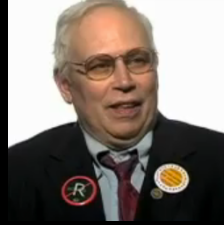


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educate.



cooperate.



participate!

est. 1982

The New Jersey Self-Advocacy Project



Promoting Empowerment and Independence in the
Lives of People with Intellectual and Developmental
Disabilities Through Education and Awareness

Created by Ashley Ritchey,
Training and Technical Assistance Specialist for
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THANK YOU! DANKE SCHÖN. MUCHAS GRACIAS!

Dear Advisors and Group Officers,

The New Jersey Self-Advocacy Project (NJSAP) would like to take this opportunity to wholeheartedly **THANK YOU** for your support of and involvement in New Jersey's ever evolving self-advocacy network.

As an Advisor or Officer, you are an **integral** part of New Jersey's self-advocacy movement. Please know that your dedication and commitment are greatly appreciated.

The purpose of compiling this handbook is to provide information about NJSAP, as well as the guiding principles of self-advocacy and your role as an Advisor or Officer of a self-advocacy group. Whether you have been involved in self-advocacy for a decade or just a handful of weeks, we hope that you find the information and resources in this handbook helpful and effective in working with your group.

Should you require assistance at any time, please contact a member of the NJSAP team at 732.246.2525, ext. 22, or email us at NJSAP@arcnj.org

Again, please know that your dedication and support are tremendously appreciated by everyone at The Arc of New Jersey and the New Jersey Self-Advocacy Project.

We hope to continue *moving forward together*.

With much gratitude,



Dennis Donatelli, Director of the New Jersey Self-Advocacy Project

CHEERS! どうも有難う MERCI BEACOUP!

New Jersey Self-Advocacy Project Staff

We welcome you to contact a member of the NJSAP team at any time, should you require assistance, information referral services or resources.

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- i. NJSAP Mission Statement, Goals and Organization
 - i. Flowchart: See How The Project and the Network Operate
 - ii. FAQ's for NJSAP and NJSSAN
- ii. Rights and Responsibilities
 - i. The Universal Declaration of Human Rights
 - ii. Rights and Responsibilities: You Can't Have One Without the Other
 - iii. Communication & Courtesy
- iii. Origins and Evolution of the Self-Advocacy Movement
 - i. A Brief History of Self-Advocacy
 - ii. Principles and Purpose of Self-Advocacy
 - iii. Why Self-Advocacy Groups?
 - iv. NJSAP Assistance: We Can Help You Start a Group!
- iv. Allies in Advocacy: Group Advisors and Officers
 - i. Expectations of a Successful Advisor
 - ii. Support vs. Smother: What's Your Style?
 - iii. Ways to Offer Support
 - iv. Voting and Officer Responsibilities
- v. Group Activities, & Team Building Exercises
 - i. Fundraising Ideas & How To's
 - ii. Icebreakers
- vi. Digital and Print Training Resources
 - i. NJSAP Video Library
 - ii. Helpful Websites and Online Forums

NJSSAN & NJSAP:

SEE HOW THE NETWORK OPERATES

The New Jersey Statewide Self-Advocacy Network

The NJSSAN is made up of thousands of individual self-advocates, as well as hundreds of local self-advocacy groups and 5 regional Councils across the state

Council 1,
Chair & Vice Chair

Council 5,
Chair & Vice Chair

Council 2,
Chair & Vice Chair

Council 4,
Chair & Vice Chair

The Advisory Board
of the NJSSAN

Council 3,
Chair & Vice Chair

Council Reports

NJSAP Provides
Education,
Information Referral,
Resources,
Support,
and Assistance

New Jersey
Self-Advocacy Project

SAP Staff Members

Director: Dennis Donatelli
Ashley Harris

Erin Caprara

Sam Boravita
Ashley Ritchey

*Ideas Flow In From Self-Advocates,
AB Members and Advisors*

*Information Flows Out to Self-Advocates,
Groups, Advisors, Independent Advocates*



NJSSAN: A Grassroots Mission

What is the NJSSAN?

The New Jersey Statewide Self-Advocacy Network (NJSSAN) is an organization dedicated to gaining respect and equal rights for all people with disabilities. The NJSSAN is made up of thousands of self-advocates, independent advocates, allies, advisors, and supporters of people with intellectual and developmental disabilities throughout the state.

The NJSSAN is made up of 5 councils and approximately 100 local self-advocacy groups.

- Council 1 comprises the counties of Hunterdon, Morris, Sussex & Warren.
- Council 2 comprises the counties of Bergen, Passaic, Essex, Hudson & Union.
- Council 3 comprises the counties of Mercer, Middlesex, Monmouth, Ocean & Somerset.
- Council 4 comprises the counties of Burlington, Camden & Gloucester.
- Council 5 comprises the counties of Atlantic, Cape May, Cumberland & Salem.

Each Council has a Chair and Vice Chair. Both positions are 3 year terms. The Chair and Vice Chair of each council are also members of the NJSSAN Advisory Board.

What does the Advisory Board do?

The Advisory Board is a group of elected self-advocates who represent people with intellectual and developmental disabilities in New Jersey. The AB meets once monthly to discuss the activities in their local groups and councils, as well as to brainstorm about public outreach activities, fundraising events, and upcoming legislative decisions that affect the quality of life for all people with I/DD.

What is an Independent Advocate?

An independent advocate is a person who is not a member of a local self-advocacy group or associated with a community provider, yet would still like to be involved in public outreach events, to testify before the Senate and/or Assembly, and to participate in research studies or surveys.

While NJSSAN membership was previously limited to individuals who were members of a local self-advocacy group or community provider, a new initiative to include Independent Advocates in the network will help to build the strength and power of the NJSSAN.

"Never be afraid to raise your voice for honesty and truth and compassion against injustice...If people all over the world...would do this, it would change the earth."

— William Faulkner

After all, there is strength in numbers!

Where does the New Jersey Self-Advocacy Project fit in?

The New Jersey Self-Advocacy Project, a special program of The Arc of New Jersey, is dedicated to assisting people with I/DD to gain the strength and support to successfully advocate for themselves and exercise greater control over their lives. NJSAP staff are responsible for supporting and facilitating the mission of the Network and its members. As a grassroots initiative, NJSAP does not dictate the direction of the self-advocacy movement but rather provides learning tools and resources to amplify the efforts and objectives of self-advocates.

grass roots, plural noun:

1. People or society at a local level rather than at the center of major political activity
2. The groundwork or source of something (i.e., change, improvement, equality, respect, representation)



The Declaration of Human Rights

The following articles were adopted from the United Nations' Universal Declaration of Human Rights

- Article I All people are born free and have **equal** rights
- Article III Everyone has the right to **live freely** and **safely**
- Article VII The law applies to every person in the **same way**
- Article XII Everyone has a right to **privacy**; no one may interfere with another person's home, family, or correspondence (phone calls, letters, emails)
- Article XVI Everyone has a right to get **married** and to start a family when they are of legal age
- Article XIV Everyone has a right to speak and to think what they want; they have the right to share their **ideas** with others
- Article XXIII- I Everyone has a right to have a **job** and to choose what they will do for work
- Article XXIII - II Everyone has the right to be **paid** the same as someone else who does the same work
- Article XXVI Everyone has the right to an **education**



ALL
HUMAN
BEINGS
ARE BORN FREE AND
EQUAL IN DIGNITY
AND RIGHTS
THEY ARE ENDOWED WITH
REASON AND CONSCIENCE
AND SHOULD ACT
TOWARDS ONE ANOTHER
IN A SPIRIT
OF BROTHERHOOD

Human Rights

Know Your Rights!

*No one can
take away your rights.*

The Right to Life

The Right to Choose, to Make Your Own Decisions

The Right to Freedom

The Right to be Heard, Listened to

The Right to Try to Find Happiness

The Right to Eat What you Want

The Right to Privacy and Respect

The Right to Choose Friends & Partners

The Right to Choose Your Bedtime, Personal Style,
Music, Home Decorations, etc.

Legal Rights

The Right to Vote

The Right to Worship and Practice

Any Religion You Choose

The Right to Live and Work in the Least Restrictive Environment

The Right to **Due Process** and **Appeals**: you have the right to know *what* is happening and *why* your rights are being restricted, also *how long* they will be restricted.

The Right to **Petition for Change**: ask for a rule to be changed if you believe it is not good for you.

The Right to **Equal Protection**: *everyone* enjoys the *same* rights even if they have a disability.



Rights and Responsibilities: You Can't Have One Without the Other

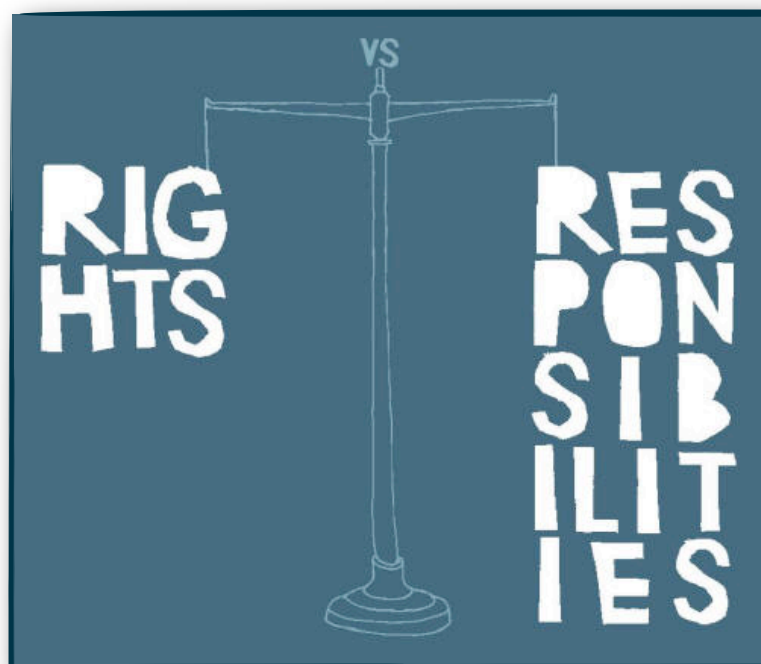
So, we know that every person has the right to life, choice, and freedom from harm.

