SELF-DIRECTION EXISTS WHEN YOU HAVE CHOICE AND CONTROL

WITH CHOICE AND CONTROL YOU HAVE SELF-DETERMINATION!
Constitution of the United States

The US constitution is a set of rules that guides how our country works.
Since the beginning of the United States, ALL citizens have the RIGHT to:

- Life
- Liberty, and
- the Pursuit of Happiness

With Self-Determination, you can exercise this RIGHT.
To use your Rights!

- Know yourself
- Know your rights and responsibilities
- Speak up so that others listen

- Solve problems
- Make a deal - Negotiate so all get some of what they want
- Advocate for yourself and with others
Self-Determination is...

- **Freedom:** you decide what happens now and in the future.
- **Authority:** you decide how your money is spent.
- **Support:** to do what is important to you.
- **Responsibility:** follow rules, laws and help others in the community. Speak up if you don’t know!
- **Confirmation:** Speak up, show that you can just do it!
Speak Up!

Steps to Becoming a Stronger Advocate:

1. Knowing Yourself
2. Communication
3. Solving Problems
4. Rights & Responsibilities
Know Yourself

Four Steps to Becoming a Self-Advocate:

Step #1 - Know Yourself
Communication is important!

Four Steps to Becoming a Self-Advocate

Step # 2 – Communication
Know Yourself

- What do you like and dislike?
- What are you good at?
- What do you need help with?
- Who do you like to spend time with?
- What do you like to do and where do you like to go?
- How do you want your staff to support you?
Know Yourself

What house rules do your staff need to respect?

- Follow your directions, like when storing groceries
- Ask you, before doing something
- NEVER, just NOT show up! Always call or text

- What are your house rules?
Know Yourself

What is important to you about your staff?
- Smoking?
- Male or Female?
- Age?
- Interests?
- Experience, education and training?

- What makes you feel comfortable and safe?
Know Yourself: RECAP

- What are your rights?
- What are your responsibilities?
- How do you want your staff to support you?
- What are your house rules?
- What makes you feel comfortable and safe?
Communication is important!

Four Steps to Becoming a Self-Advocate

Step # 2 – Communication
Communication Styles

Passive

Aggressive

Assertive
Communication Styles

- **Aggressive** – people don’t listen
- **Passive** – people won’t hear you
- **Assertive** - people will listen and hear what you say
  - **Assertive communication works for self advocacy**
  - **Assertive communication is used by good workers**
Communication is important!

Telling people your needs, desires, and ideas:

- Clearly and directly
- Speaking even if you feel shy or afraid
- It gets easier with practice
Communication is important!

It is important for you to explain what you need from staff and to tell staff what you want done.

- It is your responsibility to know what you need assistance with and how to explain it to someone.
Communication is important!

- You will lose control when you are passive about what you need and how you need it done.

- When you are aggressive, staff may negatively react to your behavior and not listen to your words.

- When you are assertive about what you need, it is up to you and your staff to decide if they can give what you need.
You are the “Captain of your own Ship!”

- Do you have something to say?
- Do you want to be heard?
- You are the expert on your life.
- Don’t let anyone else take the wheel.
- Use your “voice” to get everyone on board with the life you want. Speak up!
Negotiate

When you can’t have what you want, you can negotiate.

- You do some of what you want and agree to some of what the other person wants.
- You make a deal – meet in the middle.
- You think of a new way or new idea.

Credit to Project STIRTM training slides by OSDA.
How do you negotiate?

- Know what you want and why
- Plan what to say
- Be truthful
- Don’t give up
THINK ABOUT – TALK ABOUT: Solve Problems

Four Steps to Becoming a Self-Advocate:

Step # 3-
Problem-Solving
Examples of Problems:

1. Staff is late a lots of times
2. Handling disagreements
3. Asking staff for help for what you need and want
4. Saying no to requests that you disagree with
5. Staff doesn’t respect my choices
6. Dealing with behavior of others, including staff
The Spiral Model

1. Who else does it affect?
2. What’s the problem?
3. Investigate to get new information.
5. Just do it!

Credit Project STIR™
https://osdaohio.org/training-materials/
Solve Problems Using the **Spiral Model**

You can use these 5 steps to solve problems.

1. Answer each of the questions on your own or with your staff or some other person you trust to help you.
2. Draw a circle on your paper and place the numbers around it.
3. Answer each of the questions on your own or with your staff or some other person you trust to help you.
4. Answer each of the questions on your own or with your staff or some other person you trust to help you.
5. Answer each of the questions on your own or with your staff or some other person you trust to help you.
Example 1: I hired a new staff who agreed to quit smoking - 2 years later, he still smokes!

