

**SELF
ADVOCATES
BECOMING
EMPOWERED**

SELF
ADVOCATES
BECOMING
EMPOWERED

**SELF ADVOCACY
START-UP TOOLKIT**

**More Power, More Control
Over Our Lives!**



I am a person

I am more than just my disability.

I am valuable

I matter just as much as anybody else does.

I can choose

I decide the services I want.



Self advocate Calvin Mykl Cook

I Am a Self Advocate!

Together, We Are a Self Advocacy Group

We are led by people with disabilities.
We run our own groups.

We Make Our Own Decisions

We create our own goals.
Advisors who help our group do not vote.

We Get Things Done

Together, we make change happen.
We are a civil rights organization.

We Are Our Own Organization



Group picture of People First of Tucson

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ACKNOWLEDGEMENTS



In the late 1990s, SABE asked states to tell us their story about how their self advocacy group was started. We learned that there were many ways. We put those ideas in the original Self Advocacy Startup Toolkit in 2000. This toolkit is an update of the power of what people with disabilities say about being a self advocate.

Our paths may be different, but our goals are the same.

- To have the services and supports we need
- To get the life that we want
- To lead our own group
- To make our friends' lives better too

We hope you find it helpful to you and your group and that it helps you feel more connected to the National Self Advocacy Movement.

To create the toolkit, a committee was started to look for information about self advocacy groups. The Committee members and advisors included:

- Teresa Moore, Committee Chair from Arizona
- James Meadours from Louisiana
- Ronnie Meeker from Arkansas
- Mary Varney from New Hampshire
- Liz (Obermayer) Weintraub from Massachusetts
- Debbie Prockner from Louisiana and Bonnie Shoultz from New York, advisors and allies

After asking for information about self advocacy, the committee received tools from all over the world. This showed the committee that everybody had his or her own ways of teaching self advocacy.

The committee members worked hard looking over all the information given to them and chose the best tools to put together this toolkit.

It is nearly 20 years later and the self advocacy movement is still going strong! There are now self

advocacy groups all over the country. Over the years there have been many victories and lessons learned. It is now time to take those lessons we have learned and update our toolkit.

In 2016, SABE received a grant to create a national resource and technical assistance center. SABE used the grant to create the Self Advocacy Resource and Technical Assistance Center (SARTAC). SARTAC has an advisory committee with 13 self advocates from around the country. Their job is to make sure SARTAC provides the best resources people need to become strong self advocates.

SARTAC advisory committee members in a meeting

The SARTAC advisory committee reviews information to make sure the toolkit is easy to use. It includes lessons learned from years of people fighting for their rights. You will read quotes from the self advocates who created the toolkit as well as from today's leaders.





Bernard Baker, Georgia Brad Linnenkamp, Missouri Cheri Mitchell, Georgia Chester Finn, New York David Frye, Vermont David Taylor, Michigan Emily Rogers, Washington



Finn Gardiner, Massachusetts Jean Searle, Pennsylvania Jeiri Flores, New York Krista Howard, Arizona Nicole LeBlanc, Maryland Thelma Green, DC

SARTAC Advisory Committee Members

Technology has changed since the first toolkit was made. The new toolkit now has links to videos and websites that you can click on to view. We would like to thank the self advocates from around the country for creating such awesome videos and websites. They really help spread the word about self advocacy!

If you would like to know more about the Self Advocacy Resource and Technical Assistance

Center (SARTAC), please visit the website created by and for self advocates.

www.selfadvocacyinfo.org

The screenshot shows the homepage of the Self Advocacy Resource and Technical Assistance Center (SARTAC). At the top, there are social media icons for Facebook, Twitter, and YouTube, along with accessibility options like 'Select Language', '4AA', and 'Listen to Page'. The SARTAC logo is prominently displayed, featuring a stylized book icon surrounded by colorful dots. To the right of the logo, the text reads 'Self Advocacy Resource and Technical Assistance Center'. Below this is a dark blue navigation bar with white text for 'HOME', 'ABOUT', 'RESOURCES', 'SELF ADVOCACY', 'SUPPORT', and 'CONTACT US', and a search icon. The main content area features a large banner image. On the left, a man in a blue shirt is using a laptop. In the center, a group of people is gathered around a table, looking at various documents and devices. On the right, a woman in a red and black striped shirt is smiling while working on a laptop. Below the banner image is a purple bar with the text 'Your one-stop resource for organizing and supporting self advocacy groups'. Underneath this is a green heading that says 'How can we help your self advocacy group?'. The page is clean and professional, with a focus on accessibility and community support.

SELF ADVOCACY START-UP TOOLKIT

A BOOKLET FROM YOUR NATIONAL BOARD SELF ADVOCATES BECOMING EMPOWERED

Materials collected by SABE's self advocacy development committee and updated by the SARTAC Advisory committee members.

How to use this book

The Self Advocacy Startup Toolkit has many sections called tools to help you start your own self advocacy group.

Each tool will have important information with an activity at the end. You can do each activity on your own or together in a group.

INTRODUCTION

The self advocacy movement started in the 1960s. It is the idea that people with disabilities have the right to speak up for themselves. People with disabilities also have the **right** to choose the services they want.

As the self advocacy movement grew, self advocacy groups started to pop up. These are groups started by people with disabilities to help teach others how to speak up for themselves and fight for their **rights**.

Self advocacy groups are important because they help keep the self advocacy movement going **strong!**

Today, there are groups all over the world with members who **speak up** for the services and supports we all need. You may know these groups by different names such as: People First, Autistic Self Advocacy Network, or Youth Action Council of Arizona. Even though they have different names, they share the same goals of helping people speak up for their rights.



Members of Green Mountain Self Advocates holding up signs at a protest

The self advocacy movement is now over 60 years old and we have learned many things. By working together, we have fought for our **rights** and overcome many **barriers**.

This toolkit brings together everything we have learned about self advocacy groups. We hope you get **excited** about the self advocacy movement and join a group or start your own!

In this toolkit, you will learn about:

- What is self advocacy
- The history of self advocacy
- The beliefs, values, and principles of the self advocacy movement
- How to start your own self advocacy group
- How to pick issues or goals
- Self determination
- How to work with your advisors



Person holding a bullhorn



*Calling all
Self advocates!*

Get on Board!

*Let's keep this
movement
ALIVE!*

WHAT IS SELF ADVOCACY AND WHAT CAN IT DO FOR YOU?

What is self advocacy?

Self advocacy is about independent groups of people with **all types of disabilities** working together for justice.



We help each other take charge of our lives and fight discrimination.

It teaches us how to make decisions and choices that affect our lives. We can be more independent.

It teaches us about our rights, but along with learning about our rights, we learn what we have to do.

The way we learn about advocating is by helping each other gain confidence to speak out for what we believe in.

There are self advocates all over this country!

Here is what some advocates from Tennessee say about self advocacy.

To People First of Tennessee **Self advocacy means...**

- **taking responsibility for your life.**
- **learning to ask questions until you can understand** what is happening.
- **learning to solve the problems** that stand in the way of doing what you want to do."

