

### Green Mountain Self-Advocates Handbook For Local Self-Advocacy Groups

2 Prospect Street, Suite 6 Montpelier, Vermont 05602

Phone: 1-800-564-9990

1-802-229-2600

www.gmsavt.org

email: info@gmsavt.org

### **ACKNOWLEDGEMENTS**

GMSA wishes to thank you for taking the time to learn more about self-advocacy. The fact that you are reading this handbook proves that you are one of the dedicated leaders to self-advocacy movement. The goal of the GMSA handbook is to support self-advocates to run their own groups.

If you follow the suggestions in this handbook, your self-advocacy group will run smoothly and efficiently. These methods have helped other local self-advocacy groups stay strong over the years. If you want help putting these suggestions into action call GMSA at 1-800-564-9990 and someone will be glad to work with you and your group.

We wish to thank Randy Lizotte and Lindsey Hescock from Speak Up! Addison County self-advocacy group for putting down in writing their experiences supporting a successful local group. Thanks to Kathy Kretz for spending countless hours editing, selecting just the right graphics and for formatting the handbook. Thanks to Ryan Whipple and Karen Topper who provided overall support in making sure GMSA finally finished this handbook.

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Green Mountain Self-Advocates (GMSA) is a statewide self-advocacy network run and operated by people with developmental disabilities. The GMSA board includes representatives from 22 local self-advocacy groups. The groups come together to listen to each other, make new friends, learn about people's rights and tell politicians and others why people with disabilities are important. Green Mountain Self-Advocates is building a movement for self-advocacy through public education and awareness, peer mentoring, support, advocacy and direct action.



### **HISTORY**

Green Mountain Self-Advocates is a statewide self-advocacy organization. In 1994, we grew out of a small self-advocacy group in Burlington. With the help of allies, they connected with other Vermont self-advocates to create a network. Together they started self-advocacy groups in Barre, Middlebury, Rutland and St. Albans. Today hundreds of self-advocates speak up for themselves as members of more than 20 local groups.



### **OUR MISSION**

The purpose of Green Mountain Self-Advocates is for people with developmental disabilities to take control over their own lives, make decisions, solve problems and speak for themselves. We educate and make the public aware of the strengths, rights, wants and needs of people with developmental disabilities. We help self-advocates by letting them say what they believe. We are building a movement for self-advocacy in Vermont through public education, peer mentoring and support, advocacy and direct action.



Green Mountain Self-Advocates GMSA
2 Prospect Street, Suite 6
Montpelier, Vermont 05602

1-800-564-9990 (Toll Free in VT) 1-802-229-2600

### E-mails:

- 1. Max Barrows max@gmsavt.org
- 2. Stirling Peebles stirling@gmsavt.org
- 3. Karen Topper topper@gmsavt.org

Like us on Facebook! www.facebook.com/pages/Green-Mountain-Self-Advocates

Watch us on YouTube!



### Join A Local Group!





### **GMSA BYLAWS**

When GMSA first started, a document was written that contains rules that were created by self-advocates. The GMSA Bylaws describe basic information about GMSA and how we go about our business. It's an important thing that all non-profit organizations have. Your local group doesn't need its own bylaws. It's a long, boring thing to read, but some people like to know more about them. Contact GMSA if you are interested in learning more or check out the copy of the GMSA Bylaws at the end of this Handbook.



### Self-advocacy is...



- Speaking up for yourself and helping others to speak up for themselves
- **●** Getting to know yourself, being proud and feeling good





- Getting to know the people around you, making friends
- Learning new things, solving problems, finding resources, making your case, negotiating for what you want





### Self-advocacy is...



- Making your own decisions and knowing your responsibilities
- Thinking of all the other movements and preserving your rights





- ♣Realizing you are not alone, that there are other people who are just like you
- ♣ Being part of your community





### Self-advocacy is teamwork....





- ② Listening to people's ideas and respecting their opinions
- NOT judging people because of
  the way they look or speak





- Meeting politicians and telling
  them like it is
- Spreading the word and getting others involved in selfadvocacy, especially teens.





Helping others become leaders, feeling
 the power

### HOW TO START A SELF-ADVOCACY GROUP





### **Recipe for Success**



### Ingredients:



- 1 or more motivated
  Self-Advocates
- 1 or more Allies to help





- √1 place to have your meeting
- Note: 1 written flyer that announces where and when your first meeting will be





1 or 2 people for people to contact if they have questions





1 person who will get a snack for the meeting

1 phone call to GMSA to share the exciting news



Combine the motivated people in a comfortable location, then stir gently until slightly lumpy.

Makes 8-10 servings.





### Proceed to check the recipe for the following details:



- Talk with the Ally who is helping You about what you think you need help with and what you can do on your own.
- Decide when your meetings will be (page 0)





- Pick a name for your group. First brainstorm a list of possible names. Think about it for awhile and then vote at your next meeting
- Learn about "Group Agreements" (page 13)





Make an agenda to follow (page 15)



- Talk about what you want to accomplish as a Group See Setting Goals (page 69)
- Decide when your group wants to have the Six Basic Workshops about Self-Advocacy. The workshops are taught by GMSA



- Get everyone's contact information before the end of the meeting
- Tell everyone to spread the word about your new group
- Encourage everyone to bring someone new to the next meeting

### RULES USED TO RUN MEETINGS THINGS TO REMEMBER



• Arrive on time





O Respect everybody around you

O Stay on schedule follow the agenda





O Have fun



### RULES USED TO RUN MEETINGS THINGS TO REMEMBER



O Teamwork don't do things alone!

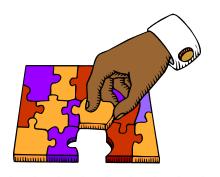






O Information: Get it. Share it!

O Everyone counts!





### RULES USED TO RUN MEETINGS THINGS TO REMEMBER

O Try to stay in the meeting until break time or the meeting is over





O Be flexible







Olt doesn't have to be "US vs. THEM" Work on issues together!