Spiral Model Step 1: **What is the problem?**
- Smoking in my house bothers my medical condition and leaves my home with unpleasant odors.
Solve Problems Using the Spiral Model

- Spiral Model Step 2: **Who does it affect?**
  - Me and anyone who visits me

- Spiral Model Step 3: **Investigate to get new information**
  - We had an honest talk about smoking. He agreed to try to quit. Until he could, we talked about times and places for him to smoke and ways to eliminate the odor.
Solve Problems Using the **Spiral Model**

- **Spiral Model Step 4:** **Brainstorm solutions and ideas**
  - We agreed to the places and times and that he would use a special body and breath spray after.

- **Spiral Model Step 5:** **Pick one and JUST DO IT!**
  - We agreed to “Just do all ideas!” and it has worked so far. (He is still trying to quit!).
Example 2: While a new agency provider staff was assigned to me, I realized that some money was missing.

- Spiral Model Step 1: **What is the problem?**
  - $100 was missing from my wallet
Solve Problems Using the **Spiral Model**

- **Spiral Model Step 2:** *Who does it affect?*
  - Me, my family, all provider staff and my case manager.

- **Spiral Model Step 3:** *Investigate to get new information*
  - Confronted all staff in a nice way
  - Case manager was asked to help. As it was considered a MUI, law enforcement was contacted.
  - Investigation did not determine who
Solve Problems Using the Spiral Model

- Spiral Model Step 4: **Brainstorm solutions and ideas**
  - Virtual alternatives to keeping cash were started.
  - Debit cards
  - Online banking
  - Safety deposit box at the bank

- Spiral Model Step 5: **Pick one and JUST DO IT!** All of the ideas were used
Negotiate

Negotiate with others

- When told “NO”, ask, “How can you help me get more of what I need?”
- “NO” may mean that more information or action is needed
- Agree to some of what others want in order to get more of what you want – sometimes called compromise.
Everyone has rights and responsibilities.

Four Steps to Becoming a Self-Advocate:

#4 - Rights & Responsibilities
Rights

- **Rights** mean fairness and freedom.
- **Rights** apply to everyone!
- **Rights** make people equal
Responsibility means ........ you have a duty to respect the rights of others--and to have your own rights respected.

You must take responsibility for your decisions and actions.
An Ohio advocate said, “...it’s his responsibility to know what he needs assistance with and how to explain to someone the “mechanics” of how to help him. If he can do that, then providers usually don’t take control.”

Quote from “Taking Charge: A Hands-on Guide to Personal Assistance Services”
An Ohio advocate also said, “...It’s when people are passive in explaining what they need and how they need it done, that providers take over because they aren’t getting any direction from the individual.”

Quote from “Taking Charge: A Hands-on Guide to Personal Assistance Services” – Click here
To use your Rights!

- Know yourself
- Know your rights and responsibilities
- Speak up so that others listen
- Solve problems
- Make a deal - Negotiate so all get some of what they want
- Advocate for yourself and with others
Rights Guide

Ohio Department of Developmental Disabilities

Bill of Rights for People with Developmental Disabilities
An Easy Read Guide
from Ohio Revised Code 5123.62

1. You have the right to be treated with respect.

https://dodd.ohio.gov/about-us/resources/Bill_of_Rights
These 4 steps of advocacy are the foundation that can lead to self direction.

Self direction is when you advocate for yourself about the support you need, how, where, when and by whom you want the support provided is self-direction.
Self Direction

- It can also mean you decide how much is paid for your supports—sometimes called “Budget Authority”

- You may also choose to hire, manage and, if necessary, fire your staff—sometimes called “Employer Authority”
Self Direction

- Self direction empowers you to have the freedom and responsibility for greater choice and control.

- This helps you to lead the life you want!

- If choice and control with staff is important to you, take a chance and speak up!
What does Self-Direction Mean to Me?

- Identify what is most important to and for me, both short term and in the future.
- Short term (Survival Mode) – What I need each day to stay alive and out of an institution.
  - Get medication
  - Get something to eat
  - Get to the bathroom
  - Get out of bed
What does Self-Direction Mean to Me?

Life, Liberty and the Pursuit of Happiness – What I need to have a good life in the future.

- This can mean different things which require different levels of support.
- Being engaged and exploring my community.
- Having a home I control, an education, job, volunteer opportunities, personal relationships, family connections.
- Developing my full potential
What does Self-Direction Mean to Me?