People First of Tennessee booklet,
Self Advocacy: An Owner's Manual.

WHO IS A SELF ADVOCATE?

You are a self advocate if you have ever spoken up for what you believe in.

You are a self advocate if you have taken responsibility for your life in some way.

You are a self advocate if you have ever questioned people's expectations of you.

You are a self advocate if you have ever joined a self advocacy group and believe that the group's work is going to make life better for people with disabilities.

Even if you have never done any of these things, you can become a self advocate by getting involved.



Start today!!

CAN YOU THINK OF WAYS THAT YOU ARE A SELF ADVOCATE?

Read these quotes from self advocates. Do you agree with what they say?

"SELF ADVOCATE: To speak for yourself... to defend yourself and make your own decisions... to make your own recommendations... to plead your own cause."

Speaking Up and Speaking Out: An International Self Advocacy Movement. (1985). Tacoma: People First of Washington.



Members of People First of Washington in a meeting

"Self advocacy means **speaking for oneself**.

It is not saying, 'Hey, I have a disability so give me this and that, give me everything.'

Instead, it is becoming a real person in today's world.

To me, **real means normal**. It means having a job, a home, and some friends, and also knowing that some **responsibilities come with it.**"



Ronnie Meeker and Teresa Moore presenting to Arkansas Self Advocates and SABE board members January 1998.

"Self advocacy means **speaking** or acting for yourself.

It means **deciding** what is best for you and taking charge of getting it.

It means **standing up** for your rights as a person."

Gardner, N.E.S. (1981). The Self Advocacy Workbook.

Lawrence: Kansas University Affiliated Facility.



"Self advocacy can help you become an active voice for yourself, and it can help the groups in your state to speak up so that the voice of people with developmental disabilities will be heard, loud and strong.

You could become a political force. You could become a future leader in your local group, or your state, or the national organization. That's what happened to me!"

James Meadours, Co-Chair, Self Advocates Becoming Empowered, June, 1999.



James Meadours in front of the Texas state capital



ACTIVITY: YOU KNOW YOURSELF BEST!

As a self advocate, ask yourself these questions.

1. Why do **you** want to get involved in self advocacy?
2. What issues or goals do **you** want to work on?
3. What strengths or talents do **you** have?
4. What challenges would **you** like to work on?
5. Who can **you** work with on self advocacy?
6. How do **you** want to get involved in your community?
7. What will help **you** be more successful?

Check This Video Out!

Check out this video from Self Advocacy On-line.org!

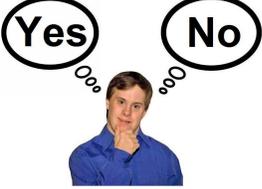
Self-advocates from across the world tell us what self-advocacy means to them.



https://youtu.be/sOX3LWUD2_g

Self Advocacy is... from Green Mountain Self Advocates

Self Advocacy is		Self Advocacy is NOT
	A civil rights movement for people with intellectual disabilities	A program
	People speaking up for what they think is important	People sitting around and complaining
	Something everyone is capable of	Only for people who can talk
	Making your case and negotiating for what you want	Keep everything the same
	Realizing you are not alone, joining a self advocacy group	Keeping to yourself
	Knowing your strengths, being proud and feeling strong	Putting yourself down

	<p>Taking risks, trying new things</p>	<p>Playing it safe, doing the same stuff</p>
	<p>Going after your dreams</p>	<p>Sleeping through your dreams</p>
	<p>Making decisions</p>	<p>Sleeping through your dreams</p>
	<p>Making mistakes and learning from them</p>	<p>Not taking any chances</p>
	<p>Being part of your community</p>	<p>Staying home</p>
	<p>Managing your emotions so others can hear what you have to say</p>	<p>Staying angry</p>
	<p>Being curious and asking questions</p>	<p>Being questioned</p>



ACTIVITY: SELF ADVOCACY IS...?

What is self advocacy... Activity

Now that you have seen the example by Green Mountain Self Advocates, it's time to make your own!

In the box titled "self advocacy picture", include a picture or describe a picture that you think shows self advocacy.

In the box titled "self advocacy is..." write down an example of you think self advocacy.

In the box titled "self advocacy is not..." Write down an example of what you think self advocacy is not.

Self advocacy picture	Self advocacy is...	Self advocacy is NOT...

Thank you GMSA for your inspiration.

BELIEFS, VALUES, PRINCIPLES

The self advocacy movement is based on beliefs, values, and principles. They include ideas such as:

- We are people first
- We have the right to choose the services we want
- People with disabilities want to live in the community

These are just a few of the beliefs, values, and principles that are most important to us.

It is important to talk about your beliefs, values, and principles when creating your own self advocacy group.

Knowing what is important to your self advocacy group will help you reach your goals.

Goals help attract more people who believe in the same things you do!

Here are some beliefs and values talked about by self advocates throughout the country!

Beliefs and Values



SABE's Value statement

- People with disabilities should be treated as equals.
- People should be given the same decisions, choices, rights, responsibilities, and chances to speak up and empower themselves.
- People should be able to make new friendships and renew old friendships just like everyone else.
- People should be able to learn from their mistakes like everyone else.

Self Advocates Becoming Empowered

- Being a person first
- Being able to make our own decisions
- Believing in my value as a person
- Having other people believe in you as a person

**Self Advocacy Committee of the Inclusion
International, 1996**

- Nothing about us, without us!
- Look at our ability, not our disability
- Disability is a natural part of your life cycle
- Dignity of risk (you have the right to fail)
- Presume competency and expectations (do not judge me by my disability, I can do more than you think)

**Beliefs and Values by SARTAC Advisory
Committee members 2017**

Principles

- Empowerment
- Equal opportunity
- Learning and living together
- Non-labelling

Self Advocacy Committee of the Inclusion International, 1996



Multi-ethnic group of arms holding each other

- Equal pay for a hard day's work
- Equal expectations for doing the same work
- Everyone is part of the community
- Listen to individual's wants and needs
- Respond to what people want in their lives
- Do not let providers decide
- Real friendships, not paid friends like staff
- Being treated equally
- No bullying
- Tolerance and acceptance

SARTAC Advisory Committee members 2017



ACTIVITY: BELIEFS, VALUES, AND PRINCIPLES

Self advocacy groups are based on strong beliefs, values, and principles. Knowing what they are will help guide your self advocacy group.

Try this activity with your group.



Group of people around a table in discussion

- Everyone take a moment to work by yourselves and write down what are your beliefs, values, and principles.
- Share what you have written with the rest of your group. If you can, write them on big sheets of paper or on a board. Group together thoughts that are the same.

Look at your results together. Are there ideas or thoughts that you have in common? These are your shared beliefs, values, and principles. The more you have in common, the easier it is to work with each other.