### WHAT TO DO WHEN OTHERS ARE TALKING?









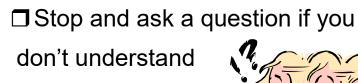
### WHAT TO DO WHEN OTHERS ARE TALKING?







☐ Listen to what others are saying





□ Don't interrupt the speaker



☐ Raise your hand and wait to be called on. Some groups elect a Sergeant at Arms to call on members, and avoid interruptions.



Respect others opinions

☐ Listen and consider others suggestions



### WHAT TO DO WHEN YOU ARE SPEAKING?





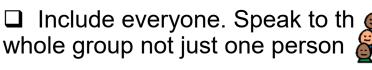
■ Be clear about what you want to say



Be sincere talk from the heart



☐ List the points you are making







- Offer suggestions about how the group can reach a decision
- Take only as much time as needed



### TIPS FOR HAVING SMOOTH RUNNING MEETINGS



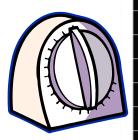


### TIPS FOR HAVING SMOOTH RUNNING MEETINGS



⊕ Set times on our agenda for each issue

©Set a timer at the beginning of each issue to remind us of how the time is passing. Some groups choose a member to be the time keeper





**%** Have regular breaks

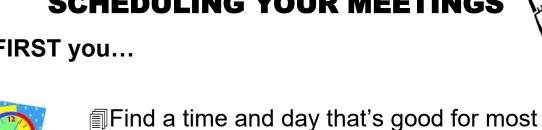


©Read or listen to the minutes and committee reports from the last meeting

### **SCHEDULING YOUR MEETINGS**

### **SCHEDULING YOUR MEETINGS**

FIRST you...



Find a time and day that's good for most self-advocates. Have your meeting on the same day and time of the week and month.

Find a place you can have your Meetings. For example: Library, Teen Center, Agency Church Hall, Town Hall. Make sure the place is convenient enough for member of the group

### THEN you...



Make a calendar every month. Include:

The name of your group



### **SCHEDULING YOUR MEETINGS**





A contact number if people have questions all the self-advocacy meetings



- GMSA Board of Directors meetings
- Special Events



Other items to include in your calendar...



- Holidays
- Some groups like to also find out when birthdays are and put them on the calendar, too.





After you write or type the calendar...

Hand the calendar out at least one week ahead of time. For example, if it's an October calendar, people will need to get it by about September 25th. This way people will have a full week to plan their schedule and transportation.

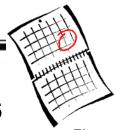


- Mail the calendars out to everyone who wasn't at the meeting.
- Give a copy of your calendar to your agency, so they can add it to their calendar.





Make sure all the staff in the agency will be getting a copy, so they can tell the people they support about the self-advocacy meetings and events.



### **SCHEDULING YOUR MEETINGS**

Once everyone has the calendar...



Stick to the calendar!

If you make a change, such as time or location you'll need to let EVERYONE know. So, be sure about what your plans are before you give every one copies of your calendar.

Be respectful of the space you have your meetings in. Leave it as clean as it was when you arrived. Better yet, show you appreciate being able to have your meetings there by leaving it cleaner than it was before your meeting!





### **GROUP AGREEMENTS**

When groups get together, they decide that they're going to come up with a list of rules that the entire group agrees to follow. We call these rules "group agreements" or "ground rules". In the workshops that teach people all about self-advocacy, these are the ones we use:

Raise your hand





■One person speaks at a time

■No put downs





### **GROUP AGREEMENTS**

■No question is a silly question



■It is OK to pass







■Give everyone a chance to speak.

Ask if there are any more agreements they would like to add.



### **GROUP AGREEMENTS**

Write up your group agreements on flip chart paper and bring to them each meeting

- ■Groups go over these rules at the beginning of every meeting. They make sure that everyone understands what they mean and still agrees with them.
- ■Some groups have had meetings and not used group agreements.

  They reported that the meetings ended up in chaos. They decided that it is important to follow the rules they had originally agreed to use.
- ⇒ If you have group agreements already, it's best to remind the group what they are.



An agenda is a list of the things that the group wants to talk about and or accomplish at the meeting. It's very important to have an agenda, so that the meeting stays on track.



Self-advocacy meetings always begin with people introducing themselves and going over the Group Agreements.



Sometimes, it's good to start out with a question of the day like: "What have you spoken up about?"



Usually, the agenda is made at the previous meeting, rather than at the beginning of the meeting. It's good to make the agenda ahead of time because:

- The group will know what they will be doing the next time they meet.
- It's easier for the Officers to be prepared for the meeting.
- You can get right to work, instead of needing to spend time figuring out what the group will be doing.
- You have all the time in between the meetings to add things to the agenda. It's easier to forget what you wanted to say if you're
   trying to come up with it at the last minute.



⊗After introductions and Group Agreements, it's a good time to ask if anyone has something they'd like to add to the agenda.

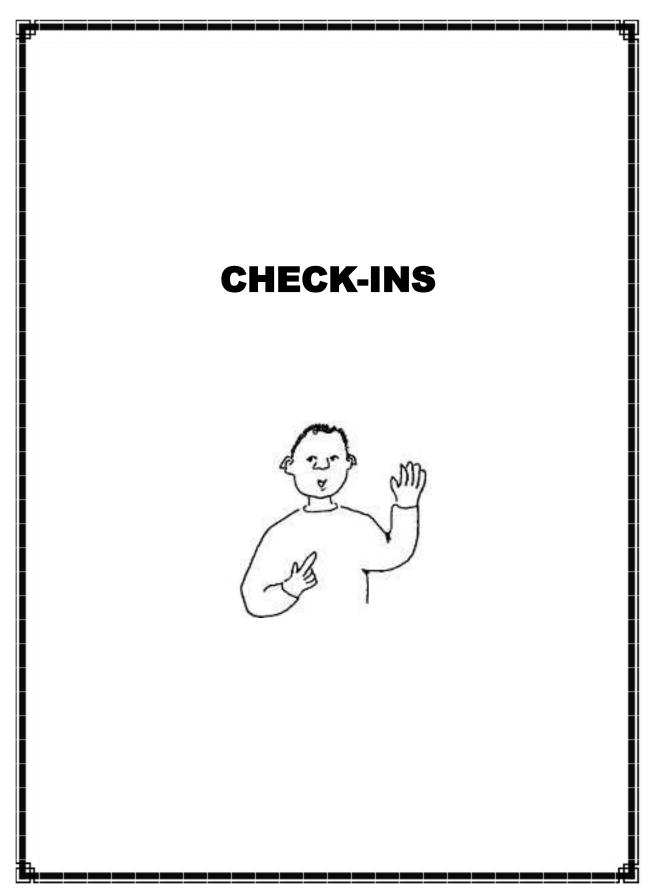




⊗It's also the perfect time to check-in with people to see how they've been and if anyone has anything they'd like to share.

