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
- Possibilities 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.

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