SELF ADVOCACY HISTORY

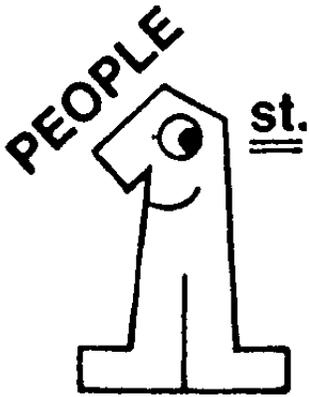
A SHORT HISTORY OF SELF ADVOCACY

The Self-Advocacy Movement started in the 1960s in the country of Sweden. A group of people with and without intellectual disabilities went out together in their community. The members of the group were allowed to have typical life experiences, and allowed to make their own choices and mistakes.



Group of people standing in front of a building

Later, the Swedish Parents' Association started a national conference so that people who participated in similar clubs could talk about their concerns. Many people with and without disabilities became interested in having their own conference.



In 1974, a national conference called First Convention for Mentally Handicapped in North America was held in British Columbia and focused on self advocacy. Many people from Oregon went and decided to hold their own conference.

The people first movement started in Oregon on January 8, 1974. It started at a meeting to plan for a conference. At the meeting, one man talked about being labeled "mentally retarded". He said,

"I want to be known as a person first!"

"People First" was chosen as the name for the convention held in October 1974. People now consider the "R word" to be offensive. Many self advocates work hard to remove that word from legal documents and stop people from using it.





A group of self advocates photographed together

Self advocacy groups started to pop up all over the world during the next 10 years. Some of the state groups are called People First.

Other groups go by different names such as the Autistic Self Advocacy Network or the Youth Action Council of Arizona. No matter what name they go by, their goals are always the same. They want to help people with disabilities speak up for their rights.

As the self advocacy movement grew stronger, people started advocating for their rights. To get the president of the United States to sign into law the Americans with Disabilities Act (ADA), 475 people with disabilities went to the White House to protest. Some people got off their wheelchairs and assistive devices and crawled up the stairs of the capital.



Group of people crawling up the stairs in front of the Capitol



President Bush signing ADA with Justin Dart

When the ADA was signed in 1990, nearly 2,000 people with disabilities arrived to witness the signing. 1990 was also the year of the first Disability Pride Parade.

In the U.S., the self advocacy movement continues to grow. Self advocates from around the country advocate for themselves and for others. Together we have closed institutions, got people to live together in communities, and continue to fight for equal rights.



Tia Nelis posing with Justin Dart and his wife Fusako Tanida

If you would like to learn more about self advocacy history, please visit <http://selfadvocacyinfo.org/>

SELF ADVOCATES BECOMING EMPOWERED



SABE is an active group in the United States that reaches people all over the country.

Many local self advocacy groups in each state support SABE.

Self advocacy is a civil rights movement led by people with disabilities.

On August 2, 1991, over 800 self advocates from across the United States and Canada met in Nashville, Tennessee. They gathered for the second Annual North American People First Conference. They elected a Steering Committee. That became the Board of Directors of **Self Advocates Becoming Empowered.**



SABE Executive members sitting at a table at a hearing room

SABE is organized by dividing the United States into 9 different regions. Each region is represented by two region representatives and two alternates to fill in when representatives are unable to attend. This gives the organization complete representation from all the nine regions of the United States. During the SABE National conference, board members and officers are elected.

Region 1 (Alaska, Idaho, Montana, Oregon, Washington)

Region 2 (Arizona, California, Hawaii, Nevada)

Region 3 (Colorado, New Mexico, Utah, Wyoming)

Region 4 (Kansas, Missouri, Nebraska, North Dakota, South Dakota)

Region 5 (Illinois, Indiana, Iowa, Michigan, Minnesota, Ohio, Wisconsin)

Region 6 (Alabama, Florida, Georgia, Kentucky, Mississippi, North Carolina, South Carolina, Tennessee)

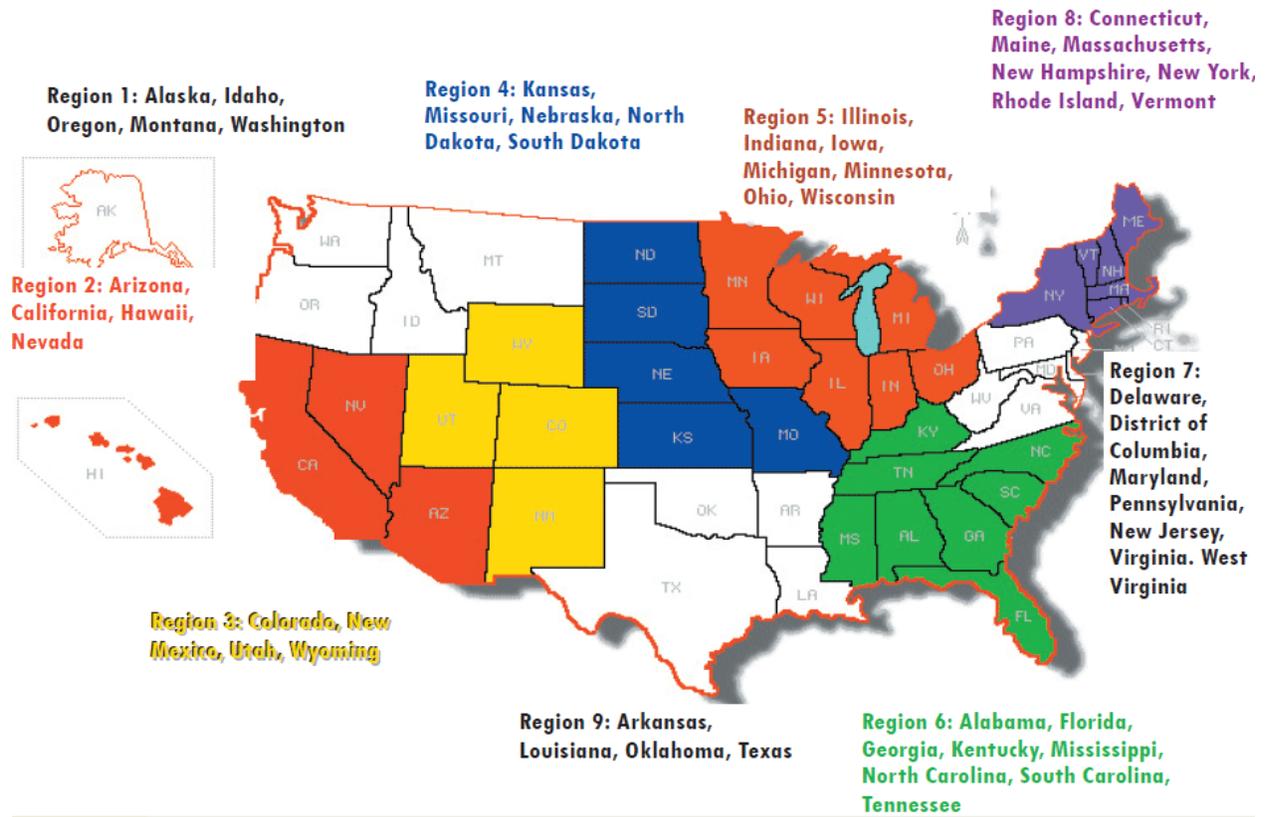
Region 7 (Delaware, Maryland, Pennsylvania, New Jersey, Virginia, Washington DC, West Virginia)

Region 8 (Connecticut, Maine, Massachusetts, New Hampshire, New York, Rhode Island, Vermont)

Region 9 (Arkansas, Louisiana, Oklahoma, Texas)



Chaqueta presenting



What region are you in?