The person I want to help me needs to:

- Be able to transfer me to and from the wheelchair I use and provide physical support for me to be active at home and in my community.
- Be compatible and open to a long-term working relationship.
What does Self-Direction Mean to Me?

The person I want to help me needs to:

- Be willing to travel with me and stay overnight.
- Be willing to drive my accessible van.
- Be willing to develop skills in the use of medical equipment and take direction in regard to medications.
What does Self-Direction Mean to Me?

The person I want to help me needs to:

- Be willing to assist me in personal care.
- Be willing to work “firemen-like hours” – each week 2 staff are on 16 hours and off 8 hours twice each week, while a third staff covers weekends and a fourth staff (agency) fills in the gaps.
Finding the right person(s) to support me.

I started with staff from provider agencies. With some of these staff, I built personal working relationships.

- Some became independent providers and began a long-term relationship.
- Sometimes I call on agency staff to fill in or in an emergency and others are family and friends. These people are a combination of paid and unpaid support.
Finding the right person(s) to support me.

My supports today evolved from the past and will, likely, change in the future.

- With every change, it is easier because I have learned from my experience. Every day, as support changes, it gets better.
I asked my case manager to help find new providers and found that a process and forms existed for that purpose.

- While it might result in a larger number of responses, it did not specifically address my needs.
- We negotiated changes to that process to be specific to me – even though we knew the responses would be fewer. It was simply adding a page to what existed and emailing it to providers known to the case manager.
What is my life today?

- Advocacy Policy Specialist with the Ohio Department of Developmental Disabilities
- Own an accessible van that others use to drive me to the places I need and want to go.
- Live in a house I share with a family member.
- Connections with statewide and local agencies, organizations and people respected in the disability field.
- Selected as a SARTAC Fellow in 2022
What I have learned from living a self-directed life

- Need the confidence to take a risk
- Embrace new opportunities
- Be open to learning new skills
- Assertive communication and compromise
- Be persistent and never give up
- Learn to navigate a system
- Be willing to help others.
My life in the future!

- Own my own home and a dog or cat
- Training to become an Ambassador for Charting the LifeCourse (CtLC)
- Hoping to become a certified Work Incentive Planning Counselor
- Working to thrive in my new job
- Prioritizing my professional development and making new connections
- Working to improve the lives of others
Closing Thoughts

- You must know what you want and learn the options you have
- You must speak up for yourself in a way that others will listen
- Be persistent. It may be hard at first, but will get easier over time.
- Dream versus Reality – Work for what you really want and need.
I challenge you to “Be the captain of your ship!” Don’t let anyone else take the wheel!”.

Self-determination / Self-direction / Choice and Control can be yours!
For more information

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Ohio Self Determination Association (OSDA) 2022 SARTAC Fellow sponsoring organization
- www.osdaohio.org
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Learn about Self-Direction from the videos on the topics listed below. Click on the title to watch the video developed by Applied Self-Direction,
INFO@APPLIEDSELFDIIRECTION.COM

- Introduction
- What is Self-Direction
- Who supports me in Self-Direction
- Managing Scheduling & Spending
- Hiring workers
- Managing Workers
- Fraud, abuse & Neglect
- Electronic visit Verification (EVV)
- Tool Kit
The Self Advocacy Resource and Technical Assistance Center (SARTAC) seeks to strengthen the self-advocacy movement by supporting self advocacy organizations to grow in diversity and leadership. The resource center is a project of Self Advocates Becoming Empowered (SABE), the oldest national self-advocacy organization in the country.
SARTAC is a Developmental Disabilities Project of National Significance, funded by the Administration For Community Living – Administration on Intellectual and Developmental Disabilities (AIDD).
The information in this manual was written to provide guidance for self Advocates and their allies to assist in understanding policy issues affecting their lives.

It is not to be used to determine a person's legal rights or an organization's legal responsibilities under Section 504 of the Rehabilitation Act of 1973, as amended; the Americans with Disability Act of 1990, as amended or any other federal, state or local laws written to protect the rights of people with disabilities.
This publication is supported in part by a cooperative agreement from the Administration on Intellectual and Developmental Disabilities, Administration for Community Living, U.S. Department of Health and Human Services.

Grantees undertaking projects under government sponsorship are encouraged to express freely their findings and conclusions. Points of view or opinions do not, therefore, necessarily represent official Administration on Intellectual and Developmental Disabilities policy.