

Goal setting and self-advocacy improve care for people with I/DD

Oregon adults with disabilities want more person-centered health care.

- Adults with intellectual and developmental disabilities (I/DD) were interviewed in 2022 about health care access needs. They told us that health care providers do not listen to adults with I/DD, and they believe listening is the most important quality of a health care provider.
- In a 2018 survey of 319 Oregon adults with disabilities, 40% said that they did not believe that providers understood their specific needs related to their disability.



People with I/DD often face health care providers and medical staff who are not person-centered in their approach to providing care. Person-centered care is important for quality care, since it makes the goals, desires, and needs of the person receiving care the focus of care.

It is important to support medical self-advocacy skills for adults with I/DD. An example of medical self-advocacy is a patient clearly describing their goals and desires for care. In 2020, the Oregon Office on Disability and Health (OODH) partnered with the Oregon Self Advocacy Coalition (OSAC) and the University Center for Excellence in Developmental Disabilities (UCEDD) to create the Taking Charge of My Health Care Toolkit. The toolkit is a set of resources and tools to support people with I/DD as they navigate health care.



The Taking Charge of My Health Care Toolkit is now being used to support participants in the OODH Linkage Project. The Linkage Project aims to link adults with I/DD who face unmet health needs to preventive health services and health promotion programs that they want. Building medical self-advocacy skills helps participants state their goals and needs clearly when they are linked to new providers and care. Tools from the toolkit also support healthy lifestyle goals so participants can maintain their health outside of the provider office.

Taking Charge of My Health Care helped Linkage participants:

- Set reachable health and wellness goals, and make plans to achieve their goals
- Gain knowledge in aspects of healthy living that meet their goals
- Communicate their needs and preferences to medical providers and clinic staff
- Build confidence in navigating complex medical systems

One tool included in the Toolkit is the My Health Passport. This is a health communication tool developed by the Florida Center for Inclusive Communities. It asks questions about support needs, preferences, and accommodations needed for successful health care experiences. Linkage Project staff help participants complete this tool to take to health care appointments.

Taking Charge of My Health Care also contains videos, plain language written materials, and fact sheets for support people. These tools support various aspects of health and introduce aspects of health care. Participants use these tools to explore topics related to their personal health care goals with Linkage Project staff.

To date, 62.5% of OODH Linkage Project participants have completed Health sessions that used Taking Charge of My Health Care to build medical self-advocacy and goal setting skills.

Two examples of Linkage participant successes

My Goal Tracker

Linkage Project staff supported one Linkage Project participant to tailor goal tracking tools to create a portion control tool that met their needs.

Following through on healthy lifestyle goals was very important to this participant, who finds joy in exercise, sport, and healthy living.

The participant wanted to use the tool with their support staff and family to keep themselves on track with goals.

Tool Used: My Goal Tracker

The participant reviewed tools in the Toolkit. Then the participant chose to make their own tool, a weekly calendar to track the portion control goal, including a scale that the participant made to track the confidence they felt with making progress on the goal as well as the time spent on the goal.

The participant decided to laminate their personalized My Goal Tracker so they could use a marker and eraser to continually track progress each week.

Mental Health Self-Advocacy

One Linkage Project participant set a goal to address mental health. They wanted to access a therapist in person for care and support.

Tool Used: Mental Health Care Video

The participant reviewed the video from the Taking Charge of My Health Care module on mental health care. This helped them learn about ways they can advocate for their needs in a mental health setting.

Tool Used: My Health Passport

To support the participant in starting care with a mental health provider, Linkage Project staff filled out a My Health Passport with the participant. This tool was used to support communication with mental health providers. It clearly listed accommodations being requested, and care needs and preferences of the person.

The participant's family shared that they took the My Health Passport to their first therapy appointment and used this as a starting point in discussions to build rapport with the therapist.