Everyone has the right to be heard and to figure out what makes them happy.

Legally, every person has the right to vote and to practice any religion they choose.

We also have the right to eat what we want, wear the clothes that we want to wear, to make decisions without being told what to do by someone else, to make our own bedtime, to choose our friends and partners.

But **rights** cannot be discussed or enjoyed without also talking about **responsibilities**.



Responsibility. What's That?

Rights and responsibilities go hand in hand.

If you are enjoying your rights, some of which you receive as soon as you are **born** and some of which you receive when reach a certain **age**, you must also learn about your responsibilities.



You have the right to make your own decisions but the consequences (or things that happen after you make a choice or act in a certain way) are your responsibility.

Example: You have the **right** to choose where you want to live. After thinking about it for a while, you decide that you want your own apartment. If you have your own apartment, you will have additional responsibilities (grocery shopping, cleaning, etc.), so you must decide whether having your own apartment is worth the new responsibilities that come with it. Many people decide that they learn more and are very proud of taking on more responsibilities.

The choice is yours!

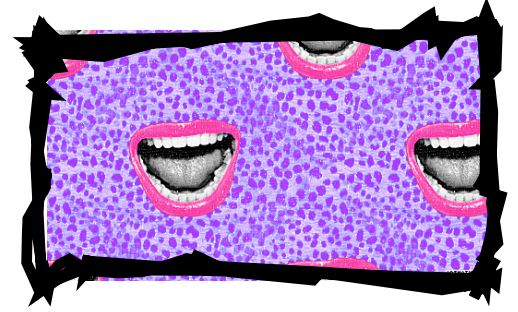
I AM RESPONSIBLE FOR MY OWN HAPPINESS

[responsible (*adjective*) : having a capacity for making moral decisions and accepting of the consequences.]

Communication and Courtesy Count!

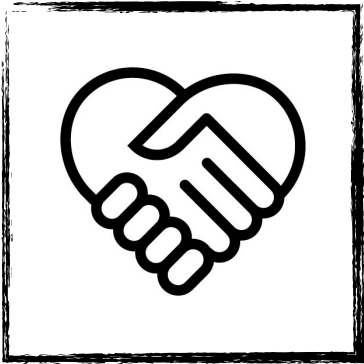
Below are some tips for communicating and working with people with disabilities. Above all, **New Jersey's self-advocates** want you to treat them like equal citizens, with respect, courtesy and dignity.

People with disabilities want to be spoken to **directly**, rather than through a friend, family member or support staff.



New Jersey Self-Advocates appreciate it when you ask if we need **assistance**, but wait until your offer is accepted until you act.

We want to be treated like **adults** and **equal** citizens. We appreciate it when you use **Person First Language**. Recognize that we are human beings, just like you. Our humanity comes before a disability.



It is OK to **shake** hands! Even if the person has limited hand use, offering your hand is an acceptable greeting.

Relax. If you say something like "see you later" to a person with a visual impairment, don't be embarrassed.

If a person has a hearing disability, look directly at them when you are speaking. **Speak clearly, slowly and expressively** so that they can read your lips. Don't shout; speak in your normal tone of voice.

Listen to me when I speak. If you don't understand, don't pretend that you do. Instead, ask me to repeat the sentence or ask for more information.

What is Self-Advocacy?

Self-Advocacy is people with disabilities speaking for themselves, knowing their rights and making decisions about their lives without *undue influence* by others.

Traditionally, advocacy has been defined as *someone else* speaking or acting in the best interest of another party or person. Self-Advocacy puts the power back into the hands of the person whose life will be directly affected.

The goal of the Self-Advocacy movement is to take the power back and assist people with disabilities in gaining greater control over their own lives, their medical care, relationships, employment and living situations.

Self-Advocacy is about being more **independent**,
discovering things about yourself you didn't know,
figuring out **what you want** and how to get it,
knowing who to ask for **support**,
taking **risks** and accepting **consequences**,
knowing your **rights** and your **responsibilities**.



Self-Advocacy is about deciding what is best for yourself.

Remember: You do **not** have to make every decision or choice alone; you have the **right** to ask for and receive advice and support.

Why Do You Need Self-Advocacy?

In the not so distant past and even today, adults with disabilities have been:



Treated like children.

Refused the opportunity to speak up and make decisions about their lives.

Called hurtful names.

Locked up, institutionalized, segregated, sterilized.

Refused information about their rights and responsibilities as citizens.

Refused the opportunity to show that they can successfully live, work, participate and contribute to society and to their communities.

Viewed as less valuable members of society, not given the respect and dignity that they deserve.

We know that people with disabilities deserve the same respect, dignity and rights as any other person. The principles and practices of Self-Advocacy help people with disabilities build the confidence to speak up for themselves and make decisions about their own lives.

Self-Advocacy encourages people with disabilities to receive education and information about their rights and responsibilities, so that they can make **informed decisions.**

Why Have Self-Advocacy Groups?

One of the most positive aspects of establishing and maintaining a self-advocacy group is that people with disabilities are given the opportunity to **come together**, share ideas and information/**brainstorm** and **discuss** ideas relating to activities, legislation, current events and issues that directly affect their lives and the lives of other people with disabilities.

Self-Advocacy groups afford people with disabilities an opportunity to develop *organizational, communication managerial, leadership, creative, collaborative, team-building* **skills**. More than just reading about leadership and agenda-planning in a handbook, being a member of a group gives you the opportunity to **put those skills to the test**.



Groups **reduce the isolation** of people with disabilities, emphasize the importance of education and gaining accurate information about any issue affecting your life. Self-Advocacy groups are energized by the *peer-support process* in which each member is partly responsible for the leadership, goal setting, content and conclusion of every meeting. Each and every member of the group bears a certain amount of **responsibility** for the meeting. This **shared leadership** builds assertiveness, confidence, and ensures that every member is held **accountable** for their actions. Engaging with fellow group members and watching your hard work turn into results can build confidence and inspire other people to join the movement, too!

Main Goals of Self-Advocacy Groups

Human Rights

Some Self-Advocacy groups will devote their time to:
Improving services and programs for people with disabilities

Learning about and exercising human rights

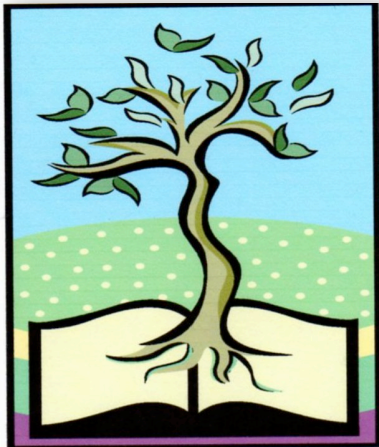
Justice, dignity and equality for all human beings

Learning about the laws that govern all people

Living in a community

Ending discrimination

Taking charge and making decisions about *their own lives!*



Educational

Other Self-Advocacy groups will be devoted to:

Learning about human rights and dignity for all people

Advocating for themselves and others

Voting and learning about how the government works

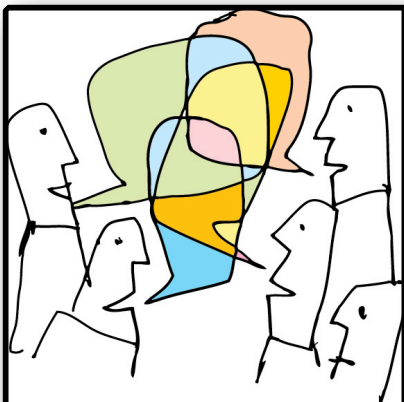
Solving problems

Learning about ways that they can volunteer and

contribute to their community

Social

Some Self-Advocacy groups will choose to focus on bringing people together, making friends, sharing ideas, and planning activities with other group members.



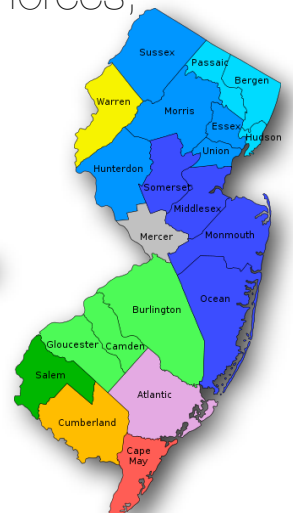
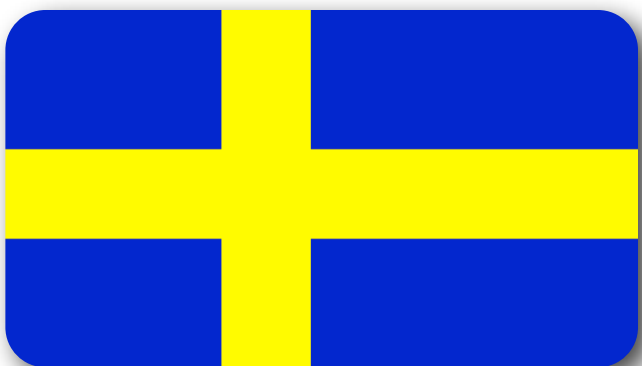
A Brief History of Self-Advocacy

The Self-Advocacy (SA) movement took root in Sweden during the 1960s. With the assistance of Dr. Nirje, people with disabilities were afforded the *dignity of risk* and began to form leisure clubs where they could discuss their rights and responsibilities, as well as their desire to speak for themselves. The Swedish Self-Advocacy motto evolved into “Don’t think we don’t think!” and national conferences began to spring up across the country.

Eventually, word about the Movement spread to the United Kingdom and on to Canada. The basic principles of the movement revolved around developing collaborative supports and education for people with disabilities so that they could successfully gain control over their lives and make decisions relating to every aspect of their care.

The first Self-Advocacy organization in the United States was founded by people with IDD who attended a Canadian conference and were disappointed by the dominance of professionals rather than self-advocates. They returned to Oregon and established the US’s first Peoples First chapter in 1974.

Currently, New Jersey is home to thousands of dedicated and educated Self-Advocates, who belong to dozens of local groups, Councils, task forces, coalitions, and speakers’ bureaus.





