

Speak Up: Your Guide To Self-Advocacy

By [MICHELLE DIAMENT](#)



No One Knows You Better Than Yourself

There are lots of experts to help people with developmental disabilities succeed. But the best expert, and the most consistent one, is often found within. After all, no one knows you better than yourself.

Whether you've got the words to express yourself or are reliant on actions alone or others to interpret, Ari Ne'eman, president of the [Autistic Self-Advocacy Network](#), shares the tools to turn anyone into a self-advocate.

It's easier than you think. Start small, advises Ne'eman, who is on the autism spectrum himself. The key is to make yourself heard however you can.

“When other people make decisions for you without you, the decisions that are made often don't fit your needs,” Ne'eman says. “Self-advocacy helps people get the outcomes that they desire and it becomes necessary — as a person grows from a child to an adult — in order to succeed in this world.”

The Time Is Now

Whether you're in formal discussions with a lawmaker or simply telling mom that you're sick of peanut butter and jelly, self-advocacy is the very basic idea of asserting yourself.

“You are the person with the most at stake and thus the person who should have the most control over your own life,” Ne’eman says.

Remember that old phrase today is the first day of the rest of your life. Take it to heart. You’re never too young or too old to start communicating what’s best for you.

Know Yourself

People with developmental disabilities are often the least able to explain their needs. Why? Their parents tend to do that for them.

Ne’eman tells the story of a friend who runs a university program for people with learning disabilities. “The single largest problem that he has when students come to his office is he asks them, ‘can you explain your disability to me,’ and they don’t know how to do that,”

Ne’eman says. “It’s hard to advocate for yourself if you don’t understand your own needs.” So, study up. Know your strengths and your needs.

Navigate The System



Home, work, school and the list of systems we live within goes on and on. The key to getting what you want out of each environment is to understand the infrastructure and what role you play within it.

“Understanding how to run your own IEP doesn’t mean you have to understand every line of IDEA. It just means you have to understand what role you play in the IEP meeting and how to assert your own needs and aspirations and get what you want,” Ne’eman says.

It's the little things in life too, like learning to share a toy with a friend or interacting with other passengers on a bus.

Cut The Cord

Yes, it is a parent's job to protect their child. But no matter a person's age or ability level, doing all the talking for them is probably not in their best interest long-term.

The best way to become a self-advocate, Ne'eman says, is slowly over the course of childhood. Ideally, by the time a person enters high school and transition planning begins, they're capable of expressing their own desires. After all, many decisions are made in high school that will impact the rest of a person's life.

“A lot of times parents don't realize that what they're doing — which was very important and necessary at one time in their life — needs to transition to something different and help support their child to speak for themselves,” Ne'eman says. “There's a very big difference between the kind of assistance that fosters dependence and the kind of assistance that empowers independence.”

Have a Goal and Stick to it!



Speaking up isn't ever a bad idea, but how you do it could be.

“Obviously you want to select the means that are going to accomplish your ends,” Ne'eman says. “It's often not terribly productive to start screaming and yelling at people.”

Instead Ne'eman advises a four-point plan:

- Know what you're looking to accomplish.
- Have a plan to get your way that works within the system that you're in.
- Consider how you'll express your position and determine what success will look like.
- If you're not successful the first time, consider working outside the system to achieve your goals

Find A Role Model

Anyone can be a self-advocate, but sometimes you have to see things to believe them. That's where a role model comes in.

"Parents as well as children can see people who are succeeding and advocating for themselves and realize that it is possible for people with a wide array of disabilities to achieve success through self-advocacy," Ne'eman says. "It's very important for those who are seen as the weakest and most dependent in society to see others like them succeeding and advocating for themselves even against significant odds or significant opponents."

Have No Fear

Speaking up can be tough. But remember, the hardest things in life are usually the most rewarding.

"It's very scary sometimes," Ne'eman acknowledges, particularly when you're just starting out or if you're surrounded by a bunch of experts who think they know best.

But it gets easier. "People have to realize and internalize that they are the number one experts in their own lives and once they understand that, they should have the self-confidence to speak out and to communicate their own needs regardless of whatever forms of backlash they may get."