

Self Empowerment, Relationships and Respect



IDEA 2: LEADING YOUR OWN LIFE: SELF DETERMINATION AND ADVOCACY

"Nothing about us without us."

-People First



How this paper was written:

Although we **all** can make a valuable contribution to the conversation about self-direction, people with developmental disabilities are the most important teachers on this topic.

For this idea paper, we asked others, more competent than we are, to provide the content of this paper. The answers and ideas contained in this paper come directly from self-advocates. Our thanks to Matthew Heady, Marilyn Martinez, Cynthia Berkheimer and Susan Weiss for being the real voices in this paper.

Not every idea in this paper will apply to everyone. At the same time, the thoughts and ideas contained in this paper

apply to people with *and* without disabilities. We hope that the ideas empower more people with disabilities and help remind all of us how important it is to direct our own lives.

BRINGING IT TO LIFE: THOUGHTS AND IDEAS

How can people advocate for themselves?

- **Go with your instinct.** Don't second guess yourself. If you feel you're being treated unfairly or disrespectfully, you probably are.
- **Don't doubt your own ideas.** If you start doubting yourself, it makes you feel uncomfortable and less confident, making it

harder to advocate for yourself.

and think through your advocacy strategy.

- **Get training.** “Training like public speaking, conflict mediation, leadership skills, self-advocacy, team building made me more confident in myself and more confident in what I’m putting out there. I now have the skills to be a more effective advocate for others.” –Matt Heady
- **If you can’t speak in front of people, it’s hard to speak up for yourself.**
- **Create your own opportunities to speak up. Don’t wait to be asked.** Whether it’s being on the provider meeting agenda or simply calling your own team meeting, it’s important to feel comfortable telling others that you need to talk with them.
- **Write down your thoughts and ideas on paper.** It helps you prepare for conversations

What are the biggest barriers people with developmental disabilities face when they try to advocate for themselves?

- **Not being taken seriously.** People often assume a person with a developmental disability doesn’t know what he or she is talking about.
- **Being pushed off to the side or ignored.** Sometimes it’s intentional or sometimes it isn’t. People assume that a person doesn’t have the skills to do the task.
- **Not being asked for their opinion about their own lives.** A person knows naturally how to live their life. People are most familiar with their own strengths and needs but are not asked for input on their own lives.

- **System and agency policies and practices often work against a person running and living his own life.**

If I could tell regulators a few things about self-determination, they would be....

- **You can't run a person's life.** We need to use more common sense and support people in natural, more human, ways.
- **Nobody has the right to dictate what goes on in another person's life.**

What can a provider can do to support people with developmental disabilities to lead their own lives and services?

- **Be open minded.** If the provider comes in and says "it's going to be like this," the provider won't end up supporting the person in a meaningful way.

- **Know a person's personal story,** not just her case record.

- **Ask for input and provide opportunities to give input.** How can a person live her life if she is not asked what she needs to *live* her life? Who better to know how to live your life than you?

- **"When a provider gives me both support and space, I am happier with my services."** I need some space to make my own mistakes. This space makes me more appreciative of my services.

- **Let people hire their own staff.** If a person chooses her own staff, she is more likely to have the schedule and do the activities she wants to do.

- **Open *People First* opportunities to those not served by provider agencies.** Some providers host People First meetings. It would

be helpful if these meetings could be open to all people with disabilities and the provider offers the support needed for people not served by the agency to attend and to participate.

- **Support people served to attend self-advocacy conferences and trainings.** By providing the staff and the transportation for people who use services to participate in self-advocacy activities, providers can show they are committed to people becoming empowered.
- **Use “people first” language.** “I don’t want to be called a ‘case,’ I want to be called a person.”- Marilyn Martinez

What are some ideas for parents about self-determination?

- **Acknowledge what most parents want for their children is for them to be happy, healthy, safe, successful.**
- **Learn to let go.** “No matter how much protection you give, the world is coming anyway. When parents are first told that their child is going to have a disability, they are told they are going to need to take care of that child and protect them from the world. But the world is going to come anyway and you can fight it off as long as you can but when it comes, it’s going to be a shock to a child who has been sheltered his entire life.

When I first started middle school, I had been sheltered all my life and the teacher I had wasn’t a nice person and I had been told all my life that because of my disability,

people would be nice to me and he wasn't because I didn't fit the norm.

