

SELF-ADVOCACY IN ACTION

A Guide to Member-Led Leadership, Choice, and Action

Purpose

A self-advocacy group is led by self-advocates.

It is a space where members come together to speak up, learn from one another, build leadership skills, make decisions, advocate for change, and take action on issues that are important to them.

Self-advocates determine the direction of the group. Members elect their leaders, identify priorities, develop meeting agendas, make decisions, plan activities, and decide what action the group will take.

Facilitators and other supporters are there to support access, not to lead the group. Their responsibility is to help ensure members have the information, accommodations, communication supports, and resources they request to participate fully.

The goal is for self-advocates to build and lead a successful self-advocacy group.

Guiding Principles

Nothing About Us Without Us

People with disabilities should have a meaningful voice in decisions, policies, programs, and services that affect their lives.

Self-Direction

Self-advocates decide what matters to the group, what they want to accomplish, and how they will work together.

Leadership

Self-advocates hold leadership positions and have real opportunities to lead meetings, committees, projects, advocacy efforts, and community activities.

Choice and Autonomy

Participation is voluntary. Members decide whether and how they want to participate. A person may speak, listen, communicate in another way, ask for support, take a break, disagree, or pass.

Equal Value

Every member's ideas, experiences, communication style, and contributions have value.

Communication Access

People communicate in different ways. The group should provide the time, tools, information, accommodations, and supports members need to participate.

Dignity of Risk

Self-advocates have the right to make choices, take reasonable risks, try new things, make mistakes, learn, and change their minds.

Supported Decision-Making

People should receive the information and support they want to make their own decisions rather than having decisions made for them.

Peer Support

Self-advocacy is strengthened when members learn from, encourage, and support one another.

Adult-to-Adult Respect

Self-advocates are adults and should be spoken to, included, and treated as adults.

A MEMBER-LED GROUP

Who Leads? Self-advocates do.

Whenever possible, the group should elect or select members to serve in leadership roles. Positions may include:

- President
- Vice President
- Secretary
- Treasurer
- Sergeant-at-Arms
- Committee Chairs
- Representatives or Delegates
- Other positions created by the group

The group decides which positions it needs and what responsibilities belong to each position.

Leadership should be meaningful. A self-advocate should not simply be given a title while a facilitator performs the responsibilities of the position.

Leaders may request support to carry out their responsibilities, but supporting someone to lead is different from leading for them.

Meeting Basics

Who Participates?

The group determines its membership, there is no required number.

Facilitators, support staff, interpreters, or other supporters may participate when their assistance is requested or needed for access.

When Do We Meet?

The group should choose a meeting schedule that works for its members. Meetings may be weekly, monthly, or follow another schedule selected by the group.

Consistency can help members plan and stay involved. Meetings of approximately 60 minutes may work well, but the group should determine the length that works best.

Where Do We Meet?

Meetings should take place in an accessible, comfortable setting where members can communicate and participate.

Members should also consider whether remote or hybrid participation would make the group more accessible.

How Do We Make Meetings Accessible?

Ask members what they need rather than assuming.

Communication and participation supports may include:

- Plain language
- Visual supports
- Large print
- Sign language or language interpretation
- Augmentative and alternative communication (AAC)
- Communication devices
- Written information
- Extra processing or response time
- Information provided before meetings
- Support understanding choices or complex information
- Breaks or quieter meeting spaces
- Remote participation
- Other reasonable accommodations requested by members

Accessibility is not something added after a meeting is planned. Access should be part of planning from the beginning.

BEFORE THE MEETING

Leadership Prepares the Agenda

The leadership team should take the lead in developing the meeting agenda.

Members can submit ideas, concerns, announcements, or topics they want discussed. The leadership team decides how those items will be organized for the meeting.

A facilitator may assist if asked with typing, formatting, printing, communication access, or gathering requested information, but the agenda should reflect the priorities of the self-advocates—not the facilitator's priorities.

Whenever possible, distribute the agenda before the meeting in accessible formats so members have time to review it.

MEMBER-LED MEETING FLOW

1. Welcome

The President or another designated self-advocate opens the meeting and welcomes members.

Members can identify any accommodations or supports they need to participate.

2. Call the Meeting to Order

The President or designated leader officially begins the meeting.

3. Leadership Reports

Officers carry out the responsibilities assigned to their positions.

For example:

- The President leads the meeting.
- The Vice President assists and leads when the President is unavailable.
- The Secretary reviews minutes and records decisions.
- The Treasurer provides financial information when applicable.
- Committee Chairs report on projects or activities.

The group may define these responsibilities differently.

4. Review Previous Business

Members review unfinished items, commitments, or decisions from the previous meeting.

The question should be:

What did we decide to do, and what happened?

5. Discuss New Business

Members introduce and discuss new topics.

Leadership helps make sure members have opportunities to communicate, ask questions, disagree respectfully, and hear different viewpoints.

6. Make Decisions

The group determines how decisions will be made. Depending on the group's rules, this might include:

- Discussion and agreement
- Consensus
- Voting
- Another process selected by members

Members should receive understandable information about their choices before important decisions are made.

7. Take Action

Self-advocacy is more than talking about an issue.

For each action item, determine:

What are we going to do?
Who wants to do it?
What support, if any, is needed?
When will it be completed?
When will we check on our progress?