⊗As the group gets bigger, it takes longer for everyone to get a chance to speak.
You might need to have longer meetings, or more than one meeting a month.
Longer meetings need breaks, at least one break per hour.









- ©A major goal of your group is to build positive relationships among members.
- ©Clearly, an important part of relationship building is being able to communicate effectively with others. Both to share your needs and opinions and being able to listen respectively to others.





- ©"Check-ins" are a good way to practice these communication skills each time you meet.
- ©A "check-in" is simply a time when each person has a chance to talk.







Points out the importance and value of each person.



⊕A person can also use this time to share that they are having a difficult time. You need to limit time for personal stories so you can keep the meeting on track.

This will alert others to be more sensitive and supportive.

©For new groups it can be helpful to provide a question or topic to reflect on.

### For example:

- 1. What is your dream job?
- 2. How does voting make you feel?
- 3. What was A+ or C- experience this week?



©Over time, as members become more familiar with each other, the "check-in" can become less structured.

©"Check-ins" give each person a chance to reflect on various aspects of their life. For example, this can be a time to share accomplishments that may otherwise go unnoticed.

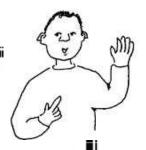


©An important benefit of "check-ins" is that it brings



up issues that many people may be struggling with. Sometimes a group will decide to work together to tackle one of the issues discussed. This helps the

group come up with possible goals to work on.





©Try to keep the entire "check-in" time to around 10 minutes. Each person talks for a short time. If your group meets more than once a month you can take turns checking-in.

©"Check-ins" are usually done at the beginning of a meeting.





©People should listen and not interrupt.
Cut them off if they start interrupting.

### May 1

### **CHECK-INS**

©If someone is shy and needs help remembering what to say it is better for a peer to help out instead of a staff person.



©A person should always have the option of "passing" during check-in if they do not want to share.







After the check-in, the group gets down to business, creating an agenda. It's up to each group to decide what they want to do. There should always be three kinds of things the group is planning and doing at their meetings:

Learning new things





Something you want to speak up about or ways to get involved in your community

Having fun socializing and supporting each other





Self-advocacy involves all **3** of these things! If you lose track of one or two, your group will be a little off-balance. So come up with what your goals are and work from there.

### At the end of each meeting, some groups will:



- Go over the main points of the meeting
- Ask for suggestions on how to make the meeting better



Make the next meeting's agenda
Make sure you include suggestions agenda
items





Then the meeting is adjourned





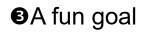
Self-advocacy groups should be talking about **3** goals at every meeting:

Something you want to learn





Something you want to speak up about or ways to get involved in your community





When you talk about goals your group needs to figure out:

♦How do you know if it's a realistic goal?

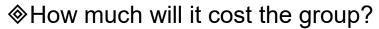


♦Do we have enough people to help?





Will people need to take time off from work?





Is someone else already doing the same thing?

♦What about the location?



And Most Importantly...

Is this how our group wants to spend their time and money?



If it is NOT realistic...

What can we do to make it realistic?

What can we do instead?

For example: The idea is to have a dance. Nobody in the group has ever organized a dance. Someone looks into the cost of a DJ and it's about \$300 (even at a discount). The group has about \$400 in their bank account. The local agency has dances twice a year. The group decides that they will offer the agency help to organize their dances. They hope to learn more about organizing a dance. Maybe they will be able to organize their own dance in the future.

If it IS realistic...



♦Who wants to help?

♦Where will it happen?





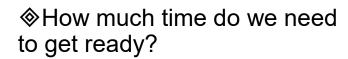
♦When will it take place?







♦When will we work on this?







♦Do we need extra help? From whom? Is it something GMSA might be able to help with?

♦Do we need to have a self-advocate volunteer to "take the lead" and be the main contact person?





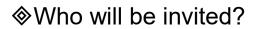
♦Do we have the supplies we need?





♦How much will it cost?

♦Do we need to raise money to do it?







♦ How will we let people know about this?

Do we need to hand out or mail people flyers?



# **BRAINSTORMING**



### **BRAINSTORMING**

How Do We Brainstorm?



- ☆ In brainstorming, each person is given 2 or 3 minutes to quietly think of ideas on their own or with a peer.
- ☆ Help each other to write all of your ideas on pieces of scratch paper or sticky notes.
- ☆ Next, go around the room in a round robin format and each person says one of their ideas. Keep going around the room until all ideas are shared.





☆ You can have a person write the ideas on a flip chart or have folks stick their ideas on the flip chart.





☆ During round robin members are encouraged to be creative and feel free to come up with "far out" ideas.