HOW TO WORK BETTER

1 DO ONE THING
AT A TIME

2 KNOW THE PROBLEM

3 LEARN TO LISTEN

4 LEARN TO ASK
QUESTIONS

5 DISTINGUISH SENSE
FROM NONSENSE

6 ACCEPT CHANGE
AS INEVITABLE

7 ADMIT MISTAKES

8 SAY IT SIMPLE

9 BE CALM

10 SMILE

Forming a Self-Advocacy Group

Be Patient But Persistent!

Starting a Self-Advocacy group is no small undertaking.

It takes dedication, patience and the proper amount of support.

Before starting a group, you must figure out what the purpose or mission of your group will be.

Try asking yourself the following questions:



Is there something in my life that I am not happy about?

If I could change one thing about my life, what would it be?

What makes me angry?

Do I know my rights? Are they being respected by other people in my life?

The answers to these questions might help you figure out what you are passionate or feel strongly about. You can figure out what types of issues are important to you and worth putting effort into changing or fixing.

Forming a Self-Advocacy Group, Continued.

After you have a clear idea of what your group will work on, you will need to **recruit members**. These potential members must be willing to attend the meetings **regularly** and should have some sort of **common ground** (an issue that they want to work on, a hobby or activity that they feel passionate about).

Second, figure out what the **format** of your group will be.

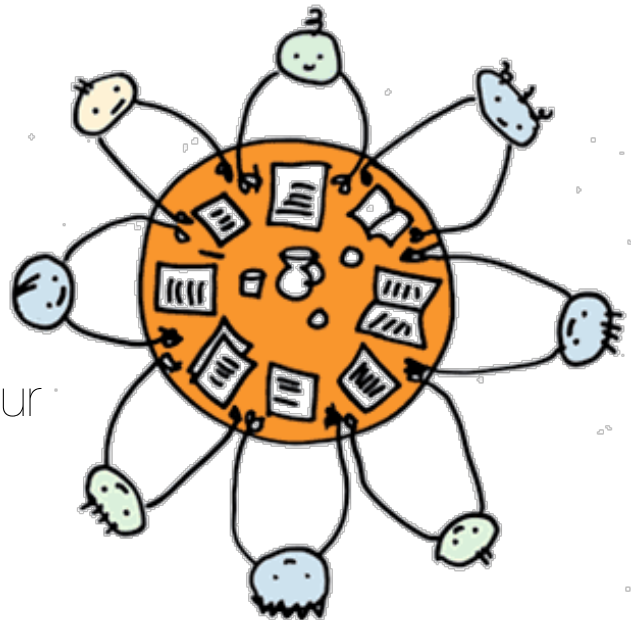
For example: Will it be a **social/leisure** meeting or a self-advocacy, **activist-based** group?

Do you want to form a **speakers bureau** to educate legislators on issues of importance to people with disabilities?

Do you want to organize a **“watch dog”** group for improving transportation services and ensuring that transportation vehicles and buildings are accessible?

Reach out to local community centers, libraries, schools, community colleges, houses of worship, or chapters of

The Arc if you need a **location** to hold your meetings. The ideal location will be 100% accessible and conveniently located for all group members.



How NJSAP Can Help You Start a Group



The New Jersey Self-Advocacy Project can help you start a group! The Project has developed a wide range of printed materials and resources related to self-advocacy and can provide:

-General How-To's, or an explanation of the specific steps you need to take to form a group.

- Information on group development, recruiting and retaining members, voting procedures, Advisor and Officer training materials
- Sample flyers, brochures, press releases; information about contacting government officials; skill building activities

Developing a Mission or Vision Statement

Before starting a group, potential members must devote time to figuring out exactly what they want to work on. Answering the following questions is helpful in creating a mission statement for your group:

Why are you starting the group?

What are the specific goals and needs of potential members?

How will the goals of the members be accomplished?

Will the group be open to anyone or only specific people?

Why should people come to the group? What will they get out of it?

Based on member feedback, look for common goals and themes. Focus on specific issues that potential members feel strongly about.

Create a list of goals, ideas, and a vision for where the group is headed.



Guidelines For Successful Self-Advocacy Groups



Success is measured by members of the group. No two self-advocacy groups have the same needs or levels of support, but creating a **code of conduct**, distributing minutes and creating an agenda for every meeting ensure that every member is on the same page.

During your first meeting, it is a good idea to break the ice, or have each member of the group share something about themselves and why they have decided to join the group. Be patient. It will take time before everyone is comfortable with one another and an **agenda** or **mission** can be formulated.

Ideas for Creating a Code of Conduct

Every group has different needs. Based on the number of people involved, the frequency and length of your meetings, as well as the location, you can develop your own set of guidelines. These *guidelines* help every member to understand what is *acceptable* behavior at the meeting and what is *unacceptable* behavior. The following examples can help give you an idea of the types of things you will want to address with your group to ensure that you are making the most of every meeting:

- Cell phones and music players must be turned off during the meeting.
- All group members must do their best to arrive ON TIME to the meeting.
- Stick to the AGENDA to make sure you accomplish all goals.
- Stay seated and do not interrupt another group member when they are speaking.
- Raise your hand and wait to speak until you are given permission by the President.
- Treat other people the same way that you want to be treated.
- Respect the opinions and ideas of all group members.

What's My Role As an Advisor?



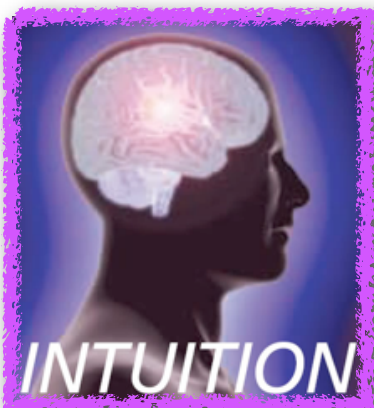
As an Advisor to a Self-Advocacy group, your primary responsibility is to support the individual self-advocates and assist them in developing the skills to speak up

for themselves and the issues that they feel strongly about.

A successful Advisor will realize that a person's potential is **boundless** and completely unlimited, regardless of an intellectual or developmental disability.

An Advisor will need to *strike a balance* and provide **just enough** assistance so that the group stays on track and proceeds with the agenda that they have worked to develop; a true Self-Advocacy Advisor will provide support and assistance only when the *time is right*. It is necessary to have a clear understanding of the **roles and responsibilities** of the group officers, that way you will not mistakenly take over or assume their responsibilities.

It will be necessary in most cases for you to work with the group officers to develop an **agenda**. Once the meeting is underway, you can assume the role of **omniscient narrator**; you are still a crucial part of the group, but you can sit back and observe the group dynamics without directing conversation or maintaining order. This lessens the group's dependence on you and empowers the group members to take ownership of their meeting. **A win-win situation!**



Support vs. Smother: What's Your Style?

Are you a true Ally? Below are 11 questions that can be helpful in discovering your Advisor style and whether you are incorporating the qualities of a successful SA Advisor into your group meetings. As an Advisor, you play a very unique and crucial role in the success of a group. Sometimes it is helpful to step back, question your own methods and reassess your involvement in the group.

1. Do I truly **listen** to what self-advocates say and do my best to support their point of view?
2. Do I tend to make decisions without consulting the President, Vice President, or other group members because it's easier that way?
3. Do I recognize the boundless **potential** in self-advocates or do I see "limitations"?
4. Are my actions based on a need to **control** the situation and impose my own perspective?
5. Do I do my best to increase the **confidence** and self-respect of group members and decrease a self-advocates dependence on me?
6. Do I teach people about the decision-making process, emphasize problem-solving skills and encourage **risk taking**?
7. Do I welcome new information and **skills** into the group?
8. Do I utilize feelings of **anger** and **frustration** as a means of promoting positive change on a personal and societal level?
9. Do I allow self-advocates to question my methods, involvement in the group and decrease the possibility that I will be seen as an **authority figure**?
10. Do I accept the fact that we are all human beings who have the right to try new things, take risks, **explore our edges**, and make mistakes together?
11. Do I welcome the chance to learn from my own **mistakes** and keep moving forward?





Ways to Offer Your Support

Based on your answers to the previous questions, maybe you want to know how you can offer more self-advocacy oriented support to group members.

1. Truly believe in and support the **rights** of self-advocates and the **principles** of the Self-Advocacy movement.
2. Encourage Self-Advocates to run their own meetings with minimal supports. *(Yes, this means that the group members formulate their **own** agenda and direct the course of the meeting based on the goals of the group.)*
3. If necessary, help the Secretary take minutes of the proceedings.
4. Work with the Treasurer to ensure that the budget is balanced and funds are accounted for.
5. Discuss the responsibilities with each officer before they assume their positions in the group.

Ways to Offer Your Support, Continued

6. Develop your own Advisor Toolkit and provide new information to the group when it is appropriate.
7. Introduce role-playing activities related to public-speaking and social interactions if there is a need.
8. Educate yourself about the opportunities available to people with disabilities and share this knowledge with group members when appropriate. Attend trainings when possible and use the Internet to conduct research.
9. Network with other Advisors to avoid isolation and **burn out!**
10. Know that **you** are playing an integral role in the success of New Jersey's Self-Advocacy movement; *thank you so much for your support and dedication!*



Successful Advisors Do...

Support the mission and goals of the group

Provide information and *resources*

Encourage everyone to speak their mind

Practice empathy and acceptance

Work with Group Officers to prepare an agenda

Acknowledge problems within the group and work with members to develop effective *solutions*

Encourage members to explore their abilities and take *risks*



Successful Advisors Avoid...

“Taking over” or directing the meeting

Carrying out an agenda other than the mission of the group members

Conducting a Lecture

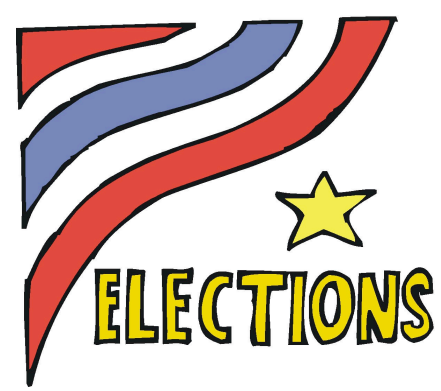
Putting pressure on quiet members to speak up (*Give it time!*)

“Saving the day” or “rescuing” a struggling group

Taking sides or favoring one group member

Imposing their own opinions on the group





Self-Advocacy groups typically elect officers once a year. In an election, every group member has equal opportunity to voice their opinion, to cast their ballot.

