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## Introduction

Self-Advocacy is based on the belief that all people have the right to make choices for themselves. We have value as individuals and believe in ourselves-we want others to believe in us too. People with developmental and other disabilities are better able to speak for themselves than anyone else.

Self-Advocacy is speaking up for yourself and responsibly living your life the way you choose. People should have equal opportunity regardless of their disability. Self-Advocates help and encourage each other to change things for the better.

## Self-Advocacy is:

- Making your own choices

Speaking or acting on behalf of yourself or others
Standing up for your rights
Learning about your rights and responsibilities
-Fighting discrimination
Asking questions if you don't understand something

Self-Advocates
help and encourage each other


## Support - Where groups fit in

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.

Encouraging people to make their own choices and keeping a positive attitude helps others to become empowered to be more independent. People learn leadership skills and how to effectively communicate. The activities of self-advocacy groups reflect the wishes and decisions of the group.

Self-Advocacy groups also are a place where people come together to make changes in their communities and society. People can take individual problems to the policy-making and decision-making levels by working together to solve common problems, like getting access to transportation.


Self-advocacy groups provide a supportive environment

## Starting A Group

Adapted from People First of Washington Officer Handbook
Self-Advocacy groups are as unique as the people who form the group. All successful Self-Advocacy groups have several things in common.

All Self-Advocacy groups need:

- a purpose or mission. This purpose needs to be shared by each member of the group.
a leader. The group needs someone to take responsibility to organize and run meetings.


## concrete goals.

members who are willing to work toward these goals.


## Why start a group?

Adapted from SABE Self-Advocacy Start-Up Toolkit
A self-advocacy group is a place to:

- find out more about the rights of people with disabilities
-work on issues with other people who share a common view
- learn how to advocate for yourself and others
discover how to make changes in your home and workplace
-develop leadership and public speaking skills
-hear about upcoming events like conferences and regional
meetings
develop friendships
-utilize the resources of the Association
-learn useful information from each other
-get support from others


## For Education...

-Help myself and others
Speak up for yourself
-Work on problem-solving and decision-making skills
Learn about rights and responsibilities and the options you have through learning other people's experiences

- Voting and how government works
- Practice public speaking


## For Human Rights...

-Work for better services and programs
-Advocate for community living and inclusion
-Advocate for real jobs and fair wages
-Promote dignity and respect

- To overcome discrimination by educating the community
-Advocate for better laws


## Social...

- To meet together to make friends
-Plan and hold picnics, parties and recreation activities
-Have fun with friends after the meeting
- To feel good about myself and others around me


# Nine Steps to Starting a Successful Self-Advocacy Group 

Adapted from SABE Start-Up Toolkit

It is important for members of the group to have control right from the beginning so that the group will belong to the members. Starting a group takes time so that everyone will understand what is going on and be able to participate in starting the group.

1. Make sure everyone understands what a Self-Advocacy group does... why people meet as a group.
2. Decide on the rsponsibilites for getting the group going... place to meet, transportation, publicity, etc.
3. Find out how other groups work and learn from them... invite another group to visit and talk.
4. Decide on the rules for how you will work together: officers, advisors, voting, etc.
5. Develop "team spirit" and a good working friendship with members.
6. Decide on goals for the group. Start small...build up.
7. Decide on ways to reach your goals...an action plan.
8. Develop "connections" within the community.
9. Evaluate the group, make changes.

# Nine Ways to Support A Self-Advocacy Group Over Time 

Adapted from SABE Start-Up Toolkit

1. Make sure people know when and 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 contact with the advisor.)
3. Have Officer's Meetings where officers in the group practice and get ready, talk about problems, etc.
4. Find ways to get everyone involved with the group (everyone has a job, a chance to talk, responsibility.)
5. Use easy words, pictures, videotapes, etc. so that everyone understands what is going on!.
6. Make sure the discussion (goals) of the group are real and 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 problems.

## Role in SANYS

## What is SANYS?

SANYS stands for the Self-Advocacy Association of New York State. We also refer to our organization as simply SA. SANYS is a not-for-profit organization run by people with developmental disabilities. The broad goal of SANYS is to support people who speak up for what people with developmental disabilities want.

