

Empowerment

“Our job
is not to
silence.”

Facilitating Voice and Personal Power

As you know, people with disabilities may need a lot of support and encouragement to speak up for themselves and to be seen as an important partner in the process of receiving medical care. Many people feel intimidated when visiting their doctor and this can be especially true when you have an intellectual disability. The words that are used, the speed of a visit and the assumption that others know better how you experience your life and your disability can lead to compliance rather than collaboration.



As a caregiver, it's tempting to want to simply step in and 'be the voice' of your family member. But as appealing as that may be, it's important to remember that your goal is to support, not to silence. Helping your family member present their issues and use their way of communicating is one of the most powerful ways of being a supportive caregiver.

You will notice as a theme throughout this toolkit that the involvement of people with disabilities in the health care process is paramount in the approach taken. What we need to look at is the everyday kind of approaches to 'voice' and 'choice' that one can take when supporting people with disabilities.

**Your goal is to support,
not silence the individual.**

It's important to be mindful of your role as a caregiver: helping your family member find their voice and ensure that they get the best of service because they have learned to ask for it and expect it.

Keep reading to learn more about how YOU can facilitate the voice of your loved one, through targeted approaches and strategies. Then, review some ideas about how to promote positive communication during health care appointments and foster positive outcomes before, during and after appointments.



Tips on facilitating assertion and self advocacy

- 1 **Use active listening skills when your family member needs to speak to you about something.** Active listening involves giving your family member your undivided attention when they have something to say, and eliminating distractions (e.g. silencing your phone). By doing so, your family member learns that you are saying, 'I value you and I value what you have to say.' It's important that people with disabilities learn, from how they interact with you, that they have importance and that their voice is welcome.
- 2 **Be there to listen and to help your family member discover their own path and their own way.** Despite our good intentions, we don't know best how someone should live their life and our advice could be seen as judgmental. It is important to know where you end and where the person you support begins. When you listen, try hard not to immediately put on the 'problem solver' or 'advice giver' or 'opinion sharer' hat.
- 3 **Offer opportunities for your loved one to express their opinion.** Watching the news or seeing a movie provides an opportunity for them to express their opinions. Allow room for respectful disagreement – if they change their opinion to match yours, understand that this is often done out of fear of disapproval; so it's important to foster opportunities for them to feel safe to express alternative and different opinions.
- 4 **Sometimes you just need to let people make their own choices.** Just like anyone else, your family member will have their own preferences and opinions, for example, the music they listen to or movies they want to see. It is important to remember not to judge or try to change their preferences, but to encourage their own individuality.
- 5 **Support your family member to be assertive in situations where *they* need to speak up.** As much as possible, help them to express themselves, rather than speaking for them. For example, if they need to complain about rude treatment at a store, work with them so they can assert themselves to the manager, with your support and help if needed. Knowing their voice matters and should be taken seriously is an important step towards self-advocacy.
- 6 **Discover strategies to support your family member to learn about speaking up and speaking out.** Use techniques such as role plays, social stories, and practical try outs; tailored to the supports they need.
- 7 **Don't be afraid of innovation and adaptation.** Explore different ways to facilitate communication. For example, a person may find it easier to make a video on their phone and play it for someone as a way to express themselves. What matters most is that you help your loved one express themselves in the way they are most comfortable.
- 8 **Make a language dictionary.** For people with significant disabilities who don't communicate by words, a language dictionary of their communication strategies is helpful - how they say 'yes' or 'no' or 'more' or 'stop' along with their way of showing sadness or anger or fear or happiness, and any other words they communicate non- traditionally. Make sure that all who work with your family member know of these strategies. Take this with you to health care appointments or other places where it may be needed.
- 9 **If a person uses alternative communication like a communication board USE IT.** It takes time but it's important. Otherwise, it's like leaving their ability to communicate at home, and you can imagine what that would feel like.