It is important that potential officers are informed and educated about what their responsibilities will include in advance of the elections. As an Advisor, it will be your responsibility to sit down with each potential officer and review the duties with each nominee.

Some groups will find that it is easier for **nominations** to take place at one meeting, then to have **elections** at the following meeting.

Election Vocabulary:

A **nomination** is a way to say that you would like a person to become a group officer. This can be done by raising your hand and saying the person's name.

An **election** is a process that allows every group member to vote for officers in their group.

A **ballot** is a piece of paper that has the name of a group member written on it, or a blank spot where you can write the name of another group member. A ballot is a way for each group member to have an **equal say** in who will become the next officers for their group.



The current President opens the nominations by saying:

“Nominations for (President/Vice President/Treasurer/Secretary/Sergeant At Arms) are now open.”

The members then raise their hands and nominate, or say the name of, the group member they want for each officer position:

“I nominate _____ for President/Vice President/Treasurer/Secretary/Sergeant At Arms.”

A group member can close the nominations by saying:

“I move that nominations be closed.”

Another group member must then support this decision or second the motion.

* At least two people should be nominated in each category, but no more than five people should run for each office.

* A group member can nominate himself or herself.

* If the person being nominated by someone else does not want to run for an officer position, they can refuse the nomination.



Voting For Self-Advocacy Group Officers

A **secret ballot** allows you to vote for anyone that you think would do a good job as a group officer. Your ballot or vote is private and you do *not* have to tell anyone who you choose.

Every group member has the right to cast their ballot, so long as they are present at the group meeting when elections are held.

For every officer position,

each person nominated should give a *speech* and talk about why they want to be an officer.

The group will *vote* for each position via secret ballots.

The Advisor or an impartial party should *tally* the votes.

The President should *announce* the group member with the most votes. The person with the *most votes* in their category will become the next group officer.

The newly elected officers should give a *thank you speech* or tell the group what they want to accomplish in their new position.

In the event that there is a *tie*, the group must vote again and choose between the two people who tied.



Group Officer Position: President or Chair

Responsibilities: A President begins each meeting, sticks to the items on the agenda, and keeps the members focused

The President or Chair also works with other officers and the advisor to develop an agenda

The President is responsible for elections/voting

They always welcomes new members and do their best to them feel comfortable at the meeting

Qualities:

Confident

Focused

Dedicated

Passionate

Comfortable speaking in front of a group

Can express their opinion about many different issues, even if they are difficult to talk about



Group Officer Position: Vice President or Vice Chair

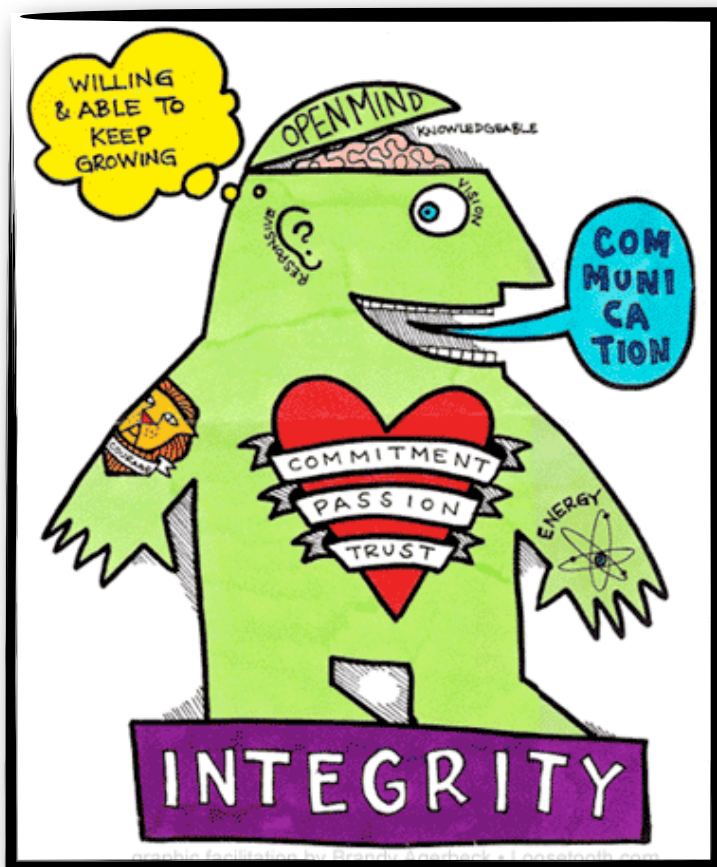
Responsibilities: A Vice President or Vice Chair is second in command. When the President is absent, the Vice President/Chair must take over their responsibilities.

The Vice President or Vice Chair also works with other officers and the advisor to develop an agenda.

Vice Chairs and Vice Presidents know the goals and mission of their group and work hard at reaching these goals.

The Vice President supports the President during the meeting.

Vice Presidents also welcome new members and do their best to everyone feel comfortable at the meeting



Qualities: Supportive,

Dedicated,

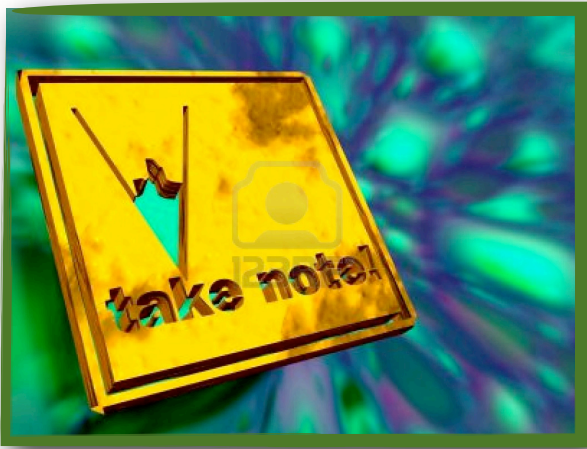
Effective Communication
and People Skills

Open to new ideas from
group members

Respectful of the opinions of
every group member

Group Officer Position:

Secretary



Responsibilities: The Secretary takes notes of what happens in the meeting (with support from the Advisor) and gives a copy of the notes to other group members

The Secretary passes out materials to the group and takes roll call.

The Secretary must be able to read and write (with supports, if needed). They are responsible for reading the minutes/notes from the previous meeting to the entire group, with support from the Advisor if they want it.

A Secretary also works with other officers and the advisor to develop an effective agenda.

A Secretary know the goals and mission of their group and work hard at reaching these goals.

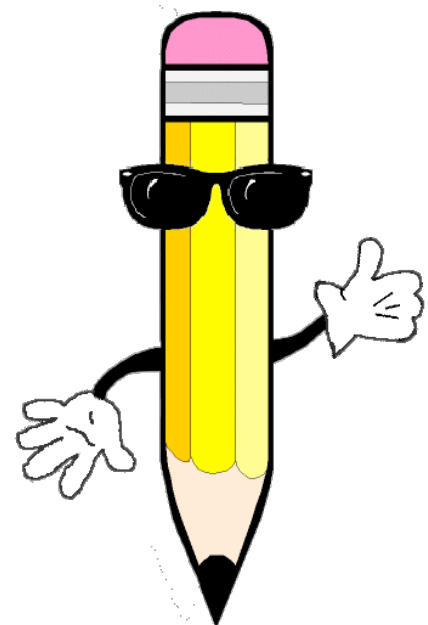
Qualities:

Notices the **details**,

Responsible,

Dedicated,

Respectful to all group members





Group Officer Position: Trea\$urer



Responsibilities: The Treasurer reads a finance report at the beginning of each meeting.

They must be able to add, subtract and count money (with support if needed) and keep a record of how much money the group has.

The Treasurer is also responsible for collecting dues (if necessary) and keeping a record of how much money was collected from each group member.

The Treasurer also helps other group officers plan an effective agenda for each meeting with support from the Advisor

Qualities: Pays attention to detail, Reliable, Honest





Responsibilities: The Sergeant At Arms is responsible for keeping the group on track, sticking to items on the agenda.

Sergeant At Arms calls the meeting to order if members get distracted, off topic or too loud.

The Sergeant At Arms also helps other officers plan an agenda, with the help of the Advisor.

This officer helps the President run the meeting and carry out plans when asked.

Qualities: Reliable, Not afraid to ask members to stop speaking out of turn, Confident and Strong

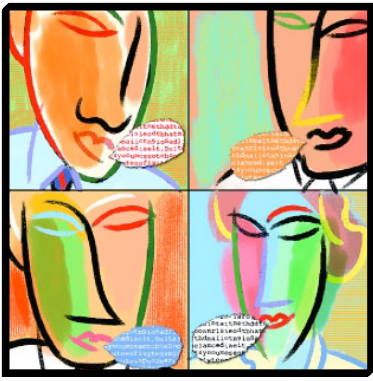
Tips for Effective Officers

Becoming a successful officer takes a lot of practice and dedication. As a group officer, you cannot do everything on your own. Instead, it is important to involve other officers and group members in the process. If you don't allow other members to voice their opinions, they will get frustrated or bored. Successful Officers use the principles of Self-Advocacy to accomplish their goals. They also know that it is important to act with respect at all times, as they are representatives for their group even when they are not at a meeting.

1. Group Officers are leaders that help other members become leaders and successful Self-Advocates.
2. Effective Officers are polite and respectful of all Officers and members.
3. Officers encourage members to get involved and to use their voice during meetings.
4. Effective Officers explain things during the meeting that allows all members to understand what is happening. If members have a question, an officer will take time to provide more information and clarity.
5. Officers believe in the principles of the Self-Advocacy movement; they use person first language and focus on the abilities of every group member.
6. Group Officers know that they represent their entire group, even outside of the group meeting. They treat everyone with respect and dignity; they want to make their communities a more positive place to everyone to live.



Give respect Get respect



Voting On Business At Group Meetings

Depending on what type of self-advocacy group you belong to, voting might be a very regular part of the meeting's agenda. Voting allows every member to have a voice and to present new issues or concerns to the rest of their group.