## Grassroots leadership...

SANYS is a grassroots organization, which means that our base of support and our leadership comes from a big pool of potential self-advocate leaders.

## Groups' role in SA structure...

Most SANYS board members are or were in SA groups, and this experience led them to want to do more. The board


Statewide Board
 is, in theory, made up of the leadership of local SA groups. A position as an officer in a group is a great asset to selfadvocates who want to get on the board of directors. SA Board members are elected by their peers at regional SA conferences.


## Members

## Being Self-Advocates within a group

Members have a responsibility to let their thoughts be known. No one should ever feel like they can't speak up, even if no one else agrees with them. A good group will make people feel like they can say whatever they think about an issue, as long as it is done in a polite way. Everyone's comments are valued. Members have a duty to respect and encourage each other.

Members should also make it clear if they do not understand somethingthe purpose of the group, by and large, is to learn. If someone doesn't understand what is happening at a meeting, they should ask questions until they understand. Many times when one person doesn't understand something, chances are there are others who do not understand too. Being in a self-advocacy group is really being a self-advocate with a group of other self-advocates. Everyone is equal and should show respect and expect to be respected. This is critical in the groups' ability to consider all sides of an issue in making a decision about that issue. Members of a group should try to attend as many group meetings as possible.

## Speaking up Participation

Some groups have time on their agenda for people to "check in" and share something about themselves. For example: "I'm Jane and I just got a kitten," or "I'm Joe and I just started a new job."

## Responsibilities to the Group

Showing up to meetings, organizing the room, cleaning up after, dues, etc.


## Officers

## Leadership (Adapted from SABE Self-Advocacy Start-Up Toolkit)

To be a good officer, you must also be a good leader.

- Effective leaders think about ways to make the groups they lead stronger. Poor leaders will make members feel like they cannot do things on their own, and refuse help from anyone.

One of the most important parts of self-advocacy is speaking for yourself, and a good leader will always try to help members to do that. This promotes leadership within the group, and establishes a group that will support itself and provide support.

- Leadership must be shared so that other members can fill offices when they become open. A good officer will teach the members how to be officers and conduct meetings. Good leaders encourage everyone to participate in the group and keeps the group focused.


Good leaders encourage everyone to participate in the group and keeps the group focused

# Here's what the various officers do! 

Adapted from People First of Washington Officer Handbook

## President:

The president is elected by members of the SA group.

## Before the Meeting:

The president is responsible for calling the other officers to plan an agenda meeting.

## During the course of the meeting:

- Calls the meeting to order
- Asks the secretary to take roll call or people to introduce themselves
- Asks the secretary to read the minutes of the last meeting
- Asks the treasurer to deliver the treasurer's report
- Opens the discussion about old business (any reports or projects people are working on)
- Opens the discussion about new business (new ideas on projects people want to work on, announcements, etc.
- The president introduces the program, if any (guest speaker, etc.)
- The president calls the meeting to an end.

The president must attend regularly. If unable to come, the president must notify the vice-president so he or she can run the meeting.

The president encourages people to participate in the meeting and also for them to attend events like regional meetings and conventions.

## Vice-President:

- Is elected.
- Helps plan the agenda.
- Fills in for president and runs meetings when needed.
- Helps the president during the meeting when needed or asked.

Attends meetings regularly, and notifies president if not.

## Secretary:

- Is elected.
- Helps plan the agenda
- Is able to read and write


## During the course of the meeting:

- Reads roll call and checks off people's names if they are at the meeting. If people introduce themselves, then the secretary checks off names as he or she hears them.
- The secretary reads the written notes of the last meeting. The notes are called minutes.
- Takes minutes (notes) about what happens during the meeting
- If both the president and vice-president are absent, the secretary fills in and runs the meeting.
- Helps the president during the meeting when needed or asked.
- Attends meetings regularly, and notifies president if not.


## Treasurer:

- Is elected.
- Helps plan the agenda
- Can count money and add and subtract numbers.
- Deposits the group's money in the bank
- Keeps track of all the money the group takes in and how much the group spends. (The group advisor can help keep the records in order and filed in a treasurer's notebook).
- Runs meetings if no other officer can do so.
- Helps the president during the meeting when needed or asked.
- Attends meetings regularly, and notifies president if not.


