

Supporting Self Advocacy

People with intellectual and developmental disabilities (I/DD) have the right to voice or express their needs and make meaningful 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 sometimes challenging role for a family member or direct support provider.

Supporting the Person 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 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, to understand their rights and responsibilities, and to problem-solve everyday issues.



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

- Identify their skills, strengths, and weaknesses.
- Identify and communicate their needs.
- Explore options about different ways they can get what they need.

Tips for Being an Effective Support Person

To be an effective support person for a self-advocate, be sure to:

- Listen – take the time to actively hear what the person is saying.
- Be present – learn about the person, their needs, and their goals without distraction.
- 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 or when 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
- Requesting accommodations
- Filling out forms
- Explaining what their healthcare provider has told them, 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: <https://ucedd.uihc.org/disability-exchange>
- Possibilities Newsletter: <https://www.disabilitytraining.org/our-newsletter/>

Related fact sheets:

- #1 Accommodations
- #3 Supporting Communications and Doctors Appointments

This fact sheet was edited in April 2024. It contains general information only and does not address individual circumstances.

This fact sheet is adapted from materials developed by NSW Council for Intellectual Disabilities (2009), Australia. Its components are supported in part by Grant/Cooperative Agreement #5 U27 DD000014 from the Centers for Disease Control and Prevention, Disability and Health Branch. The contents are solely the responsibility of the authors and do not necessarily represent the official reviews of the CDC.