I went deeper into depression and started cutting myself off from the world. I figured if I didn't have any contact with the world, I'd be happier. It worked for a while but then I became lonely and felt like I wasn't getting support."
-Matt Heady

- **"I'm afraid to say certain things when my mom is around."**
-self advocate
Be aware that sometimes people are uncomfortable talking about certain parts of their lives in front of their parents. Parents can respect their son's or daughter's wishes to talk privately with others he or she trusts.
- **Mistakes happen.** Good intentions are good intentions but oftentimes what parents intend as protection results in control over their son or daughter. You need to

be willing to let the child go into the world, make their own mistakes, and learn from them.

- **Doctors and service providers don't have all the answers. It's important for parents to educate themselves about the options.**

"When I was first diagnosed with a disability, my mother was told I would never be able to function on my own. The doctor told her I had one of two choices for when I got older: live with her or go into a group home. And this hasn't changed much. Parents still get told that and aren't given many options.

Parents end up seeing the system and local providers as the 'be all end all' because they don't know what other options are available."
-Matt Heady

- **Parents don't have to do it alone.** Talk to your pastor. Talk to a school guidance counselor. Talk

to other parents. Talk to anyone you would trust who you believe would support that person to be happy, healthy and support that person to grow and learn through their mistakes.

- **Relationships keep people safer.** By talking and building relationships in the community, you end up developing a community network and safety net for their child.
- **Talk with your child.** Parents need to ask their child what he needs to survive and what he wants in life.
- **Start early.** The sooner parents begin empowering their child with decision-making opportunities and chances to advocate for herself, the safer and more independent a person will be.

What are some ideas for supporting a person who doesn't use words to advocate for herself?

- **Even without using words, people still communicate.** People need to be aware of a person's body language and facial expressions. A machine can be programmed to say what a person needs to say, but it doesn't substitute for a person's body language.
- **Learn how a person communicates even if doing so requires stepping outside of your comfort zone.** It takes time and effort to pay attention to someone who doesn't use words or speaks slowly.
- **Don't assume you have all the answers or know what a person is thinking.** Sometimes you have to put your ego aside.

- **Reassure people that their input is valued.**
- **Personalized communication devices are a person's link to the world.**
Communication supports need to be developed by people who know the person well. Communication devices need to contain phrases that support self-advocacy like "please talk to me directly" or "I deserve to be treated with respect."
- **Give people time to think about what they want to communicate.**
Sometimes people need a little extra time to put their thoughts together. Be patient.

What are some ways to encourage a person's safety while leading a full life?

- **Let a person make her own mistakes.**
Be willing to intervene when necessary and DO NOT intervene when it's NOT necessary.
- **Don't think about getting in trouble for supporting a person.** Before you can support somebody, get the notion out of your head that you're going to get in trouble if the person takes a risk. It's not the end of the world. "If we can get the state to relax, the provider can relax."
—Matt Heady

The more an agency gives you the room to make mistakes the more comfortable the person is with the agency. If a person is comfortable with an agency, it's less likely there is ever going to be a lawsuit if

- something bad happens.
- **Always look for opportunities to promote freedom and independence.**
Put these opportunities into the Individual Service Plan.

Other Words of Wisdom

- **Talking “person to person.”** People are often more relaxed when talking one-on-one with another person where both people are treated as equals.
- **People sometimes respond like a child when staff are present.**
- **“Never hinder a person’s will to try something new.”**

✓ CHECK IT OUT: GOOD RESOURCES

- People First of New Mexico and the Self Advocacy Project, 505-688-4225
<http://peoplefirstofnewmexico.blogspot.com/>

- The New Mexico Center for Self Advocacy, (505) 341-0036,
<http://www.nmddpc.com/csa>
- Self-Advocates Becoming Empowered (SABE)
www.sabeusa.org
- For thoughts about promoting self-determination in services, check out “The Meaning of Self Determined Lives in Publicly Funded Systems of Longterm Care” by Tom Nerney available at
<http://www.self-determination.com/articles/meaning.pdf>
- “People First Language” by Kathie Snow. Available at:
<http://www.disabilityisnatural.com/peoplefirstlanguage.htm>
- “Developmental Age vs. Chronological Age” by Kathie Snow. Available at:
<http://ftp.disabilityisnatural.com/articles/documents/DevAge.pdf>

TRY IT OUT: ACTIVITIES, EXERCISES AND COMPELLING QUESTIONS

- **“People with disabilities are our best teachers.”—Judy Stevens**

To schedule conversations or trainings about self-advocacy, contact one of the resources listed in *Check it Out*.