Issues important to SABE include:

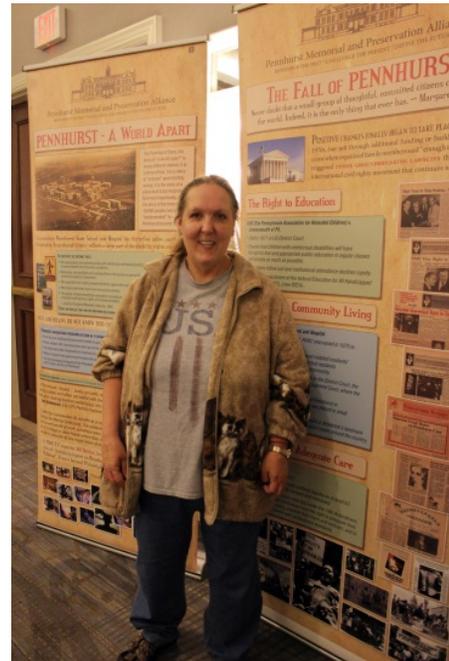
- Segregation (being separated from other people)
- Abuse
- Stereotypes (labeling a person)
- Community support (the help you need to live your life)
- Inclusion (part of a community)
- Speaking up for others who can not



Chester Finn and Steve Holmes singing

People still face barriers and challenges to living in the community:

- Physical
- Attitude
- Environmental
- Communication
- Poverty



Jean Searle giving a presentation

In the past 26 years, SABE has worked on:

- Closing institutions
- Filing lawsuits to:
 - Ending segregation by enforcing Olmstead decision
 - Improve voting access
 - Increase employment and fair wages



John Britton using his tablet and voting machine to vote

- Remove the “R” word
- Work on policy changes in services and supports
- A National Self advocacy organization as the 4th partner in the DD Network

For more information about SABLE, please visit our website at www.SABEUSA.org.



Partnering in your state

One of the most important laws for people with disabilities is the Developmental Disabilities Assistance and Bill Of Rights Act. It is also known as the DD Act. The law supports self-determination, independence, and inclusion in all parts of community living.

The DD Act requires the Administration on Intellectual and Developmental Disabilities (AIDD) to give support to certain organizations in each state. They help fight for the rights of people with developmental disabilities.



SABE began its public policy advocacy at the federal level with the Administration on Intellectual and Developmental Disabilities (AIDD) in 2000. As part of its national policy, SABE advocates for a national self advocacy organization to be the 4th equal partner in the Developmental Disabilities Network.

Today, there are three DD Partners. SABE works closely with them on projects to improve all services and supports for people with developmental disabilities.



Members from National organization

These organizations are in each state. They include:

Developmental Disabilities Councils (DDC)



The role of the DD councils is to:

- Develops a state plan for developmental disabilities
- Fund projects in the state that help people with developmental disabilities and families have the lives they want to live
- Help legislators understand needs of people with developmental disabilities
- They also must support state self-advocacy groups with money and leadership tools.



Panel group of people presenting

You can find more information by visiting their national organization at www.nacdd.org

University Centers for Excellence in Developmental Disabilities (UCEDDs)



Their job includes:

- Does research that proves the best way to support people and families
- They train college students to work with people with disabilities
- They train and help community providers work better with people with developmental disabilities
- Share information about developmental disabilities with the community



AUCD talking to SABLE Board members

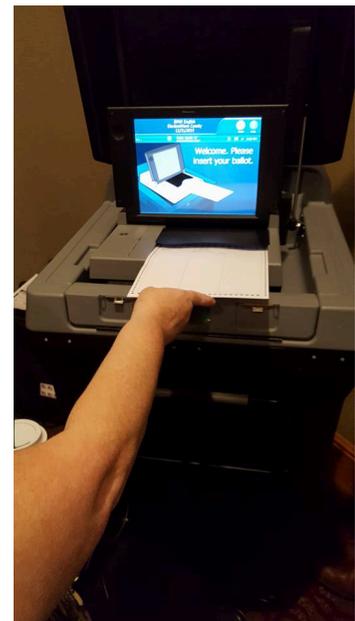
You can find more information by visiting their national organization at www.aucd.org

Protection and Advocacy (P&A)



Their role is to:

- Use lawyers and advocates in institutions, group homes and sheltered workshops to make sure services are safe and help make conditions better for people
- Give information about services and programs in the state
- Have a way to help people access developmental disability services they have a right to get.
- P&A's might be called another name like disability rights law, or advocacy in your state



A Person placing their ballot in voting machine

You can find more information by visiting their national organization at www.ndrn.org

Dear Self-Advocates and All People with disabilities,
Voting and being involved in policy is important for you to do. Many of your legislators need to be educated on the services and waivers you receive and how important these things are in your life. In addition, how it would be hard for you to be without them.

Sometimes they vote against the things that are important to us without even know how it helps us or not. In addition, things like services, supports, waivers and more can make a difference in someone's life.



We need to make appointments with our legislators and tell our stories and educate them so they know what people with disabilities want and need. Right now, they do not hear from us they hear from others. If we do not speak up, we can lose the things that are important to us. It is time for you to use your voice and fight! Because your life depends on it.

Tia Nelis, President of SABE 2018

SELF ADVOCACY TOOLKIT FOR GROUPS



Members from People First of Alabama group picture

Here is some good information to help you and your friends start a group. This information comes from groups that have started in different states. Many states gave their information to us, so that we could share it with you in this tool kit.

TOOL COLLECTION 1: MATERIALS FOR STARTING GROUPS



SABE members at a rally march in Chicago

SUCCESSFUL SELF ADVOCACY GROUPS...

Successful groups try to have three goals or reasons for coming together. Each of these goals or reasons helps to keep members in the group.

Successful groups are fun, help you learn, and keep you active in the self advocacy movement.

When creating your self advocacy group, ask yourself, "Are we meeting these three goals?"



YACAZ members presenting on a panel

1. Goal: Be part of the community

Make time for each other...

- Share drinks and snacks
- Welcome new members
- Spend time to catch up with friends
- Plan and hold picnics, parties and other fun activities
- Invite members from the community to speak at your meeting
- Develop partnerships with other self advocacy groups



Group of people holding hands marching on a street

2. Goal: To learn new things

To meet together to learn how to...

- Help myself and others
- Be a strong self advocate
- Speak up and speak out
- Solve problems
- Make decisions
- Use my rights as a citizen
- Advocate to the government
- **Vote!**
- Be part of the community
- To feel good about myself and **BE PROUD!**



Nancy Ward from Oklahoma using an accessible voting machine

3. Goal: Advocate Human Rights

To meet together to work for...

