signs of Sickness



In this module, you can find information about:
 1. Signs and symptoms
 2. Understanding levels of illness
 3. What do I need to know?

Module 7: When My Doctor Recommends Surgery



In this module, you can find the following information:
 1. Why do I need surgery?
 2. What are the risks of surgery?
 3. What are the benefits of surgery?
 4. What do I need to know?

Module 8: Mental Health



In this section, you can find the following information:
 1. What is mental health?
 2. What are the signs of mental health problems?
 3. What are the symptoms of mental health problems?
 4. What are the causes of mental health problems?
 5. What are the treatments for mental health problems?
 6. What do I need to know?

Module 9: Staying Healthy



In this module, you can find information about:
 1. Healthy eating
 2. Physical activity
 3. Importance of sleep
 4. Stress management
 5. Other tips to maintain good health
 6. What do I need to know?

Leader's Guide

- Coming soon!
- For self-advocate trainers and co-trainers to conduct workshops on the Toolkit
- Instruction on how to do a workshop
- Ideas for interactive activities to facilitate discussion

Health Care Resource for Parents and Disability Service Providers

- Coming soon!
- 19 Factsheets on various health and I/DD topics and resources



Videos for Modules

9 videos to accompany each module of the Toolkit



Creating Videos for Modules



- Six, 12-14 hour days of filming
- 2 videographers
- Over 7 locations including clinical offices at OHSU

Taking Charge of My Health Care Actors



27 actors total

12 self-advocates

- Members of OSAC and community
- From all parts of Oregon

15 staff, nursing students, other community members

How can the Toolkit be used?

-Peer-facilitated training

-One on one

-IEP or ISP

-Parents

-Advocacy groups

-Disseminate via doctors offices



Next steps for the Toolkit

- Developing and disseminating Leaders Guide
- Developing and disseminating Fact Sheets
- Conducting pilot trainings in communities around Oregon with OSAC trainers



Thank You