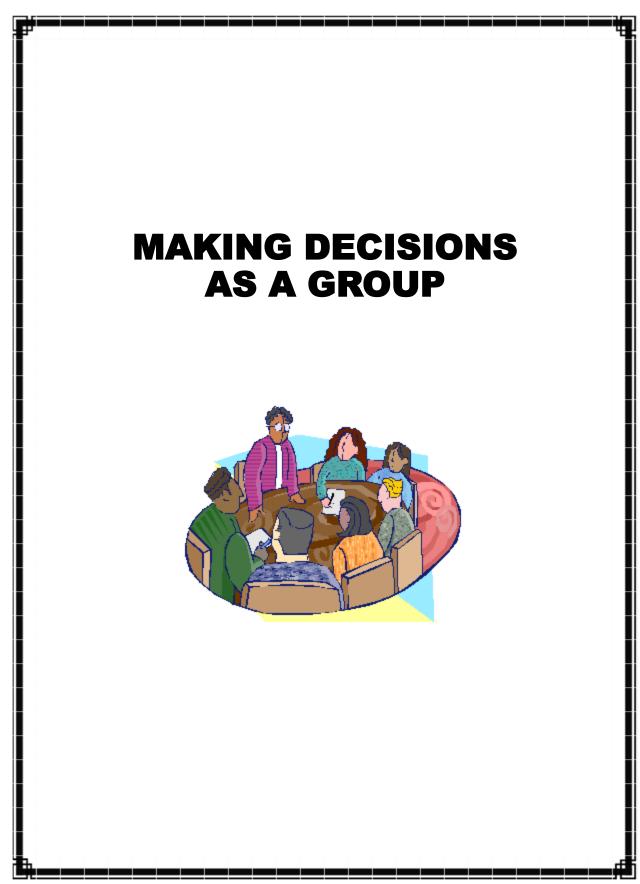


☆ Others are not allowed to make comments or judgments about the ideas presented.

☆ There is no discussion or rewording of ideas. Ideas are simply said and written.



- ☆ When all ideas are exhausted the group takes 2 or
  3 minutes of quiet time to see if any more ideas
  pop up. Sometimes several new ideas do pop up.
- ☆ Next, talk about ideas, reword and combine ideas, or create new ideas. If all agree, then cross out ideas. After discussion the group selects the best ideas for action.





### **MAKING DECISIONS AS A GROUP**

It's not always easy for the whole group to agree on something. All groups go through this. Here are some tips to help your self-advocacy group learn how to make decisions together:

- Have discussions that everyone gets to participate in.
- Make sure everybody is on the "same page" which means:



description of the descript



deliveryone understands what will happen if they choose one thing or the other



### **MAKING DECISIONS AS A GROUP**



<sup>™</sup> Use a flip chart paper to brainstorm a list of things to do or solutions to a problem.

### TRY THESE DIFFERENT WAYS TO VOTE

Each person votes or puts their name next to every idea they want to do. Vote as many times as you want. The idea that gets everyone's vote or almost everyone (minus one or two) wins.

or



Each member gets 5 stickers to vote with. You can put your stickers on anyway you want to. It's okay to put all 5 stickers on the same idea.

or

Divide the list of ideas into 3 separate lists. Everyone picks their favorite idea on each of the 3 lists. The items chosen most often become the group's list of greatest ideas.



### **MAKING DECISIONS AS A GROUP**

- Some groups also just ask people to raise their hands to vote on things. We do not suggest that you vote this way on important issues or when trying to solve a difficult problem.
- Think WIN WIN. Remember what you learned from the 7 Habits of Highly Effective People. Don't be in a hurry to just make a decision.
- Keep talking until you can come up with a solution that everyone can agree on. It may take more than one meeting. Maybe there's more information that can be shared. Sometimes having more information can change people's opinions and what they want to do.
- The goal is to find a solution that works for everyone.





### **COMMITTEES**

Some groups decide that they want to have committees.











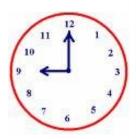
### **COMMITTEES**

### When would we consider forming a committee?



✓ Sometimes there are projects that a
few people are really interested in,
but the whole group only wants to
spend a little bit of time on it during
their meetings.

✓ Sometimes there's a project that's going to take a lot of time, but only certain people have the time to work on it.





### **COMMITTEES**

✓ Some committees that self-advocacy groups have had include:



✓ Dance Committee

**✗** Finance Committee





✓ National Conference Committee





✓ Voices and Choices Conference Committee





✓ Workshop Committee

### GETTING PEOPLE INVOLVED AND KEEPING PEOPLE INVOLVED





### GETTING PEOPLE INVOLVED AND KEEPING PEOPLE INVOLVED

### How do you get people involved?



♦ Invite people you know to a meeting.

♦ Offer workshops and events that anyone can attend.





♦ Tell your friends about it.

♦Tell your agency and local high schools about it.





### GETTING PEOPLE INVOLVED AND KEEPING PEOPLE INVOLVED

♦ Start a mailing list.





Make a calendar. Hand it out at your meetings. Mail it to everyone on your mailing list.

Make flyers about your meetings, workshops, and events. Make a handout or pamphlet about your group.





# GETTING PEOPLE INVOLVED AND KEEPING PEOPLE INVOLVED

# How do you keep people involved?

The group should vote on the best time to have meetings. Find a convenient place to have your meetings.





♦Do things that involve everyone, that everyone is interested in. Try new things from time-to-time.

♦ Think of ways that people can be a leader, like reading the Group Agreements, running a meeting or taking charge of a project or committee





# GETTING PEOPLE INVOLVED AND KEEPING PEOPLE INVOLVED

How do you keep people involved?



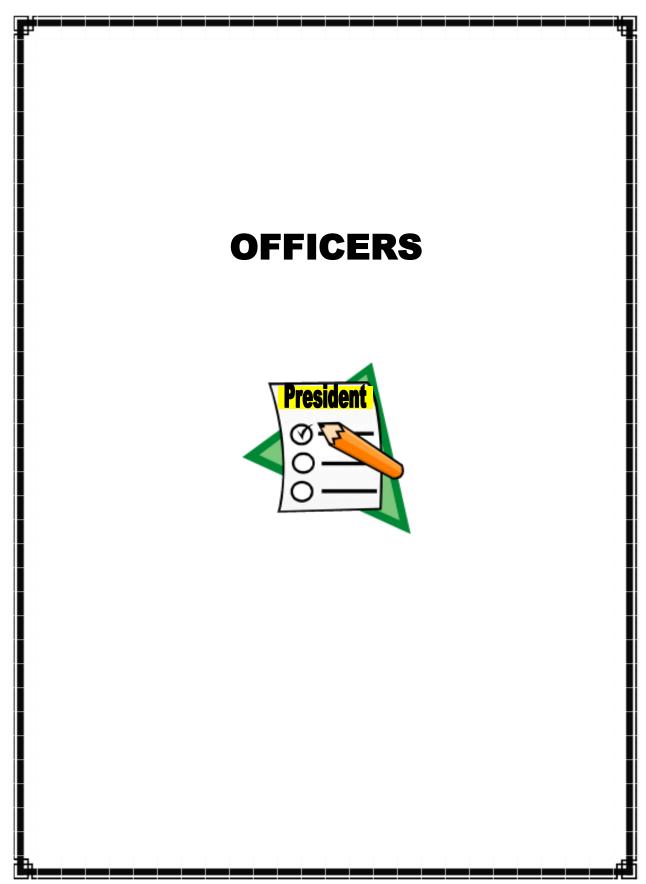
♦ Have a snack at your meetings.