- Better services and programs
- Community living (not institutions)
- Human rights and dignity
- Ending discrimination (stop bad treatment of people with disabilities)
- **Justice**
- Real jobs with real wages
- The right to live in your community
- Better laws
- **Take charge of our lives!**





ACTIVITY: SUCCESSFUL SELF ADVOCACY GROUPS

You just learned about the three goals or reasons why people get together for self advocacy groups.

Talk with your group members to find out what are your three goals. It is okay to go back and read about the three goals if you need some help.



Goal 1: Be Part of the Community

What can you do in your self advocacy group to bring people together?

Goal 2: To Learn New Things

What do you want to learn as a member of your self advocacy group?

Goal 3: Advocate Human Rights

What do you want to work on together as a self advocacy group?

EVERYONE HAS A "JOB" WITH THE GROUP...

You are important. Everyone in the group needs a job. Possible jobs in a self advocacy group include:

- Speakers Bureau (people who speak to groups)
- Membership Committee
- Officers
- Legislative Committee
- Refreshments (take turns)
- Flag Salute (Pledge of Allegiance)
- Fundraising Committee
- Greeting Committee





ACTIVITY: EVERYONE HAS A JOB

Running a self advocacy group is a lot of work. To make things easier, it is a good idea to give people jobs to do within the group.

What are some of the different jobs that can be done? Talk with your group members and see how many jobs you can come up with for your group.

Check This Video Out!

Alyssa Mills is the secretary of the Youth Action Council of Arizona (YAC-AZ).



Check out this video to see how YAC-AZ organizes its meetings. Everybody has a job. We elect officers to help make each meeting successful.

<https://www.youtube.com/watch?v=X0OwOwxF5WW>

GOOD LEADERS AND OFFICERS

Leaders work hard to make the group stronger.

Officers are the elected leaders of the group.

Members pick these officers when they vote.

Officers help run the meetings that keep you on track to reach your group goals.

No matter how you choose your leaders, a good leader brings people together.

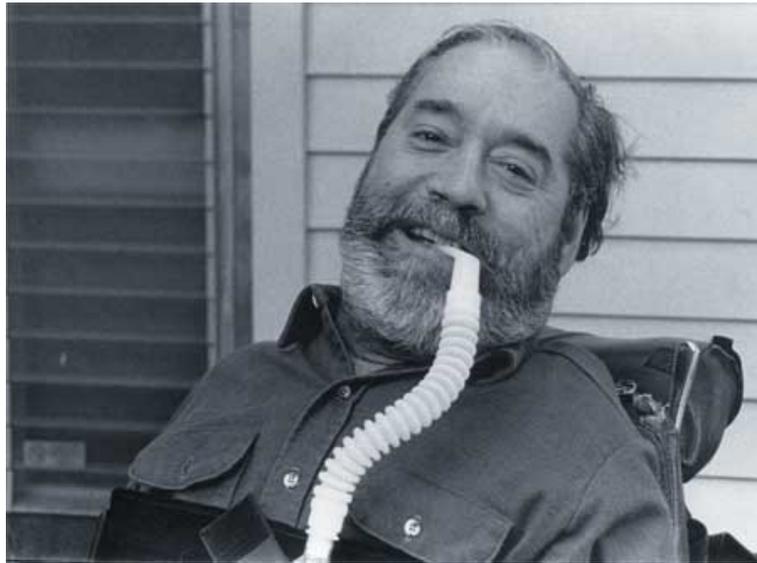
To be a leader you must:

- Have a **positive** attitude
- **Care** about people
- Want to **help** people
- Be **kind** and **polite** to others
- **Listen** to others and what they have to say



Group of people hiking up a hill

- Give everyone a chance to speak
- **Respect** other people's ideas
- **Finds** a way for everyone to be part of the group



Ed Roberts, father of the independent living movement.

- **Encourage** other members to become leaders
... Show them how to lead
- **Share** officer's duties with others
- **Be on time** to the meetings
- **Meet** with the other officers to plan the agenda



ACTIVITY: GOOD LEADERS AND OFFICERS

It is important to pick leaders and officers that will help your group grow and reach your goals. Think about the type of leader you would want in your group.

Talk with your group about the type of leaders you want. Try this activity with your group!

- On a big piece of paper or whiteboard, work together as a group to write down all the qualities you are looking for in a good leader.
- Once you have finished writing down all the qualities, take turns and circle three things you are looking for in a good leader. It's okay if people choose the same qualities.
- As a group, talk about why you picked those qualities in a leader.

PICKING YOUR OFFICERS



Heartland Self Advocacy group picture

Officers are the leaders you choose to run your group. Their job duties should be written in the rules of your group, which is also known as your bylaws.

Picking officers is one of the most important activities your group members will have to do. The people they choose will be responsible for moving the group forward in reaching the group's goals.

The group should choose officers by a secret ballot. By voting for your leaders, everyone will have an equal chance to choose the right person for the job.

Officer roles you may know:

President: responsible for leading the group. They make sure the group stays on track in reaching their goals. The President is also the public face of the group. They are the only ones allowed to give the official stand of the group at events or to the press.

Vice president: responsible for leading the group if the president cannot lead the group. They take over the job of the president when the president is not available to run the group.

Secretary: responsible for recording the group activities. The secretary handles all official documents of the group including meeting minutes, contracts, and financial documents.

Treasurer: responsible for keeping track of the group's money. The treasurer updates the group on how the group is doing with money. They may work with the president and the secretary to handle all the banking needs of the group.



ACTIVITY: PICKING YOUR OFFICERS

It is important to choose a way of voting that will be equal, fair, and secret to all members. Talk with your group about what kind of voting process you would like to have for your group. Ask yourself these questions:

How are we going to vote for our officers?

Is the process easy to understand?

Will it be fair to all the people who choose to run for office?

Is the voting process secret so nobody knows who voted for who?

Who will get to vote?



Check This Video Out!

Everyone can learn how to be a good leader!

Alyssa Mills talks about the roles of officers in her self advocacy group.



Check out this video from the Youth Action Council of Arizona!

<https://www.youtube.com/watch?v=HyqFNSDLKVA>

NINE WAYS TO SUPPORT A SELF ADVOCACY GROUP OVER TIME

The right planning and supports can really make your group successful.

Sure, running a self advocacy group can take some work. We think these nine steps will start it off in the right way.



1. Make sure people know when & where the meeting is (call people, send letters or calendars, put up notices, etc.).
2. Make sure the advisor(s) know what their jobs are (make a contract with the advisor).

3. **Have Officer's Meetings** ... Officer's meetings are a time to practice and get ready, to talk about problems, etc.
4. Find ways to **get everyone involved** with the group (everyone has a job, a chance to talk, and responsibility).



2 Figures talking to each other

5. Use easy words, pictures, videotapes, etc. so everyone understands what is going on!
6. Make sure the discussions (goals) of the group are **REAL & IMPORTANT** in people's everyday life.