The voting process goes like this:

1. A **Motion** is an idea that someone would like the rest of the group to consider or to think about. To make a motion, the group member must say "*I move that...*" followed by an *explanation* of their idea.
2. **Support.** When a member says "*I second the motion*", this means that there is another supporter in the group and they want the idea to be considered by the rest of the group.
3. **Discuss.** The President *repeats* the motion again, so that everyone knows what is being discussed. The President leads the discussion about the topic and makes sure that every member stays on track.
4. **Vote.** The President asks the group if they are ready to vote. The President then says "*All in favor (support) of (repeat the motion/idea), please **raise your hand.***"
5. **Results.** Based on how many group member support the idea/raise their hands, the President then says "*the motion carried*" (many hands raised) or "*the motion failed*" (hardly any raised hands).
6. **Plan of Action.** If the motion or idea is supported, the group must brainstorm about how they can successfully accomplish their goals related to the motion that just passed.

Successful Self-Advocacy Groups: **We** Vs. Me, Me, Me!

Self-Advocacy is about speaking up for yourself, building confidence, and making decisions about your own life. Still, your group can accomplish much more if you begin to think in terms of “WE” versus “ME.” Working together and collaborating on projects helps the group reach their goals with ease.

Advantages of Working Together:

Sharing Responsibility. Tasks and responsibilities can be divided throughout the group. If everyone does a little bit, a lot will be accomplished. Working together allows everyone to accomplish more!

Teaching Others Helps You Learn. If you teach someone else about something, it allows you to practice a skill and understand the concept even more. Also, it is important to share your knowledge and skills; when you are not around, that person will still be able to succeed and fulfill their own self-advocacy goals.

Developing Relationships. People will keep coming back to your group if it is cooperative and supportive, respectful and successful. Get to know the other members of your group. Ask them about their interests and abilities.





New Jersey's Self-Advocates:

Leading The Way!

Leaders **inspire** other people with their passion, dedication, and creativity. They are not afraid to use their voice and they are confident in their own **abilities**.

Leaders know that there is no use in **comparing** themselves to other people. No one else can be you or do what you do!

Leaders **plan ahead**. They ask questions like "what's next?" and "what if?" They plan for the best and prepare for the worst.

Leaders know that **working together** is the best way to accomplish tasks. Leaders can figure out what needs to be done and work with other people to assign responsibilities and tasks based on abilities and needs.

Leaders focus on **progress** (what can be accomplished) rather than worrying about past mistakes.

To be a leader, you also need followers, people that believe in your abilities. Leaders **respect the opinions** and voices of their supporters. Leaders also take every opportunity to **share knowledge** with other people. Leaders know that once they leave a group, their **attitude** and **positive contributions** will continue to help the members of the group.

For Your Group: Setting Goals



Step One: Write or Draw the Goal.

Write down or draw *one* goal that you want the members of your group to work on together. Why is this goal important to you and to the group? If you reach this goal, what will it *look* like? Visualize or imagine a successful outcome and describe what that is. What will it *mean* to the group?

Step Two: Develop a Specific Plan

Be as *specific* as possible when you are exploring the ways that you and the group will accomplish a goal. Each step must be broken down into smaller, manageable

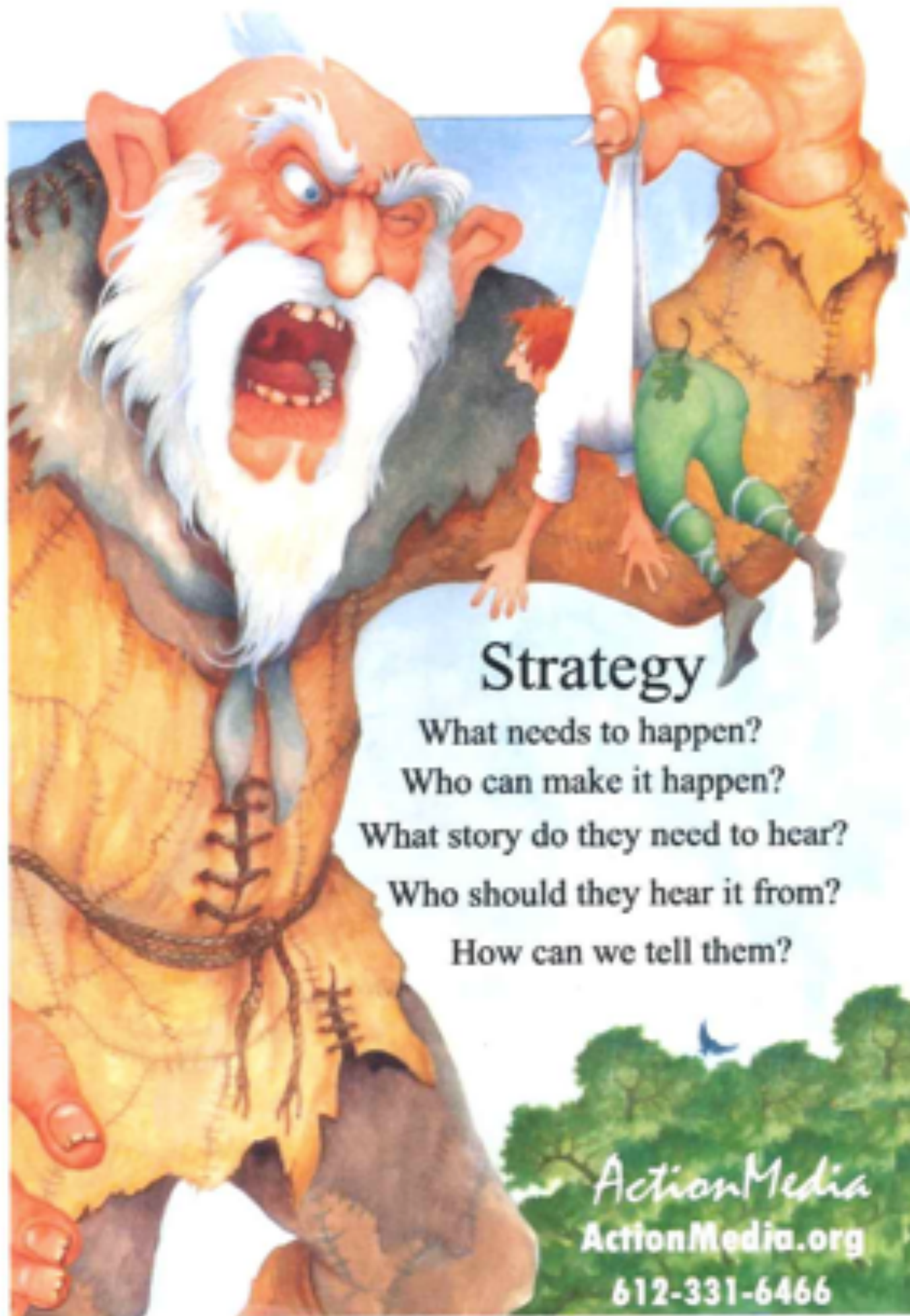
tasks. Instead of simply saying that you will *mail a letter to a decision maker*, be sure to include *who will write the letter, what it will say, who it will be sent to, how you can figure out who the decision maker is, and who will follow up to be sure that the letter is delivered*. This part of the plan allows everyone to get involved and have something to do. Teamwork allows us to *achieve more!*

Step Three: Plan for the Best, Prepare for the Worst.

The group must brainstorm about the ways in which their plan could be unsuccessful. After you have developed a plan, pick out the parts that don't seem detailed enough and give more thought to that area. There will be obstacles in the way of achieving your goal, but that does not mean you can't succeed; you must plan ahead and prepare for setbacks. Accept small disappointments or setbacks as part of the process. If you notice a problem with one part of your plan, don't be afraid to try something else.

Step Four: Deadline.

Work with your group to decide on a *deadline* for achieving your goal. After breaking down the small tasks/responsibilities that you need to work on, assign a timeframe to each task (hours? days? weeks?). Be sure to update the group on the progress of the tasks and hold the members *accountable* for the tasks they were assigned or volunteered for. Success or failure is dependent on *every* member of the group; if you succeed, you can celebrate the victory *together!*



Strategy

What needs to happen?

Who can make it happen?

What story do they need to hear?

Who should they hear it from?

How can we tell them?

ActionMedia

ActionMedia.org

612-331-6466

For Your Group: Action Plan!



The Issue:

Facts & Important Information:

The Goal/End Result:

What is the best case scenario?

What will success look like for your group?

Contact Information for Decision Makers:

Who Can Help?:

Allies, Experts, Supporters for this issue.

Contact NJSAP for information.

Taking Action:

Write a letter? Create a petition? Media interview? Press release?

Make a call? Request a meeting? Flyers and public outreach?

What's the Plan?:

Be Specific!

What supplies do you need?

Who is responsible for doing what?

Timeframe.

Creating an Agenda: Turn Your Dreams Into Plans!

An agenda helps keep the group on track and provides a basic outline for the purpose and goals of the meeting. An agenda is not just a “to do” list, but rather a review of the previous meeting, objectives for the current meeting, and a plan for the future of the group.

Creating an agenda should be done in advance of the meeting, along with a transcription of the minutes, and given to each member of the group for review .

An agenda can also help group officers get familiar with their **responsibilities**.

For example, the **President** can take charge of calling the meeting to order, while the

Treasurer can read the finance report and the **Vice President** can provide a brief review of the previous meeting, or task forces/coalitions/ other meetings they have attended since the last meeting. This way, every officer has the opportunity to **participate** in the meeting.

Group members should also be encouraged to participate in the meeting at the appropriate time. For example, part of the agenda can be dedicated to “any other business” or objectives, issues, concerns that group members can address. *Shared leadership* and *respect* for all opinions is crucial for the development of a successful group.



Super Cool Self-Advocacy Group Agenda

January 1st, 2011

123 Rockycliff Road, Creepytown, NJ

6:30 AM - 7:30 AM

1. Welcome.

Meeting called to order when and by whom? Roll Call? Does the group devote time to welcoming and introducing themselves to new members? Recruit, then retain.

2. Read and Review Minutes from Previous Meeting if no changes are requested.

Who reads the minutes? Who hands out copies? Who transcribes the minutes? Can anyone make the motion to accept? An excellent opportunity for group involvement.