♦Plan fun parts of your meeting.





♦Plan fun events.





Self-advocates nominate and elect people to lead their group. It's good for people to know what their role is at the meetings. The Officers are your leaders, to help the group do what they want to do. Members must talk about what they want to do and take an active role in the group. Members run their group and make decisions together.



# Election 'RR

#### **OFFICERS**

#### **PRESIDENT**

- Will run / lead meetings or ask for a volunteer to run the meeting. Must be willing to share the spotlight.
- Reach out to members who are shy and find something for them to do to get involved.
- 3. Show courage. Be willing to be completely honest and tell others how you see the situation.
- 4. Be willing to represent the group.
- 5. Help keep committees on track





#### **PRESIDENT**

6. Show consideration. Be willing to listen to and respect the other person's point of view.

- 7. Work with others to prepare the agenda, possibly at the Officer's meeting. Make sure it's done before the meeting.
- 8. Sign official documents.



# Hection 'RR

#### **OFFICERS**

#### **VICE-PRESIDENT**

- 1. Will do the work of the president if the president is absent.
- 2. Study the duties of the President so they know what to do if they need to fill in for the President.



- 3. Work closely with the President and other Officers to accomplish the goals of the group.
- 4. Contact people who are absent and support them to get involved.



5. Attend scheduled Officer's Meetings.

# Election 'RR

#### **OFFICERS**

#### **TREASURER**

- 1. Be on the Fundraising Committee.
- 2. Collect dues (if applicable).



3. Know how to keep track of a bank account (or be willing to learn).



- 4. Keep a record of all the money we earn and spend.
- 5. Give a monthly Treasurer's Report (account balance, what we've spent money on) at every meeting.
- 6. Attend scheduled Officer's Meetings.



7. Work with the other Officers to accomplish the group's goals.

# Election 'RR

#### **OFFICERS**

#### **SECRETARY**

- 1. Take attendance.
- 2. Write down or get help to write down all the decisions made during the



meeting.

- 3. Maintain the mailing list & phone number list
- 4. Distribute calendars and remind members to come to meetings
- 5. Work with others to create flyers, brochures, thank you cards and any other written messages for your group.



- 6. Attend scheduled Officer's Meetings
- 7. Work with the other Officers to accomplish the group's goal



## How do you choose good OFFICERS?

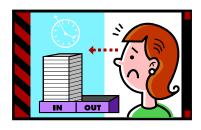
Choosing good officers is very important.

Self-advocates need to know what the Officers are supposed to do, so they can choose people who are qualified to do a good job.



Voting is not a popularity contest!

Officers have a lot of work to do!



Choose Officers who can make a commitment to the group for the entire year.





## There are 2 Kinds of Officer's

## One Kind:

☑Does everything themselves.





☑Makes members feel like they do things on their own.







☑When this kind of Officer leaves group, things fall apart because haven't learned to do things on their own.





### There are 2 Kinds of Officer's

## The Other Kind:



☑Teaches the members how to do things on their own and how to speak for themselves.





☑When this kind of Officer leaves the group, things keep going because people know how to do the work.



### **HAVING OFFICERS MEETINGS**

Once the group elects their officers, each officer must learn what their job is and how to do it. Some groups schedule "Officer Meetings" once a month or before each group meeting. The Advisor and the officers get organized during the Officer's Meeting by:

- Sharing information
- o creating an agenda
- giving each other feedback and encouragement





#### **LEADERSHIP AND OFFICERS**

What is "leadership"?

A. The boat Columbus sailed on when he found the New World.





B. Ordering people around so they do what you want them to do.

C. The name of Darth Vader's space station.





D. One person who does all the work.

#### This is a TRICK QUESTION!

None of these answers are correct!

We went online and saw that there are hundreds of ways that people describe leadership and qualities of a good leader. Here are some of the things we saw that we liked the best, in our own words...

# Election 'HR

#### **LEADERSHIP AND OFFICERS**

Leadership is...

- ◆ A person or persons chosen or elected to take charge of the group that chooses them.
   They help manage activities and help the group go in its chosen direction.
- ♦ Being optimistic. Believing in one person's ability to make a difference.
- Having the ability to encourage and nurture people to help them grow.
- Being a good role model.
- ✦ Following through with things.
  - Listening to what people say.
- ➤ Relating to what another person is going through or thinking, like the old saying "walk a mile in someone else's shoes".



# Election 'RR

#### **OFFICERS**

## What qualities do you look for in a good leader?



- Good leaders don't criticize and talk behind peoples' backs.
- ☑ Good leaders welcome new members.
- ☑ Good leaders can make a commitment.