7. Make a 3 to 6-month plan for the group (once a year set goals with the group).
8. Make meetings **FUN!!!** Self-advocacy can be hard work ... have some fun sometimes.
9. Face any problems with the group **"head on."** Part of self-advocacy is solving



Self Advocates Becoming Empowered members

SUCCESSFUL SELF ADVOCACY GROUPS

In many states, self-advocacy groups have joined to form a statewide self-advocacy group. These groups have "incorporated," developed "by laws" (rules) for how the group will work, elected a Board of Directors, written grants, opened up an office and hired people to work for the organization.



Successful self advocacy groups...

- **Support** growth & development in your area
- **Employ** self advocates and support people
- **Involve** local chapters in planning and hosting regional meetings, retreats and conventions

- Have **Open Board meetings** in different parts of the state so local chapters can attend
- **Provide** training for Board members



- **Develop** and use materials for members to learn about self advocacy
- **Recruit** new and young members
- Involved in presentations to community groups and conferences



2 women seated using voting accessible machines

- Involve in **voter education**, local & state government
- **Grow** slowly... work for quality not quantity...
- **Stability** with members, advisors and funding

TOOL COLLECTION 2

WORKING ON ISSUES



Group of people helping someone in a wheelchair up a flight of stairs

WHAT IS AN ISSUE?

Each time the group meets, members may talk about their lives and the things they are worried about the problem.

An issue is a topic or problem that affects many or all members of your group. Issues are important to self advocacy groups.

WHY?

Working on issues helps groups stay alive.

WHY?

Working on an issue gives the members hope that change can happen and that you can make it happen.

WHY?

Self advocacy groups work best when the members work together on issues.

HOW SELF ADVOCACY GROUPS WORK TOGETHER...

Assist and support people in taking individual problems to the policy and decision making levels.

By **working together** we can solve common problems!



Self advocate from Colorado

We need to **work together** to get real jobs and real wages for people all across the state.



Self advocates from Arizona

Let us **work together** with other groups to get real jobs for people.

We can meet with the legislature, do speeches to employers, get better laws, etc.

People with disabilities face many problems. Many of the problems we face are a result of the decisions of people in power.

Possible Issues

Issues groups often first tackle are about making the group stronger, such as:

- Increasing membership
- Raising money
- Planning a conference or social event
- Our rights to personal and sexual relationships;
- Our rights to have dreams for our lives



Self advocates attending a rally in Washington DC

Other possible issues your group can consider:

- Closing institutions
- Transportation
- Jobs
- Living where you choose
- Improving accessibility
- Learning about rights
- Self-determination rather than control by staff or family members
- Putting an end to abuse



self advocates having a meeting

Now you are ready to start working on issues.

Issues that are important to us:

- Healthcare (Medicaid)
- Choices in friendships and relationships
- Affordable and accessible transportation
- Quality education
- Community living (help you need to live your life)
- Choices in the expression of sexuality
- Prevent physical, sexual and emotional abuse
- Americans with Disabilities Act
- Access to community services and supports

~SABE



ACTIVITY: HOW TO PICK ISSUES

Think about the things that are currently affecting your life and those with disabilities. What do you think needs to be talked about or changed?

When you share your ideas, it's called "brainstorming". Try this activity with your group!



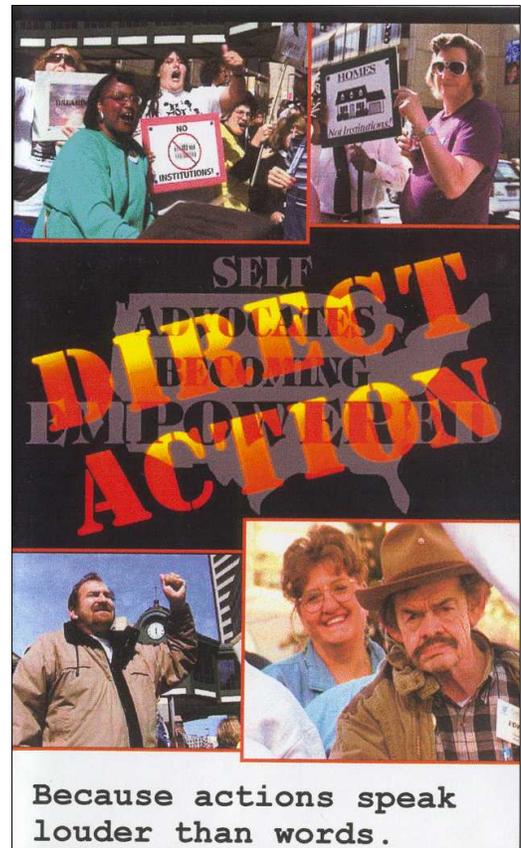
- Work on your own to write down issues you would like to work on as a group.
- As a group, list your ideas on big pieces of paper or a white board. Be sure to group together issues or ideas that are the same or very similar.

Look at all your ideas to see which ones are the most common. Pick the issues that match with your beliefs, values, and principles. Do not pick more than two or three issues. You do not want to take on too much all at once!

WAYS OF WORKING ON ISSUES

First, your group must have some good information about what it takes to work on an issue. Here are some of the things they will need to know:

- How to work as a team with each other and with other groups that agree with you
- How to collect information
- How to organize around an issue (keep documentation of what you do in notebooks, steps you can take such as letter writing, meetings with officials, letters to the editor)
- Learning how and when to speak up



- What is appropriate (is crying okay, or yelling at an official, or arguing?); and so on

After your group has decided on an issue, you will need to do many things in order to work on it.

First, you may need to do some research so that you understand more about the problem and the causes for the problem.

Who has the power to make changes?

What might get them to use that power to do what you want them to do?



Self advocates at a rally in Washington DC

STRATEGIES

After you have done your research, you need to think about strategies, which are ways of tackling the issue you have chosen.

Here are some examples of strategies you could use:

- Letter writing campaigns
- Meeting with public officials
- Rallies and demonstrations
- Nonviolent Civil disobedience: means you join a group in peaceful protest to influence legislation



Self advocates holding the letters they wrote

- Posting on Social Media like Facebook, Twitter
- Holding a public forum on an issue
- Having workshops where people can learn about issues
- Sending information on an issue to lots of people

It all depends on the issue and the people you are trying to influence. Use this form to make a plan of action and to work on issues, alone or with your group.





ACTIVITY: HOW TO PLAN YOUR STRATEGIES

Strategy planning is the steps we need to take to solve a problem or reach a goal. Think about all the different things you will need to do in order to reach your goal. Answer these questions below to help you plan your strategy.

What issues does the group want to work on?

Is there anybody we can partner?

What strengths or skills do we have?

By when do you need to achieve your goal?

What are the steps we need to take to work on our issue?

Think about your strategy as a step-by-step process to achieving your goals. Make sure to take the time to celebrate each step you achieve.

Working on a plan is hard work but taking it step-by-step can make the process easy and fun.

It might be helpful to come up with a timeline.
 Timelines are dates when you would like to have the activity completed.