3. Old Business.

Were group attempts successful or is more work needed? Did members volunteer to fulfill duties? What about follow up, such as calling to make sure letter was received by a decision maker? ACCOUNTABILITY.

4. New Business.

What can we say about the present state of the group? What do the members want to accomplish? Is there a clear timeframe for achieving goals?

5. Close the Meeting.

Any mention of the next meeting? Responsibilities assigned to members to fulfill before the next meeting? Any other business? News and information from other groups? Upcoming events? Another opportunity for group involvement.

Growth and Progress Take Time.

It is important to remember that the needs of the group members are completely **unique**. No other group will have the same exact needs, aims, or aspirations, so the growth and progression of the members and their group cannot be predicted or directed, only **supported**.

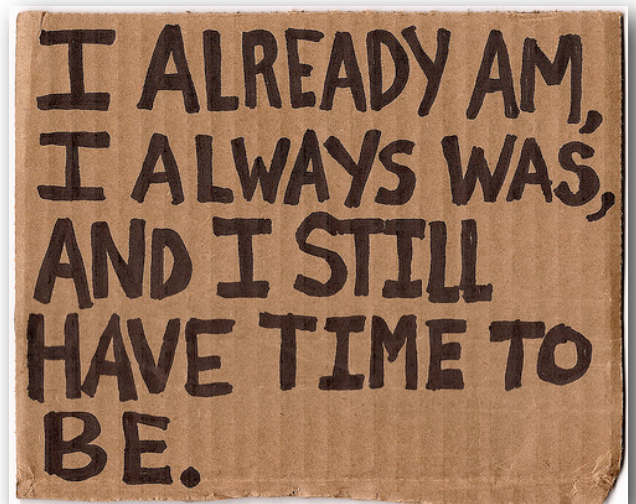
As an Advisor, your role is to provide **education** and resources, opportunities for putting their skills to the test, and provide *just enough support*.

As an Officer, it is important that you know your **responsibilities**. If you have questions about what your role is, ask an Advisor or another Officer for more information. Do not be afraid to ask questions.

Keep in mind that positive *change* and meaningful *progress* within a Self-Advocacy group takes time, dedication, practice, and patience. If you believe in and support the mission of the Self-Advocacy movement, as well as the **abilities** of each and every member of the group, your group will accomplish its goals in due time.

Find out what moves you, what motivates you and remain **committed** to your goals.

We **know** that Self-Advocacy works!



FOR YOUR GROUP: PROBLEM SOLVING

Define in detail the problem or problematic behavior.



Is it a group problem or a conflict between 2 or more members (interpersonal)?

How much does the problem affect the overall success and functioning of the group?

Brainstorm Session! How can we solve the problem? (Remember: There are no wrong answers!)

Pick the two strategies that you believe will produce the most successful results and explain *why*.

1. _____

2. _____

Aftermath: How well did the strategies work out? Were they very successful or do you need to brainstorm more ideas?

For Your Group: Avoiding Burn Out and Boredom.

"I just don't know what else we can talk about!"

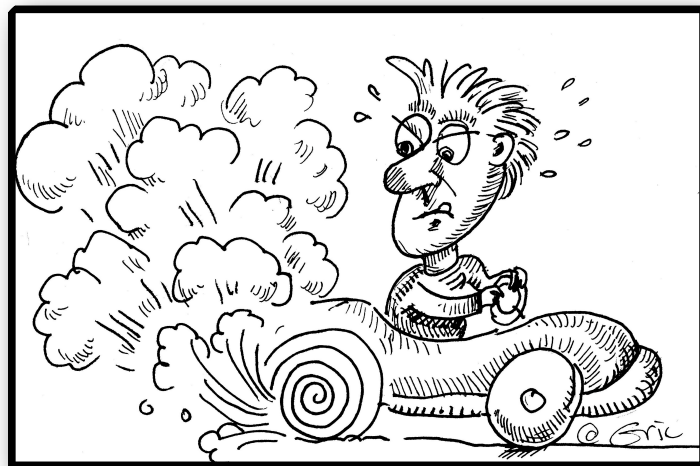
"The last two group meetings turned into whine-fests."

"I feel like I have run out of activities!"

Sound familiar? If so, you are definitely not alone. Advisor burn out can become a problem if you feel

unsupported in your role and are

unsure as to what your group wants to accomplish. If it feels like you are *spinning your wheels*, it is time to re-group!



Speak with members of your group about how *they* feel. Do they have a clear understanding of the *purpose* of the group and Self-Advocacy?

After all, *group meetings are not just a time to whine or complain* about your situation, but an opportunity to voice your concerns and *develop a plan of action* to change things for the better!

Is the group accomplishing its *goals*? If not, why not? Is there a *plan of action* in place? Is someone being held *accountable*? Have *responsibilities* been assigned to members?

If you feel like you are going at it alone, *you don't have to*. Call the NJSAP Team for assistance, ideas, activities, resources, contacts of other group advisors in your area:

732.246.2525, ext. 22 or email NJSAP@arcnj.org

Issues We Care About:

1. _____

2. _____

3. _____

Why Do We Care About Them? How Am **I** Affected?
How Does the Issue Affect the Lives of **Other** People
With Disabilities?:

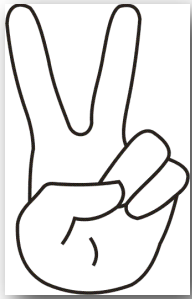
What We Can Do to Affect Change:

Who Is the Decision Maker?:

For Your Group: Contacting Decision Makers

1

Decide where the group stands on an issue. In order to affect change and motivate the group to act, it will be important to choose an issue that is important to everyone.



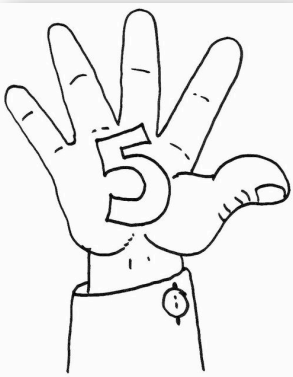
Locate the decision maker(s) on this issue. This could require research: Googling their name or the name of their organization; looking in the phone book for their telephone number.



Imagine the most successful scenario. If you could affect a change, what would it LOOK like? How would it affect your life and the lives of other people with disabilities? (i.e., you write to NJ Transit about a bus that is consistently late. They retrain the driver or improve the schedule. You can get to work/meetings/doctors appointments on time.) What does a SUCCESSFUL outcome look like to YOU?



Draft a letter on the issue. Express your point of view, your needs and request a meeting with the decision maker if applicable. Check the Resources section of your handbook for tips and techniques. Be clear. Be respectful. Follow up to make sure your letter was received (within 2 weeks of mailing it).



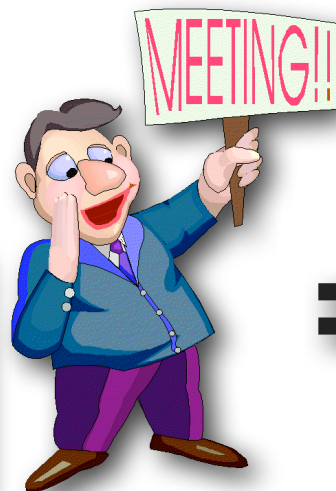
Draft a list of questions/concerns/suggestions before your meeting. Again, be clear and know what you want *before* meeting with the person.

For Your Group: Contacting Legislators

If you want to affect **change**, you have to know who is making the decisions about issues that matter to you!

You will need to conduct research in order to find out who the decision makers/legislators are. If you have access to the Internet, you can locate Senators in your state by visiting the National Association of Councils on Developmental Disabilities website (www.NACDD.org). Once you have their contact information, you can craft a letter that respectfully expresses your opinion, state how their decision will affect your life directly and urge them to support you.

You can write emails or letters, send faxes, leave voicemail messages or send text messages with information about an issue that is important to you and your group. You can also directly contact decision makers on the phone or by requesting an appointment to meet with the legislators (or their aides/assistants).





For Your Group: Tips for Contacting Decision Makers

Whether you decide to write or call the decision maker, it is important to keep a few things in mind:

- Do tell them your name and the name of the group you represent.
- Do provide your contact information/address in an email or letter.
- Do keep it short and sweet.
- Do address the decision maker *properly!*

If you are writing to a **Senator**:

The Honorable Jim Doe
U.S. Senate
Washington, D.C. 20510
Dear Senator Doe:

If you are writing to a member of the **House**:

The Honorable Jane Doe
U.S. House of Representatives
Washington, D.C. 20515
Dear Ms./Mrs. Doe:

- Do use examples of how the results of a decision will directly impact the lives of you or a person you know.
- Do focus on ONE issue per letter or call. Don't scatter your efforts!
- Do be respectful. No name calling, cursing, yelling, or threats.
- Do THANK the person for their time, attention and support.

AVOID being long-winded or talking about a whole bunch of different issues. Focus on one issue at a time.

AVOID being rude or self-righteous.

AVOID making demands. Offer *solutions* to the problem, but don't use threats or make demands.

AVOID focusing on the legislators that are opposed to your issue.

Write to decision makers who support your issue, too, and thank them for their support.

AVOID assuming that lawmakers and decision makers know the whole story; share your personal experience as it applies to the issue. Don't be afraid to make it "real" and explain how their decision will *directly* affect the lives of people with disabilities.

For Your Group: Tips for Contacting Senators and Members of Congress



When writing to lawmakers, keep it simple.

Your subject line should include these two sentences:

I support/oppose Bill # _____

I am from (town/city and state) and I request an appointment to discuss (state your issue specifically).

Identify yourself.

Be sure to include your name, address, contact information, the group that you represent. If you are in a district/county that the decision maker has jurisdiction over, they are more likely to invest time in your issue (and gaining your vote in the next election).

Be specific.

How will this decision or issue affect YOUR life or the lives of other people with disabilities? The more humanity and "realness" you can bring into your statement, the more likely the decision maker is to favor your position. Use realistic examples whenever possible.

One page, one issue.

No need to be superfluous. Keep it simple and focus on one specific issue at a time.

Being *nice* makes the difference!

