

# Supporting Self-Advocacy

People with intellectual and developmental disabilities (I/DD) have the right to express their needs and make decisions about their own lives. Each person should be supported in a way that allows them to be the first person to choose his or her own medical providers, make lifestyle decisions and decide what happens to their body.

Supporting a person with I/DD to make their own decisions about their health and health care needs is an important, yet challenging role for a family member or direct support provider.



## Support the Person to Learn to be an Effective Self-Advocate

Encouraging someone to learn to be a self-advocate is a great first step in supporting them to live the life they choose. Learning how to effectively advocate does not happen overnight, can start at any age, and can be built upon throughout life. Self-advocacy helps a person learn how to get the information they need to make decisions about their life and understand their rights and responsibilities.



### You can encourage self-advocacy skills by helping the person:

- Identify their skills, strengths, and weaknesses.
- Discover things important to them.
- Communicate their needs.
- Support the choices they make.

## Tips for being an Effective Support Person

- Listen – take the time to actively hear what the person is saying.
- Be present – learn about the person, their needs, and their goals
- Encourage – support the person to try things on their own. You can still support them in the “background.”
- Ask - instead of doing something for them, make sure they want your support.
- Apologize – if you make a mistake, apologize. Building trust goes both ways and helps build respect and accountability.

# Your Role in Supporting a Self-Advocate

When supporting a self-advocate, it is important to remember to put the person first. You are there to help them if they need it.

In a health care setting, the person may ask you to support them with:

- Contacting their insurance provider
- Making or preparing for an appointment
- Securing or providing transportation
- Requesting accommodations
- Filling out forms
- Explaining what their health care provider says, in a way they understand.
- Asking questions
- Taking notes during the appointment so they can remember important information later.
- Weighing their options and helping them decide.
- Filing a complaint or appeal.



## For More Information:



**Disability Exchange podcast**  
[bit.ly/4fJyKjD](https://bit.ly/4fJyKjD)



**Possibilities Newsletter**  
<https://bit.ly/48OUUib>



### Acknowledgement

The Iowa Taking Charge of My Health (TCMH) curriculum, including power points, worksheets and fact sheets is inspired by Oregon's University Center for Excellence in Developmental Disabilities (UCEDD) Taking Charge of my Healthcare Toolkit which can be found at <https://www.ohsu.edu/oregon-office-on-disability-and-health/taking-charge-my-health-care>.

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The information provided is for general use and not medical advice or intended to address any individual situation.