## Group Meeting Basics

- The group should decide the tone of the meeting. Meetings range in formality and structure. Some groups meet monthly and others may meet weekly or twice a month.
- Officers can meet with the advisor prior to each meeting to review the agenda.
- Some groups collect dues to use for activities they plan or to order food after the meeting.
- The advisor or Secretary should take notes.
- President calls the meeting to order and welcomes new members.


## Here are Sample Meeting Elements

These are some steps a group can chose to use when running a meeting:

Old business - The group reviews previous meeting minutes
New business - President asks the group if there is any announcements etc..

Project updates - If committees have been formed to work on specific issues in between meetings this is when they would take turns talking about the progress they have made.

Check in - Some groups give people 1-2 minutes each to share how they are doing.

Group discussion and planning - Groups work on projects together and need time to discuss the things they want to work on. Everyone should have a job to do with project work. Relationships are also a part of groups and some groups plan to have snacks or a meal after a meeting to give time to socialize.

Group Rules - Groups decide on how to organize and meet. This includes taking turns to speak and respect for everyone. Some groups decide on rules when they start to meet while others develop rules as they go along.

Robert's Rules of Order - This book is often used as a resource to clarify rules and etiquette for conducting meetings.


Take turns to speak and respect everyone

## Agenda - In Depth

## Adapted from People First of Washington Officer Handbook

All officers should hold a meeting before the whole group meats to plan the agenda for the group meeting. The agenda is a list of things that need to be discussed during the meeting. All officers should help to plan the agenda.

## Suggested agenda items:

1. Call the meeting to order. The president or officer in charge gets everyone's attention and says "This meeting will come to order." Everyone should quiet down so the meeting can start.
2. Roll call or introductions. Secretary reads roll call or people introduce selves.
3. The Minutes. The secretary reads aloud (or has someone else read) the minutes of the last meeting and people have the opportunity to add or make corrections to the minutes. The officer in charge asks the members for a motion to accept the minutes (as read, with additions, or with changes.) There is a vote to accept the minutes.
4. Treasurer's Report. The report is read aloud by the treasurer.
5. Old business. Old business is the list of items that were not fully discussed at the last meeting. This is the time for committees to report on things the group has been working on. Before ending this part of the meeting the officer in charge asks "Is there any other old business?"
6. New Business. New items not discussed at the last meeting. The officer in charge opens the discussion and asks "Is there any other new business" before ending this portion of the meeting.
7. Announcements. This is the time to remind members about upcoming events. Members can also share things happening in their lives like work, home life, hobbies, new skills, volunteering or vacations.
8. The Program. This is the time for learning new things of interest to members. If possible, this should be done in an entertaining way. Groups could consider guest speakers, a relevant video, or working on a group volunteer project.
9. End the Meeting. The officer in charge asks for a motion to end the meeting. After someone motions, the president calls for a vote to end the meeting. After the vote, the meeting is ended by the president.
10.Refreshments and social time are fun and give members time to get to know each other.


Refreshments and social time are fun and help members get to know each other...

## Decision-Making

If there are many different issues the group wants to work on, you may need a way to decide which issue to work on even if people feel strongly about several different issues. One way to do this is with a brainstorming and vetting process.

- First, people should bring up whatever ideas they have and the secretary should record those.
- Then, people can vote by a show of hands on what issue they think is the most important as the list is read aloud.
- Keep the narrowed down list and have everyone vote again to narrow down the list further until the choice is only between two options.
- Then take a final vote (using the procedure described in the next chapter) to democratically decide which issue to work on.


Set reasonable goals. When working on an issue, think about what small steps you will need to take to reach your larger goal and plan them on a realistic timeline.

For example, if you wanted to hold a bake sale to raise funds to send some group members to the statewide conference, you would need to decide a number of things.

Who will be in charge of money?
Who will do the cooking or purchasing?

- Where will it be?