Whether you support their decision or not, it is important to remain diplomatic and polite when contacting lawmakers. Always thank them for their time and attention, if not for their support.



The Honorable Senator Richard Jolson

Dear Senator Jolson:

My name is Jenny Bixby and I am the mother of a 33-year old woman, Jo, with disabilities. I live in West Bank, New Jersey.

My daughter is a wonderful woman, who loves meeting new people, is very generous, and hard working. She has been working part-time at a local health food shop for the last 4 years. We are very proud of her.

My family's life is greatly affected by the State of New Jersey's budget. The budget influences the services and supports that are available to families and people with disabilities. This is the reason I am writing to you.

Here are a few of my concerns about this year's proposed budget:

1. My family spends hours working with Jo and we have very little time together that is not dominated by her needs. This year's budget includes a \$2 million expansion for family support and we desperately need it. This support will help keep my family together.
2. My partner and I are getting older and it is difficult to care for Jo at home. Imagine a 62 year old woman, caring for an adult daughter, helping her dress in the morning and brush her teeth at night. We help her prepare all meals, make sure she gets to work on time, and do her laundry. There are over 5,000 people in the same position as us, waiting for their children to find homes in the community. Please help us see to it that Jo finds a good home before we are too older to take care of her ourselves.

Senator Jolson, I ask you to please protect the budget for people with disabilities and their families. Please help us find housing in the community for our daughter and for other people like her. Our lives, and the lives of other parents like us, will be profoundly impacted by the decision you make.

Thank you so much for your time and attention.

Respectfully yours,

Jenny Bixby

_____ **SAMPLE LETTER. Revise to suit *your* needs and *your* perspective!** _____

Be sure to include:

Your name and address. This way, the legislator/lawmaker knows if you are in their district and how to contact you.

"I am..."

Who are you? Let the decision maker know how you are affected and connected to the issue you are writing to them about.

Remember:

Legislators are, in most cases, concerned and dedicated to doing the *right thing*. They want to act in the best interest of the people they represent and who voted for them. Often, however, they are not fully *educated* on every issue; it is your responsibility to provide information and education to them, so that they can *help* you.

For Your Group: Raising Funds

1. Set **One** Goal. Do not scatter your efforts. Focus on a specific goal and allow everyone to get involved in reaching it.
2. Develop a **Plan**. *Why* does your group need the money? How will it *benefit* every member of the group?
3. Decide on a Fundraising **Activity** that **Every** Group Member Can Participate In and Support. The group should discuss and assign responsibilities to each member.
4. Create a Fundraising **Schedule**.
5. **Promote** Your Fundraiser
online and/or in print
(local newspapers, flyers at the supermarket, on Facebook or Twitter)
6. Focus on **Succe\$\$!**



For Your Group: Fundraising Ideas

Having a clear goal in mind helps motivate the group to get involved in the fundraiser. Figure out exactly how much money the group needs. Create a fundraiser chart, which can be updated at the event and allows contributors to see that they are giving to a worthwhile cause.

“Day Drop”

The advantage of the Day Drop is that it doesn't cost much and every group member can contribute at least some of the time.

On the 5th day of the month, ask group members to drop a NICKEL into the bucket.

On the 10th day of the month, ask group members to drop a DIME into the bucket.

On the 20th day of the month, ask group members to drop 20 cents into the bucket.

By the end of the first year, each group member will have donated **\$4.20** without making much of a dent in their wallet.



Other Ideas...

Bake Sales: Very profitable, so long as you have good recipes and enough money to purchase supplies.

Bowl-a-Thon: A portion of the day's proceeds directly benefit your group.

Recycling Drive: You can collect cans from friends, family and neighbors to return to recycling centers for pure profit!

50/50 Raffles

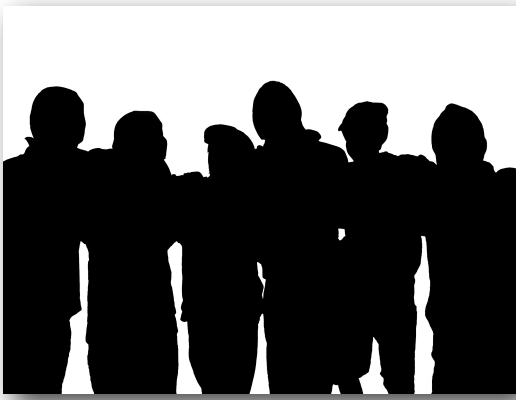
Yard Sale

Car Wash

Chocolate Sales: People LOVE sweets!



For Your Group: Recruiting Members



Post Flyers: Flyers are one page, eye-catching advertisements. Be sure to include contact information, as well as the dates and location of the meeting. You can hang up the flyers anywhere that potential members will see them: at hospitals, health fairs, mental health agencies, day program locations, etc.

Cable TV Bulletin Board: Ask your local cable TV station about running an announcement about your group.

Reach Out Through the Radio: Radio stations devote a certain amount of airtime FREE of charge to non-profit organizations and groups. Contact your local radio station to see if you can submit a short radio spot.

Church Bulletins: If members of your group attend a church or house of worship, ask the decision makers at that location about putting an ad or information about your group in their weekly bulletin.

Develop a Speakers Bureau: Members of the speakers' bureau can provide information about your group, such as what you do and why others should join, at local organizations, such as Kiwanis, Rotary clubs, churches, community service organizations, human service agencies, etc.

The World Wide Web: Create a FREE Facebook page to advertise your group and to provide information about your meetings to potential members.

Newsletters: You can distribute a monthly, quarterly (4 times per year), annually (1 time per year) newsletter to let members and potential members know what your group has accomplished and what they are currently working on.

Fund Raising: Holding a fundraiser is an excellent way to earn money for your group, as well as to let other people in your community know what you are all about. Some fundraising ideas include a bake sale, "tricky tray", a car wash. Be sure to display information about your group at the event and write a letter to the editor of your local paper to **thank** your community for their support after the event.

Word of Mouth: Speak to your friends, family members, friends of family members, and people in your community about your group. There is no substitute for reaching out to someone individually and asking for their support .

Adapted from the NJ Self-Help Group Clearinghouse's Worksheet "Recruitment Techniques"

For Your Group: Getting Involved, Staying Active

If your group has voiced concerns about feeling bored or unmotivated, here are some ideas to reenergize and invigorate the group:

Recruit new members. New voices can bring a fresh perspective to the group.

Hang up flyers with the date and location of your next meeting in stores, office buildings,

or areas in your community where potential members might visit.



Rotate positions of responsibility. Change things up! In assigning new responsibilities frequently, people will not get bored of their roles and will have an opportunity to practice new skills.

Practice **shared leadership**. Every member should feel like their voice is important and that they are contributing to the group. Do your best to involve every member of the group in the discussion, or planning the agenda, or passing out information to other members.

DON'T BE
AFRAID OF CHANGE.

Take a **risk**. Invite a guest speaker to the meeting, bring in an article to read and discuss, watch a short film, take a trip. If something is not working, don't be afraid to change it up (location, date, time, current goals, leadership roles, etc.)!

For Your Group: Lively Up Your Group!

If group members are complaining of boredom, here are some fun and energizing things to try:

1. Create an Events Calendar.

This **calendar** can include regular meeting dates, birthdays, events in the community, special events.



2. Opening the Meeting.

Begin each meeting differently. Stretch, sing a song, do a dance move!

What is one awesome thing that has happened in the last week (big or small!)?

What is your greatest **strength**?

What is one thing you have learned after going through a tough time?

3. During the Meeting.

Pick a random topic from an envelope filled with current and related topics.

Discuss and figure out where the group members stand on an issue.

Pick a **yoga pose** and have the whole group try it out.

Show a short *film* or video and discuss how it relates to self-advocacy. If it features a character with DD, is it realistic and respectful?

Role playing gives members a chance to develop communication skills.

Invite a guest speaker to visit the group. Depending on group interest, you can

Google a person in the community or contact NJSAP staff for a referral.

4. Close the Meeting

Relaxation exercise or guided meditation/visualization.

Read a poem or short story.

Share personal writing/journal entry.



For Your Group: Practicing Mindfulness

Printed below is a list of *affirmations* for group advisors. Perhaps not every item will apply to you or your style of advising, but the list can serve as a nice refresher on the basic *elements* of advising a self-advocacy group, as well as a practice in *mindfulness*.

I listen intently. I am a model for listening.

I maintain eye contact, use a person's first name and work on building a connection to the members of the group.

I believe in the mission of my group and the abilities of each member.

I remain focused on the process of accomplishing the goals of the group. I do not impose my own agenda on the group.

I provide just enough *support*, not *guidance*.

I am an advisor, not a performer. My role is to remain interested, alert, and committed to the mission of the group.

I collect resources and information, and then share it with the group members in a way that can be understood by everyone.

I remain mindful of the goals of the group, but stay flexible in my approach to achieving these goals.

I encourage every member to express their point of view and their ideas.

I encourage balanced participation and shared leadership.

Adapted from the Facilitator's Fieldbook by Justice and Jamieson.



For Your Group: Ways to Support Self-Advocacy

New Jersey's Self-Advocacy Group Advisors:

Help people identify alternatives and other “outside the box” choices when making a decision

Help people understand the possible outcomes of their choices and learn to accept responsibility

Help people identify barriers or roadblocks, then help them explore ways to overcome the barriers to their goals

Help people identify their personal, civic, interpersonal, and legal rights

Help people develop new ways to fulfill their responsibilities

Help people become active partners in the design of their support services and goal setting

Provide information and resources to people by signing up for self-advocacy and disability rights newsletters or e-mail lists; attend conferences or workshops related to self-advocacy; network with other self-advocacy groups in your area; get involved in the statewide self-advocacy network.

Advisors should feel comfortable:

- Explaining the content of a meeting beforehand (to officers) and be willing to repeat information a number of times if needed

- Helping group officers plan an agenda based on the goals and ambitions of the group members

- Believing in and supporting the dreams and aspirations of group members

- Promoting active participation and involvement of all group members

- Mediating between two group members that don't see eye to eye



For Your Group: Open Letter from People's First Org. of Oregon

A great way to educate other people about your group is to draft an **open letter** on behalf of every member of the group. An open letter allows the group to express their unique perspective, share their stories, and decide what issues are truly important to the whole group. Below is an open letter from the People's First Organization of Oregon; you can use this letter as a guide for crafting an open letter for your group.