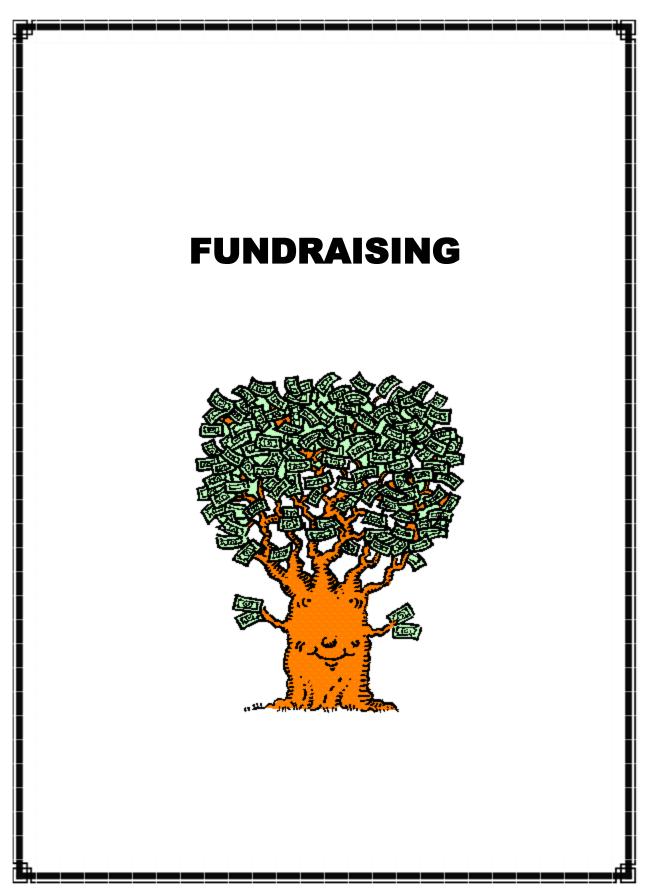
#### **LEADERSHIP AND OFFICERS**

#### A FEW MORE THINGS TO THINK ABOUT...

- People who have disabilities usually don't get the opportunity to use their leadership skills or learn how to be a leader in other parts of their life.
- Self-advocacy groups offer people many opportunities to be a leader.



- Your group advisor is there to help, but it's very important that the self-advocates are the ones "running the show".
- Whether you have leadership experience or this is the first time you've thought about it, anyone can learn how to be a strong leader.
- Contact GMSA to find out about the leadership training workshops they offer throughout the year.





# Things you should know to get started on your fundraiser ....



¤Know your mission statement!

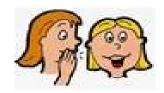
¤Clearly define the reason and goals for your fundraiser.





¤Be excited about your goals because the more you are, the more you will sell.

Spread the word. Tell everyone you know about your fundraiser.





# Listed are some *How To's* to make your fundraiser successful...



■Decide as a group which fundraiser you want to do.

■Each member should make a list of family & friends who may be interested in supporting your fundraiser.





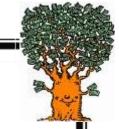
■Set a start date. For fundraisers that need the sun, schedule a backup date.

■Set a closing date. For fundraisers such as 50/50 raffles, coin drops, 2-3 weeks is about the right amount of time.



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- ■Assign tasks. Each member should have a job to do.
- ■Send thank you notes when appropriate.



The following are some fundraising ideas.....



■Bake Sales

**■**Bottle Drives





**□**Car Washes

**□**Coin Drops





More fundraising ideas.....







**□**Garage Sales

■Put on a dance *श* 



SELLPRODUCTS such as:



■Dutch Garden Flower Bulbs

■Current Gift Wrap

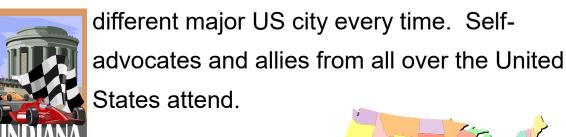




There are many special events for self-advocates and allies that happen in Vermont throughout the year.

- A Voices and Choices is a big conference that happens once per year in October.

  Hundreds of self-advocates come to learn new things in workshops, listen to speakers, and have fun meeting new people.
- ▲ The "SABE Conference" is an even bigger national conference that happens every two years. SABE stands for "Self-Advocates Becoming Empowered". The conference is in a





# **GMSA AND SPECIAL EVENTS**

GMSA also offers many training opportunities all year long.

- ▲6 Basic Self-Advocacy Workshops
- ▲ 7 Habits of Highly Effective People
- **▲** Voter Training
- ▲ Reaching My Own Greatness
- **▲** Staying Safe
- **▲**Our Bill of Rights
- ▲Know Your Legal Rights
- ▲ Speaking Up at the State House
- **▲** Officer and Board Member Training
- ▲ How To Start a Self-Advocacy Group
- ▲ Peer Sexuality Educator

Call the GMSA office at **1-800-564-9990** for information about these trainings.





#### The Advisor's Role

# **Tips On What To Do**

- ☆ Give advise to the group when asked
- ☆ Treating people with respect means being open to all the options we suggest
- ☆ Have creative ideas—think outside of the box
- ☆ Look at the person as a person not at their disability Focus on our strengths
- ☆ Feel comfortable with people with all different kinds
  of disabilities
- ☆ Believe that labels hurt us: mental retardation, client, consumer
- ☆ Talk to us like other people
- ☆ Help us get to meetings
- ☆ Show us how to make our own decisions—even if you do not agree.
- ☆ Encourage us to speak out for what we want to do
- ☆ Give and take criticism
- ☆ Encourage us to use our own words



#### The Advisor's Role

## More Tips On What To Do

- ☆ Go to all the meetings
- ☆ Be our equal not our boss
- ☆ Remind us about group agreements
- ☆ Listen
- ☆ Find ways to help everyone get involved
- ☆ Make sure everyone knows when and where the meetings are happening.