Each of these questions lends itself to a task. We have to come up with someone to take care of the money and to get the baked goods, and someone else will have to secure a place to hold the sale. Who will that be? Another smaller decision must be made.
Think through what you want to do and write down the steps.
There are a number of ways to assign responsibilities but everyone should have some role--asking for volunteers is always a good first step.

## Decision-Making \& Voting

Anything that is the business of the whole group should be decided among the members by voting. The president does not vote unless there is a tie.

A motion is an idea that someone would like the members of the group to consider. Here is the process for making a motion and seeing it through to a vote.

- First someone makes a motion.
- Before there is any discussion, another member must second the motion, which means that they also want to consider the issue.
- After the second, the secretary writes the motion in the minutes, who made the motion, and the fact that it was seconded.
- The secretary is then asked by the presiding officer to restate the motion (say it aloud).
- After the motion is read there is discussion about all aspects of the motion, and not about other things.
- If there is no discussion, ask a couple of questions or wait for a little time for people to think of what they have to say, if anything, about the topic.
- If someone brings up something that is not part of the topic being discussed, you can use a big paper or flip chart to record the topic that person is talking about and get to it later on the agenda. These topics can also be put as "old business" on the agenda for the next meeting.
When discussion seems to stop, the presiding officer asks if there is any more discussion.

If there is no other discussion, the presiding officer asks if there is a call for a vote. Any member can call for a vote. You can vote by a
show of hands or by saying "Yea" for Yes I am in favor of the motion or "Nay" for I am opposed to the motion. The presiding officer then announces the results of the vote.


Example: The group has decided to work on accessibility issues in the community. Adam and Sue have a different opinion on something. Adam thinks the group should work on getting curb cuts installed downtown, but Sue thinks the group should work on a letter-writing campaign to businesses to advocate for wheelchair ramps. Sue motions that the group work on the letter-writing campaign. The group discusses their options for choosing a project, then when it is time, they decide to put the letter-writing campaign to a vote. Adam knows what he has in mind--he thinks wheelchair ramps are really important, but also has his own idea--he wants to work on curb cuts. So he votes "Nay!," or no. Sue really wants to work on wheelchair ramps, so she votes "Yea!" for yes. After everyone votes the project with the most votes is the one the group will work on.

## Electing Officers

Adapted from People First of Washington Officer Handbook
A nomination is the way a member says that he or she would like to have a particular person be an officer. Here's the process:

1. The presiding officer opens the nominations.

- The members nominate who they want to be elected
- If the person nominated wants to run for the election they accept the nomination
- No one can nominate themselves
- There should be at least two and no more than five people running for an office

2. Nominations are closed by a motion from a member

- A vote is carried out after the motion is carried

3. The presiding officer continues the nominations for each other office.

## On the day of the election, for each office:

- Each person who is nominated gives a campaign speech telling why they would be best for the office
- The vote is taken (by secret ballot or whatever the group decides is best)
- The votes are counted
- The presiding officer announces the winner
- The winner gives a thank you speech
- If there is a tie, the members should vote again, choosing between the two nominees who got the most votes


## Secret Ballot:

Voting by secret ballot is the way many groups prefer to handle the election of officers. On a slip of paper a member will write the name of the person they would like to vote for, or check off a ballot made listing the candidates on a pre-made ballot (which can include pictures). The slips are dropped into a box or other container. The slips are then tallied. When members can't write, a box is prepared for each nominee and a picture of each candidate is put on their box. The members are each given a slip of paper which they drop into the box of the candidate of their choice.


Secret ballot is the way many groups... handle the election of officers


## Projects that groups have worked on:

Adapted from SABE Self-Advocacy Start-Up Toolkit
Changing the name of an agency
Changing the location of or having a cross-walk put in on a busy road

- Public Education - increasing public awareness of disabilities by speaking to staff of agencies, schools, faith based organizations, boards, and other community and political groups.
- Organizing events - conferences, dances, holiday and other parties, picnics, political events, sporting events, trips, etc...

Letter writing campaigns
Mentoring students with disabilities
Voter registration drives

- Blood donor drives

Volunteering in the community - anything from teaching reading and math skills to helping out at a local food bank or nursing home.