Example: Meeting with a legislator

Activity	Who is responsible?	What resources or materials do you need?	By when will you need to complete activity?
Call to set up appointment with an elected official			
Invite a few members to go to the meeting			
Work on 3 minute presentation			
Transportation strategy			
Practice presentation together			
Prepare packet of information to leave at Legislator's office			
Arrive 30 minutes ahead of your appointment time			
Follow up with a thank you letter and or another appointment			

TOOL COLLECTION 3: SELF ADVOCATES AND SELF-DETERMINATION

"Self-determination is speaking up for our rights and responsibilities and empowering ourselves to stand up for what we believe in.

This means being able to:

Choose where we work, live, and our friends

To educate ourselves and others

To work as a team to obtain common goals

To develop the skills that enable us to fight for our beliefs, to advocate for our needs, and to obtain the level of independence that we desire

Defined by Self Advocates Becoming Empowered, 1996

DECLARATION OF SELF-DETERMINATION

We, the people with disabilities of America, met in Nashville on November 1, 1997 to define Self Determination as our basic civil rights including all the freedoms guaranteed by our Constitution and our Bill of Rights.

We believe self advocates are the professionals, ask us first, and we should be the decision makers and planners in all our daily living activities, such as working, voting, conferences, leadership development and taking financial control of our service and personal dollars.

As a disability community, we are all one unified voice, we include everyone, we are not "special," we respect and trust each other and are willing to help each other in the fight for our rights.

We also stand firm on the enforcement protections of the ADA, which will assure self-determination for all people with disabilities.

Adopted November 1st, 1997 at the First National Call to the Table Meeting issued by the Southern Collaborative on Self-Determination (People First of Alabama, Georgia, Tennessee and many other states), the New York Self-Advocacy Association, and Speaking for Ourselves of Pennsylvania.

THE FOUR PRINCIPLES

The self-determination movement was founded on four basic American principles:

FREEDOM

People with disabilities have the same rights as everybody else.

With help from others if they need it, they can make decisions about how they want to live their lives.

People with disabilities do not need to give up their rights to have supports or services.



Group of people jumping up in the air

AUTHORITY

People with disabilities should have the right to control how the money is spent for their supports and services.

SUPPORT

People with disabilities should receive the supports and services they choose so that they can live within the community.

Support and services does not mean that people with disabilities need supervision or staffing.



2 hands holding up puzzle pieces

RESPONSIBILITY

We all have a responsibility to make sure the right supports and services are being offered to make sure people with disabilities are able to live and contribute in their communities.



Self advocates in support of Olmsted

Check This Video Out!

Cynthia Berkheimer is a self advocate from New Mexico. In this video example, Cynthia talks about the importance of personal freedom for people with disabilities.



<https://www.youtube.com/watch?v=tpMTNd4Cp2>

C

TOOL COLLECTION 4: ADVISOR ISSUES



Group of people holding up the word support

Self advocacy groups sometimes need the help of someone to assist in running the self advocacy group. These people are known as "Advisors".

It is important to meet a few times with your group members to talk about what their role will be in your group.

Remember, the power belongs to the self advocacy members.

- ❖ **Advisors do not vote in the decisions made by the group**
- ❖ **Advisors do not make decisions for the group**



Self advocates from Texas presenting their ideas

WHAT MAKES A GOOD ADVISOR?

- **Helps** run the meetings but won't take over
- Is nice and kind
- Needs to **show up**, be responsible, and on time
- **Doesn't criticize** us for who we are
- **Explains** what you do not understand
- **Helps** with the agenda
- Might **assist** people schedule their rides to meetings and events
- Is **committed** to the group
- Is **understanding** and **patient**
- **Supports** members when they want to talk about a sensitive issue
- Is **trustworthy**

ADVISORS WITH SELF ADVOCACY GROUPS

- **Believe** in, **Recognize** and **Foster** the skills of members
- **Understand** why people join the group



Panel members presenting in Nevada

- **Recognizes** and **legitimizes** the passions of members
- **Teach** a process for working together and solving problems
- **Connects** members with the community and community resources

- **Build** leadership
- **Develop** cultural competence or making sure everyone understands and communicates well with people with disabilities
- **Support diversity** of interests within the group



Group of figures in a circle with Earth in the middle

- **Develop systems** to support individual self advocacy
- **Recognize** and avoid "conflict of interest" which is a personal gain by someone from a group decision
- Avoid depending on money or an "office" for self advocacy to **thrive** and **grow**

HOW DO YOU FIND AN ADVISOR?

Once you decide you need an advisor, it is important to make sure you find somebody you can trust. Here are some steps to think about when looking for an advisor.

Requirements:

Talk with your group members and decide what you are looking for in an advisor.



What skills or talents will they need?

What are the job requirements?

Do they need to experience being an advisor?

Use your network:

Ask people you know and trust if they would be interested in being an advisor or know anybody who would be interested in being an advisor. Your friends and family know the type of support you may need

and might know someone that they trust that can help your group.

Interview:

Don't be afraid to interview several people. This is an important decision and you want to make sure you pick the right person for the job. Have a list of questions ready so you do not forget to ask them about things that are important to you. Here are some things you might want to ask:

How do they feel about working with people with disabilities?

Do they support the self advocacy movement?

Do they have enough time in their life to support the group as an advisor?

Make a group decision:

Choosing an advisor is an important decision that has to be made by the whole group. Talk about each possible advisor with your group to see how they feel about that person. Be sure to vote on who will be your advisor.

HOW DO YOU FIND A NEW ADVISOR?

Sometimes an advisor has to leave or does not work out because they are too controlling or not helpful enough. This can be a difficult time for your self advocacy group.

Hiring a new advisor can be done just like you hired your first advisor. Here are some things to think about when looking for a new advisor:

- See if your old advisor can give support to find a new one
- Talk about what he or she did wrong
- Support each other during the struggle to find or change an advisor



ACTIVITY: FINDING AN ADVISOR

Talk with your group about what are you looking for in an advisor. Answer the questions below and write down your responses.

What are their responsibilities?

How often will you need their assistance?

What kind of skills or qualifications do you require?

TOOLKIT RESOURCES

These pages include resources related to each toolkit. Be sure to check out the SARTAC website for additional resources.

We add more every day!



www.selfadvocacyinfo.org

TOOL COLLECTION 1: MATERIALS FOR STARTING GROUPS Resources

Organizational and Leadership Development for a state self-advocacy organization in Maine

By Speaking Up for Us Maine, April 18, 2017

This resource is a recording of a webinar and helpful handouts. In this webinar, Speaking Up For Us Maine gives a presentation on Board Development and how their group developed their Strategic Plan.

<http://selfadvocacyinfo.org/resource/organizational-leadership-development-state-self-advocacy-organization-maine/>

All About Groups

By Self Advocacy Association of New York State, April 19, 2017

all
about
groups

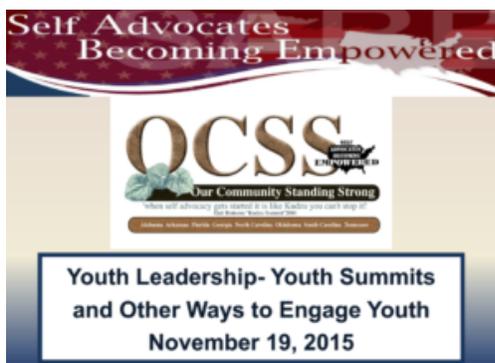


This resource is about forming self-advocacy groups; Self-advocacy groups provide a supportive environment where individuals can develop confidence and independence while working on issues that are important to them. It is important to help each other and always try to

include and value the opinion of everyone in the group. Self Advocacy groups are as unique as the people who form the group. All successful Self-Advocacy groups have several things in common. <http://selfadvocacyinfo.org/resource/all-about-groups/>

Youth Leadership Summits and Other Ways to Engage Youth

By Self Advocates Becoming Empowered | April 19, 2017



Participants will learn about successful strategies for the recruitment and development of youth leaders.