#### **PLEASE**

- ⊕ Don't run the group
- **② Don't have a closed mind**
- On't take over for the leader
- © Don't tell us what we should do
- © Don't make decisions without the members
- On't assume that everyone agrees
- On't talk too much
- © Don't do too much for us



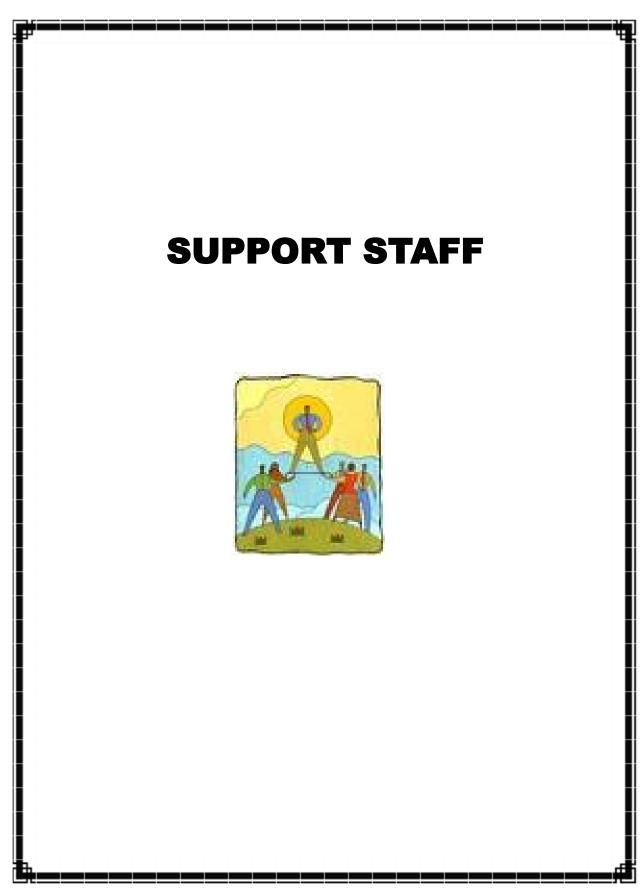
#### The Advisor's Role

One important role an advisor plays is to support the group to evaluate their meetings.

#### How Did It Go?

Take 5 minutes at the end of each meeting to talk about how the group is doing. Members comment on how they are interacting with each other and building a positive group spirit. There are many useful questions to get positive suggestions and comments.

- ☆ Did we follow our group agreements?
- ☆ Who talked the most?
- ☆ Did everyone have a chance to talk?
- ☆ Did we try to draw people out?
- ☆ Did those talking seem to be listening?
- ☆ Who shared information?
- ☆ Who gave support and encouragement?
- ☆ Did we get a lot of ideas before making a decisions





# **Support Staff Quiz**

Some Self-Advocates bring a Support Person with them to the meetings. The following is a quiz to help you better understand the role of the support person at a self-advocacy meeting.

- 1. What does a good support person do at the self-advocacy meeting?
  - A. Talk for the self-advocate
  - B. Tell the self-advocate and others in the group what they should do for activities
  - C. Talk on their cell phone outside of the meeting
  - D. None of the above



## **Support Staff Quiz**

- 2. How can the support person help the self-advocate?
  - A. Be ready to help if the self-advocate asks for help
  - B. If someone asks for help and it's something they can probably do by themselves, encourage them do it on their own
  - C. Help a person participate in the meeting
  - D. All of the above
- 3. What are some things that self-advocates have needed help with?
- A. Keeping track of the meeting schedule & things that the self-advocate has volunteered to do
  - B. Encourage self-advocate to participate in the meeting
- C. Getting a ride to and from the meetings
- D. All the above



# Cutting the Strings: Suggestions for Self Advocacy Groups

#### By Dave Hingsburger

Everyone around me was having fun. My mother applauded heartily and the other kids were laughing uncontrollably. The characters on the stage moved around with jerky motions. They had high voices, which said silly things.

Perhaps it was just that I couldn't suspend disbelief. Perhaps it was because I couldn't take my eyes off the people standing behind the stage. Whatever it was, I found the whole situation vaguely menacing and highly disturbing.

To this day, I hate puppet shows. I hate those who want to control my movements and tell me what to say. Moreover, I hate almost anything that comes with strings attached.

All this went through my head as I watched, with a gathering sense of gloom, a presentation done by self advocates at a large state conference. One by one they stood, with no animation in their voices, and trotted out a spiel, obviously scripted and practised.

"How moving," shouted one audience member. "How revolutionary," praised another. But for me, I couldn't take my eyes off the facilitator standing at the side giving small directions and encouragements-a puppeteer very much loving the limelight. Afterwards, as she stood in a rushing torrent of praise, she demurely said, "But this isn't about me."

Until the self advocacy movement began, people with developmental disabilities were the only minority not to lead their own movement. The self advocacy movement was to put an end to this inequity. Unfortunately, it didn't. It hasn't. It can't. Not the way things stand now.

I have been in the fortunate position to travel throughout North America lecturing and consulting on disability issues, taking every opportunity I can to meet



with self advocate groups and their facilitators. But watching what happens in many groups has caused me a growing sense of alarm. Groups are either wildly successful, well-meaning but unfocused (these die out fairly quickly), or they are under the control of facilitators who have not dealt with their own position of power and whose personal issues become the political issues for the group. The latter is the most concerning.

These groups demonstrate how people with disabilities are not free from control by the "betters who know better." From these observations I present a comparison between healthy and unhealthy self advocate groups.

#### **Disability Pride**

Disability is a defining condition, not a confining condition. One of the most amazing disability-oriented Web sites is Canadian. It's called "Disability Cool" and its message to all surfers is that it's cool to have a disability. This is shocking imagery and content for many. To identify as a person with a disability, to accept that disability is part of who you are, is the beginning of power. By this definition, the teens who developed this Web site are powerful.

Compare this to a movie put out by a Canadian self advocate organization wherein the lead spokesperson rails against having been labeled and speaks of others with disabilities in a patronizing manner-- not acceptable by even the greenest staff. So much emphasis has been put on the fact that "labeling is wrong" that many self-advocate organizations shrink from using the word "disability," let alone the word retardation.

Alternately, a proud woman with a disability recently gave a speech where she acknowledged her developmental disability, talked about being a victim of rape, and demanded that she be respected as a disabled woman and be listened to as a survivor of violence. Her outspoken, proud manner shocked people.

In New York City a man with a disability gave an incredible presentation at a self advocate meeting in which he referred to himself as "retarded" and talked about how society calls him names because he is "slow," names because he is "black," and names because he is "poor." "The only thing they don't call me is my own

name. That's cause they never even tried to learn it," he said. "But I know their names ... I know more than they do."



Both people come from vital self advocate groups where disability is on the agenda. Indeed, it is the agenda. Neither group is shamed by disability and both recognize that poor treatment is because of bigotry not because of personal attribute or blame.