- Fund-raising - Bake sales, car washes, ticket sales, 50/50 raffles, spaghetti dinners, tag sales etc...

Bringing their agenda to politicians, and law makers.

...groups have worked on having a cross-walk put in on a busy road...

## SA Group vs. Advisory Council

## What is an official SA group?

Note: We want to answer this question for two reasons. One, there is a lot of confusion about the difference between a self-advocacy group and an advisory council. Two, we want to make sure that SA groups are formed and controlled by self-advocates. This is not to say that an advisory council is a bad thing. It's good for agencys to involve people in decision-making and seek input; that is part of self-advocacy too.

## Criteria for status as an official group of the

## Self-Advocacy Association of New York State:

1. Groups must elect their leaders-president and vice-president etc.
2. Groups choose their own advisor(s)
3. Groups develop their own agenda and activities. They participate in regional and state SA activities (even if only one person goes to the regional meeting, conference, etc.)
4. The main purpose of the group is self-advocacy activities
5. If affiliated with an agency, the group remains independent of that agency and the way that agency functions. These groups would not be SA groups unless they also have the above listed elements.
6. The group maintains membership records and a list of current officers with SA's main office.


## The Role of the Advisor

## Self-advocates found the following traits and skills in an advisor helpful to groups:

Assist the group with making contacts, this could be by inviting guest speakers to the meeting and in supporting group members to write letters to legislators and local officials.

- Be supportive and stand by the group. Support us to do the work we want to do.
- Listen. It can be hard to sit back and listen to us process ideas without giving yours.
- Don't be fearful of your role as an advisor, know that we know there is potential for conflict with your job as an advisor.

Look at yourself in the role as a Support Person - considering all ethics and legalities.


The Advisor's role is as
Teacher/Counselor / Motivator: be a resource and provide information

Help us to explore our community.

- Be flexible and open minded, we need to try different projects and if we fail we can always modify our project and try again.
- Teacher Counselor Motivator - Be a resource and provide information


## Examples of tasks advisors often do:

- Assist secretary with taking notes
- Assisting the group in drafting a letter
- Assisting the group with finding an accessible meeting space, opening/closing room if needed.
- Encourage members to do as much as they can.
- Assist group to make a schedule and discuss the format options
- Invite other people to the group
- Assist with transportation - even when running smoothly
- Help us to publish our accomplishments and be heard by our directors
- Help get us to regional meetings
- Assist the group to get back on track
- Inform group of their options as they make decisions


## Ten Questions to Ask Yourself as an Advisor

These questions were developed by People First of Washington:
1 Am I really listening to what self-advocates have to say or am I imposing my point of view?

2 Do I see the real human growth and potential in self-advocates or do I see "disability" and "limitations?"

3 Have I "checked out" my actions and feelings with selfadvocates?

4 Are any of my actions based upon a potential conflict of interest or need to be controlling in any way?

5 Do my Actions:

- increase the self-respect, self-confidence, self-reliance in self-advocates, and encourage them to take risks?
- decrease the self-advocates' dependence on me?
- increase a peer support system and encourage self-advocate leaders to take over my role
- teach people a process for making decisions, solving problems, and doing things on their own vs. controlling things
- decrease the chance that you will be seen as a "manipulator"
- increase the self-advocate's opporunities to understnd and participate in the decisions that affect their lives?
- encourage a positive role for diverse membership?

6 Do my actions promote respect and recognize individual growth as well as group spirit?

7 Do my actions encourage and assist self-advocates in obtaining and understanding a wide variety of information and different points of view so that people can make informed decisions? Have my actions developed "allies" for the selfadvocates point of view?

8 Do my actions recognize that anger is okay and and indeed justified in many instances and encourage people to use anger for positive growth and societal change?

9 Do I recognize that is okay for self-advocates to:

- question my point of view?
- work me out of a job?
- tell me that they don't need me and can decide on their own?
give me negative feedback about what I am doing?
- not see me as an authority figure

10Do I realize that advisors as well as self-advocates and selfadvocacy organizations are fallible (or imperfect) human beings prone to making mistakes and having problems just like anyone else in any other organization?