<http://selfadvocacyinfo.org/resource/youth-leadership-summits-ways-engage-youth/>

Getting Local Members to Come to Statewide Meetings

By Green Mountain Self-Advocates, April 19, 2017

People First of New Hampshire asked Green Mountain Self-Advocates of Vermont to let them know what we do to support people from local

groups to attend our board meetings and statewide events. This resource shares tips on how to make meetings interesting and support people to attend. <http://selfadvocacyinfo.org/resource/getting-local-members-come-statewide-meetings/>

Working Better Together: Embracing Good Conflict and Solving Bad Conflict

By Autistic Self Advocacy Network, April 19, 2017

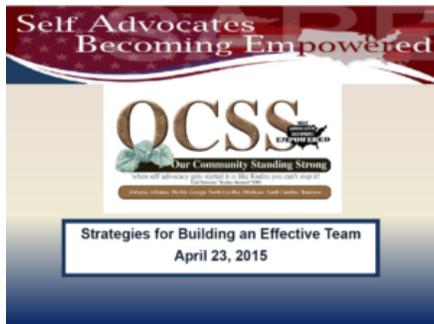


Are your members of your group fighting with each other? Are your leaders not getting along and not working well with each other? Then, you might be interested in this resource guide on working better together.

<http://selfadvocacyinfo.org/resource/working-better-together-embracing-good-conflict-solving-bad-conflict/>

Building an Effective Team

By Self Advocates Becoming Empowered | April 19, 2017



Participants learn basic strategies for building effective teams and share their experience with teams in their self advocacy organization.

<http://selfadvocacyinfo.org/resource/building-effective-team/>

Organizational and Leadership Development for a state self-advocacy organization in Maine

By Speaking Up for Us Maine, April 18, 2017

This resource is a recording of a webinar and helpful handouts. In this webinar, Speaking Up For Us Maine gives a presentation on Board Development and how their group developed their Strategic Plan

<http://selfadvocacyinfo.org/resource/organizational-leadership-development-state-self-advocacy-organization-maine/>

Conflict Resolution

By Autistic Self Advocacy Network, April 19, 2017
Trena Wade and Kris Guin



Are your self-advocacy organization's members fighting with each other? Are your self-advocacy organization's leaders not getting along and working well with each other? Then, you might be interested in this webinar on conflict resolution.

<http://selfadvocacyinfo.org/resource/conflict-resolution/>

Managing a Grant

By Self Advocates Becoming Empowered, April 19, 2017



Once you are awarded a grant it is important to manage the grant correctly to make sure you do the work intended and you meet all requirements. This presentation talks about important terms and sections of the grant that should be reviewed constantly by project managers to make sure they manage grant properly.

<http://selfadvocacyinfo.org/resource/managing-a-grant/>

Being a Strong Self Advocate

By Connie Coleman, IMPACT South Carolina, April 20, 2017



This resource is a video blog by a self advocate leader describing how to be on a board

<http://selfadvocacyinfo.org/resource/strong-self-advocate/>

TOOL COLLECTION 2: WORKING ON ISSUES Additional Resources

SMART Goals Guide

By Autistic Self Advocacy Network | April 18, 2017
How can you and your group create goals that make the best action plan possible? This guide explains SMART Goals. SMART goals are a way to create those kinds of goals. What do the letters in SMART stand for? What are some good things about using SMART goals? What are some examples of groups using SMART goals? You can download the SMART goals guide to find out!

<http://selfadvocacyinfo.org/resource/smart-goals-guide/>

People Coloring Pictures

By Advocates in Action of Rhode Island, April 19, 2017



Advocates in Action created this book as a fun way and comfortable way to have conversations about Person Centered Planning and other important issues. It is an adult coloring book that includes artwork and ideas from members of the

Advocates in Action Rhode Island Leadership Series. Class members drew these pictures as we discussed topics such as:

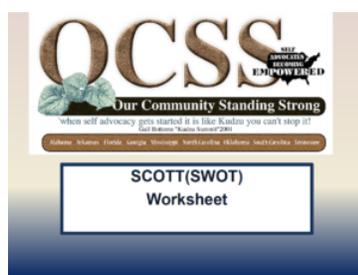
- Self-Advocacy
- Americans with Disabilities Act
- Informed Decisions and Choice
- “Home Sweet Home”
- Real Jobs
- Community Integration

These topics, and others, are all part of something called **P**erson **C**entered **P**lanning. We hope you enjoy it!

<http://selfadvocacyinfo.org/resource/people-coloring-pictures/>

Planning for the Future Worksheet

By Self Advocates Becoming Empowered, April 19, 2017



A handout on how to do your own SCOTT analysis (also known as a swot analysis). SCOTT stands for Strengths, Challenges, Opportunities, Threats and Trends.

This will help your self-advocacy group plan for the future

<http://selfadvocacyinfo.org/resource/planning-future-worksheet/>

TOOL COLLECTION 3: SELF-ADVOCATES AND SELF-DETERMINATION Resources

APSE Employment First Statement

By Self Advocates Becoming Empowered | August 9, 2017



APSE, Green Mountain Self-Advocates, Self-Advocates Becoming Empowered, and Think Work got together and wrote about what Employment First means and why Employment First is important.

“Employment First means that finding work in the community is considered the first option for people with intellectual disabilities who receive state agency services,” says Think Work.

This statement is plain, simple, and to the point.

<http://selfadvocacyinfo.org/resource/apse-employment-first-statement/>

The Riot Newsletter – We Are Watching You!

By Human Services Research Institute (HSRI)

August 9, 2017



The Riot Newsletter is written by self advocates about topics that are important to self-advocacy. The summer 2017 issue of The Riot is all about speaking up and speaking out on issues important to people with disabilities. The newsletter outlines current topics and issues, personal stories, and gives tips for speaking up.

<http://selfadvocacyinfo.org/resource/riot-newsletter-watching/>

TOOL COLLECTION 4: ADVISOR ISSUES Resources

Owning Your Organization: Working with Advisors and Facilitators

By Autistic Self Advocacy Network, April 18, 2017

Owning Your
Organization:
Working With Advisors
and Facilitators



What is a facilitator or advisor? What do they do? How do I know if an advisor or facilitator is the right fit for my self-advocacy group? Owning Your Organization: Working with Advisors and Facilitators has answers to these questions and more!

<http://selfadvocacyinfo.org/resource/owning-organization-working-advisors-facilitators/>

“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.”

“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.”