Members of People's First Organization of Oregon believe in meaningful involvement.

Every adults wants to feel as if they have control over the course of their lives. Feeling empowered to make decisions and direct your life is part of maturing and becoming

What does it mean for a self-advocate to get involved?

Find out what their choices and opportunities are. Feel free to pick something you truly believe in and feel strongly about. Take a risk and give it all you've got.

Ask questions and receive answers that you understand.

Attend trainings to receive more information and become familiar with your rights.

How can self-advocates support one another get involved?

Network. Introduce yourself to other advocates and make sure they feel welcome and valued in your group.

Do things together. Develop relationships with other self-advocates and brainstorm about ways to reach your goals together.

Create a vision for your future and the future of your group.

Help people experience an improved quality of life. Be aware of locations that are accessible and can be enjoyed by all people, regardless of their disability.

Take time to listen to others. Practice patience and understanding.

How can professionals help self-advocates reach their goals?

Invite people with disabilities to get involved. Fill us in on what you are doing. Ask for our opinions on different issues.

Facilitate meetings between self-advocacy groups.

Be honest. Treat us with dignity and respect.

Teach us the skills we need to succeed. Teach us to balance a budget. Coach us in public speaking. Work with us to develop organizational skills. Believe in us. We are human beings and productive citizens.



How can we all stop tokenism?

Adults with disabilities should accept responsibility for their choices and actions. If you want to be treated as an equal, do not act like a child (whining, complaining without offering solutions, being hostile or mean to others for no reason).

Reach out to students and children. They are the future. Teach them about disabilities, both intellectual and developmental, and allow them to ask questions.

Do not let people with disabilities be ignored. Speak up for yourself. Feel confident in your abilities, despite a disability.

New Jersey Department of Human Services Division of Developmental Disabilities



Personal Rights

In New Jersey, your rights cannot be taken away from you when you live in a developmental center or a community residence operated or paid for by the Division of Developmental Disabilities (DDD). The people who manage and work in DDD's residential programs must make sure that your rights are protected and that you are given the help that you need.

These rights shall be explained to every developmentally disabled person over ten years of age and above the severe level of development, in language he or she will understand, and shall be shared with the parents or guardians of all individuals at or below the severe level of retardation. A copy of this document shall be given to all developmentally disabled individuals and/or to their parents or guardians within five days of admission to services administered by the Division of Developmental Disabilities. This document shall also be visibly displayed in residential and other appropriate areas of DDD and private facilities.

These are not all of the rights to which a person is legally entitled, but DDD is responsible for ensuring that...

You have the right to:

1. privacy and respect;
2. keep and use your own clothes, money and personal possessions, and to have a place to put them so that no one else may use them;
3. associate with members of the opposite sex;
4. practice the religion of your choice, or choose not to practice any religion;
5. send and receive mail without it being opened or read by other people and to receive assistance, should you want it, reading or writing the letters;
6. make or receive private phone calls during set times;
7. have a healthy diet;
8. have visitors of your choice during established times;
9. request release from a program or transfer to another program;
10. register and vote in all elections;
11. share in developing your "Individual Habilitation Plan" (IHP) [Plan of Care] to determine what supports are needed for you to live your life based on what is important to you;

- 12. have your IHP and all records about you, kept private, unless you or your legal guardian give permission for someone else to see them;**
- 13. receive regular educational instruction if you are between the ages of 3 and 21 years old, and to participate in learning and recreational activities at any age;**
- 14. receive guardianship services, if you are an adult who needs them;**
- 15. be informed of the condition of your health and to be able to contact your doctor;**
- 16. be free from unnecessary medical tests or treatment;**
- 17. be free from unnecessary restraints or from being isolated, unless in an emergency;**
- 18. be free from physical punishment.**

If you think that your rights have been violated or that someone is keeping you from being able to do the things listed above, tell or write to the person in charge of the facility in which you are living. If you are not satisfied with the answer you receive, then please write to the address listed below.

The rights listed here are from the Developmentally Disabled Rights Act and NJ State statute. New Jersey law states that persons who receive residential services from DDD may not be denied their rights when they are served in a public or private facility. (Updated through P.L. 42 U.S.C. §§ 15001 et seq. - DDRA) and (NJSA 1:1-1, 30:4-165.5, 30:6D-4, 5, 33-41). If any limits are placed upon a person's rights, the reasons for these limits must be documented yearly.



**KNOW YOUR
RIGHTS**



The New Jersey Self-Advocacy Project Resource Library

DVDs by topic

Autism and ASD

Autism & Law Enforcement

Breakthroughs: How to Reach Students With Autism

Autism and Asperger's Syndrome with Dr. Temple Grandin

Asperger Syndrome: Living Outside the Bell Curve

Abilities

Living the Smart Life

Attainment Series

Keeping House(Mary on the Move)

Plan Your Day

Home Cooking

Select-A-Meal

Multicultural Perspectives on Adults With Developmental Disabilities

Tools for Support Staff

Ten Performance Standards for Staff

The Ten Commandments of Communicating With People With Disabilities

A Credo For Support

A Little History Worth Knowing

Wake Up Call!

Diabetes: Prevention, Control and Management

Employment

Hired For My Ability

Accommodating Employees with Disabilities: Good Access is Good Business

Person First Language & Respect

Offense Taken: A Community Responds to the R Word

It's So Much Work to Be Your Friend

Voting and Voters Rights

What Voting Means

Your Vote Counts

Monday Morning Voting Process

For Your Group: NJSAP Resource Library



The New Jersey Self-Advocacy Project has accumulated a large resource library, which includes DVDs and VHS tapes, brochures, pamphlets, and a variety of other training materials. We offer these printed and video resources to your group, **free of charge**, provided that these materials be returned to NJSAP in a timely manner.

Please review the list below and contact a member of the NJSAP team to request materials.

Phone: 732.246.2525, ext. 22

Email: NJSAP@arcnj.org

Self-Advocacy and Speaking Up (DVDs)

A Life of Choices

Technology Assistive Resource Program: Making It Happen

Tools For Change (DVD): I Can Speak for Myself

Self-Advocacy for People with Developmental Disabilities

This Is Your Right: Disability Advocacy with Humor, Part 1 & 2

Whose Decision Is It Anyway: Parents Prompting Self-Determination

A VideoGuide to Disability Awareness

Align Your Dreams With Your Power (Nancy Shugart)

Safe and Strong, Volume I

Synchrony Series

Understanding Human Rights

Understanding Individual Human Rights

Protecting Human Rights

Disability Culture Rap DVD

Abandoned To Their Fate: A History of Social Policy Toward People With Disabilities

The Freedom Tour

Self Determination: Enabling People to Make Choices

My Country: The Movement That Led to the Passage of the ADA

VHS Tapes and Box Sets

Sticks and Stones: Origins of the Self-Advocacy Movement in Minnesota

Tools for Change: Lasting Leadership, Popular Education and Self-Advocacy

Tools for Change: Shaking Off Stereotypes

Self-Determination: Tools for Direct Support Staff

Planning For the Future and Working With Families, Program IV

What Would You Do?, Program V

The New Jersey Self-Determination Process

NJUSA: Person 1st, Label 2nd

ADA, Part I

The Arc of Warren County: Introducing Self-Advocacy In School

Tools for Change: Self-Advocacy, Freedom, Equality and Justice For All

Autism and Law Enforcement

This Is YOUR Right: Disability Advocacy With Humor, Parts I & II

Planning For Life: The Role of Direct Support Professionals In Self-Directed Supports

Let's Talk About Health: What Every Woman Should Know

Self-Determination: Service Providers

NJTARP (Technology Assistive Resource Program): Making It Happen, English & Espanol

Step By Step: Understanding the Spiral Model of Organizing

My Choice, Your Decision

Toastmasters Communications: Be Prepared to Speak

A Life of Choices: Lois and Elaine's Story

Your Vote Counts (12 minutes)

Good Neighbors: NJDHS

The Arc: The Americans With Disabilities Act at Work, Parts I & II



The Principles & Practices of Building Community Series

Part I: Skills of Courtesy - Quality of Interaction

Part II: Age Appropriateness - Achieving Adult Status

Part III: Supported Routines - Best Practice Strategies for a Fulfilling Life

Part IV: Positive Behavioral Supports - Meeting Unmet Needs

Part V: Universal Language - It's All In How You Say It

Part VI: Instructional Strategies - Feat. Thomas Pomeranz

Part VII: Transition: From Consumer to Producer





For Your Group: Digital Resources

The Arc of New Jersey's Homepage: www.arcnj.org

New Jersey Self-Advocacy Project's Homepage:
www.njselfadvocacyproject.org

National Association of Councils on Developmental Disabilities: www.NACDD.org

Find Your State Senators: http://www.senate.gov/general/contact_information/senators_cfm.cfm

Excellent PowerPoint Presentation (Select "Open" or "Save" to view), courtesy of the Self-Advocate Coalition of Kansas: http://www.sackonline.org/uploads/The_Role_of_the_Advisor_Online.ppt#260,6,Empower

Florida Grassroots Self-Advocacy Group Development: <http://thechp.syr.edu/floridas/resources.htm>

American Association of People with Disabilities Homepage: www.aapd.com

Texas Project FIRST: <http://www.texasprojectfirst.org/SelfAdvocacy.html>

Human Service Research Institute (I/DD, Substance Abuse, Mental Health): www.hsri.org/

Universal Declaration of Human Rights, courtesy of the University of Minnesota: <https://www1.umn.edu/humanrts/instree/b1udhr.htm>

Museum of Disability History: http://www.museumofdisability.org/advocacy_self_1800s.asp

The Minnesota Governor's Council of Developmental Disabilities (Promoting Independence, Productivity, Self-Determination, Integration and Inclusion) : <http://www.mncdd.org/>

Yoga and Autism article: <http://www.wellsphere.com/weight-loss-article/yoga-s-benefits-for-autistic-children/808874>

Learning Disabilities Association of America's *Self-Advocacy In The Workplace* site:
<http://www.ldanatl.org/aboutld/adults/workplace/self-advocacy.asp>