Interestingly, disability deniers usually come from groups where the facilitator believes that "disability is irrelevant." Right! Tell a feminist that gender is irrelevant. Tell a black man that race is irrelevant. Tell a lesbian that sexual orientation is irrelevant. Disability-proud groups recognize that disability makes a difference--but that difference shouldn't lead to poor treatment, victimization, or discrimination. It's important for a woman with Down syndrome to be able to look in the mirror, actually see herself reflected back, and like what she sees. This is the birth of power.

#### **Minority politics**

Almost every minority has shucked off the idea of Normalization. This philosophy wasn't born here with people with disabilities. It was born the first time a black woman used powder to lighten her skin, the first time a gay man erased gender from his language when discussing his lover, the first time a woman slugged back a whiskey after work to be like the boys. And it has never worked. Aping the majority just reinforces its sense of power.

One of the hottest selling disability rights T-shirts is black with a message written in bright, bold letters: Piss on Pity. The idea that people with disabilities are a genuine minority, are genuinely oppressed, and are genuinely pissed off is smothered under the dictums of Normalization, a philosophy that says people with disabilities shouldn't gather in groups, a philosophy which ultimately cuts people with disabililities off from one another.

Consider for a moment the People First group in one state that successfully closed institutions through a court case. Or the People First group that staged an "in your face" action during a Memorial Day parade, which got them a lot of public attention. Or the couple with developmental disabilities, and their self advocate group,

who fought the court for the right to adopt.

Unlike the "Normalization groups" (led by well-meaning but disability denying facilitators) who, week after week, remain stuck on such issues as "being teased," each of these groups was successful because they identified as a minority and used minority politics to wild success.

#### The need for training

Skill-building has always been a critical part of self-help groups. A good example comes from the beginning of the women's movement when women first started gathering together in consciousness-raising groups. Women came together for support, but also to learn new skills and gain confidence in using those skills.

In unhealthy groups, the facilitator takes a back seat when it comes to teaching anything. There is an attitude that "disability doesn't matter." The idea that people may need help to learn meeting, planning, organizing, and leadership skills is somehow considered "demeaning." This approach, of course, leaves people with disabilities forever under the control of the facilitator. They will always need to rely, defer, and depend on a non-disabled person to "help" (lead) them in the group.

Withholding information, or denying training, is just another abuse of power. Recognizing that people with disabilities lack certain skills is not demeaning, but refusing to teach and train is.

In healthy groups, the facilitator recognizes a need for training and encouragement in an atmosphere that is non-threatening. Some training is provided for during each meeting--not in a standard lecture style but through an interactive learning approach involving practice, feedback, and lots of laughter. Most people learn better by doing than by hearing, and people with disabilities are no different. Many meetings falter and groups fade because people with disabilities come to meetings that are poorly planned and take so long to run that they become boring.

One organization actually has classes for self advocates on how to speak up, how to organize their thoughts when doing a presentation, how to work with media, how to chair a meeting. In another group, at least one fun and functional learning game is planned for each meeting. The facilitator, along with the group chair,

decides what goals to set for the group. From teaching about voting to chairing meetings, they learn it all. And often from each other. There is a self-advocate group right now planning to make a video about how to run a meeting, which is a good reminder that trainers can be people with disabilities themselves.

To acknowledge that a developmental disability is a severe learning disability isn't demeaning; it's liberating for everyone. As one self advocate put it, "Yeah, so I'm slow. Big deal." To refuse to acknowledge the disability is to keep it cloaked in shame and denial.

#### **Everyone speaks out**

In healthy groups, all people have opportunities to speak out. Every individual has a right to speak for themselves and for the group. Sharing the spotlight makes sure that a multitude of voices is heard.

One self advocate group sent a person who uses a picture board to an elementary school as part of the school's training on disabilities. The school was flummoxed, but when the individual got into the classroom with the kids, she spent all her time showing them her picture book and having conversations. The kids were fascinated to learn they could communicate with her through this board. In a letter to the self advocate group, the school said the kids learned more from the picture board than they would have from a standard "disability" talk. That self advocate group operates a very successful speaker's bureau and everyone who wants to, gets a chance to learn how to make a presentation and is then given an opportunity to present.

In unhealthy groups, a spokesperson is chosen more often than not by some "approving" body. This spokesperson then becomes elevated and in an odd way "blessed" by the powers that be. He or she is trained in what to say and how to say it, not by members of a group raising issues, but by people outside the group.

In healthy groups, the group develops its own philosophy and norms. People who speak, do so from positions developed within the group. Interference from "powerful others" is not welcome.

This is not to say that in some healthy groups there aren't natural leaders

A.

and speakers who take on more of these challenges. However, all people are given opportunities and all people participate in the message to be given.

#### **Process versus power**

He is terrified of her. He is supposed to be the chair of the group, but every word that is spoken is filtered through the facilitator. He feels like he is on trial every minute of his existence as group leader. He loves being the chair but fears her disapproval.

She presents herself as a "true advocate" for people with disabilities. She loves her role as a facilitator and loves standing beside the flip chart. She must be there every time he makes a speech, and therefore her schedule determines his schedule. She is in control. If there is such a thing as passive-aggressive, this is passive controlling.

It's hard to see at first. In healthy groups the facilitator does have a role: facilitation! Helping develop a process for decision-making, and then assisting individuals in making the process work, is a wonderful job. But it's difficult.

Keeping oneself out of power positions while assisting is an art. Clinicians spend years learning how to provide service without leading. Police take special training on how to ask questions without leading. Yet people who become facilitators are expected to naturally know how to assist without leading. It doesn't make sense.

Process-oriented people ask for help, for feedback, and are constantly monitoring their own positions within the group. Power-based individuals see feedback as threatening, and training as an unnecessary bother. Those with power abuse it-always.

Facilitators want to be oil that keeps the meeting moving. Power people want to be the engine that drives the meeting. The problem with Pinocchio wasn't that he was a puppet. It was that his desire to be a human child blinded him to the beauty of his own wood.