8. Close the Meeting

Leadership reviews important decisions, action items, and the next meeting date.
The President or designated leader adjourns the meeting.

THE FACILITATOR'S ROLE

A facilitator is a support to the group, not the leader of the group.

Facilitators help remove barriers so self-advocates can participate and lead as independently as possible.

A facilitator should:

- Ask before providing help whenever possible.
- Find out what type of support a person wants.
- Provide information in accessible and understandable ways.
- Allow enough time for members to process information and communicate.
- Support the group's elected leaders in carrying out their responsibilities.
- Help members access requested accommodations and communication supports.
- Direct questions and decisions back to self-advocates.
- Encourage members to communicate with one another rather than automatically looking to the facilitator.
- Present options without pushing members toward a preferred decision.
- Respect privacy, boundaries, consent, and individual communication methods.
- Avoid speaking for a self-advocate unless the person has asked for that assistance.
- Support members in connecting with community resources when requested.

A Helpful Question for Facilitators

Before stepping in, ask:

- "Is my help needed for access, or am I doing something the self-advocates could be doing themselves?"

The goal should always be to provide the amount of support requested or needed, not the greatest amount of support possible.

LANGUAGE THAT SUPPORTS LEADERSHIP

Instead of directing the group, facilitators can use questions that return authority to self-advocates:

- "What does the group think?"
- "What would you like to do?"
- "What options do you see?"
- "Who would like to take the lead on this?"
- "Would you like support? What kind of support would be helpful?"
- "How would the group like to decide?"
- "Who else would like to share their perspective?"
- "What information would help you make this decision?"
- "This is your group's decision."

GROUP CODE OF CONDUCT

Self-advocates should develop their own group Code of Conduct rather than having rules created for them. The group can review its agreements regularly and change them when members believe something is no longer working.

Examples the group may consider include:

- We treat one another with respect.
- Different opinions are welcome.
- Different communication styles are welcome.
- Everyone should have an opportunity to participate.
- It is okay to disagree.
- Members may choose to pass or not speak.
- Members may take breaks when needed.
- We ask before giving personal assistance or touching another person.
- We respect privacy and personal boundaries.
- Personal information is not shared outside the group without permission, except when disclosure is required for safety or by law.
- We listen to one another.
- We address problems without attacking people.
- We make decisions together using the process selected by the group.

These are examples only. The members decide their Code of Conduct.

WHEN CHALLENGES COME UP

When the Group Is Quiet

Silence does not necessarily mean something is wrong. Some people need additional time to think, process information, or prepare a response.

Leadership can ask:

- "Would more time help?"
- "Would anyone like to write, point, use a device, talk with someone first, or pass?"

If members want more structure, the group can decide to use prompts, discussion questions, small groups, or another method.

When Everyone Looks to the Facilitator

The facilitator should return the conversation to the members.

For example:

"That's a decision for the group. What do you think?"

Members should become accustomed to looking to **one another and their elected leadership**, rather than the facilitator, for the direction of the group.

When One Person Is Talking Much More Than Others

The goal is not to embarrass or silence anyone.

Leadership can remind the group that everyone should have an opportunity to participate and ask members how they want to handle turn-taking.

The group might choose a speaker list, time limits, a talking object, raised hands, communication cards, or another accessible method.

When Someone Says the Group Is Boring or Wants to Leave

Listen to the feedback.

Ask what the person would like to see changed and what would make the group more meaningful to them.

Participation in self-advocacy should be a **choice**, not an expectation or requirement.

When Members Disagree

Disagreement is a normal part of leadership and advocacy.

Members can:

1. Identify the issue.
2. Make sure everyone understands the different viewpoints.
3. Ask questions.
4. Listen to one another.
5. Identify possible solutions.
6. Use the group's decision-making process.

A facilitator should intervene more directly when necessary for immediate safety, while otherwise supporting members to work through disagreements themselves.

When a Decision Has Risks or Consequences

Self-advocates should receive clear and unbiased information about available options, including possible benefits, risks, consequences, and alternatives.

Support should help the person make their own informed decision, not replace their decision.

A person's disability does not eliminate their right to make choices, take reasonable risks, learn from experience, or change their mind.

BUILDING STRONGER LEADERSHIP

Starting a New Group

- Early meetings may focus on:
- Getting to know one another
- Understanding self-advocacy
- Identifying communication preferences
- Creating group Code of Conduct
- Learning about leadership positions
- Identifying issues members care about
- Choosing or electing leaders
- Deciding how meetings will operate

A successful self-advocacy group does not need to look like a corporate board meeting.

Success means members have meaningful opportunities to participate, make choices, lead, and take action.

As the Group Grows

Self-advocates can take on increasing responsibility for:

- Leading meetings
- Preparing agendas
- Taking minutes
- Managing group funds
- Speaking at public meetings
- Meeting with community leaders
- Participating in conferences
- Educating others

- Serving on committees
- Planning events
- Inviting guest speakers
- Contacting community organizations
- Learning about disability rights
- Advocating for changes in services or policies
- Mentoring new self-advocates
- Connecting with local, regional, and statewide self-advocacy organizations

The facilitator's role should become less visible as member leadership grows.

TOPICS SELF-ADVOCATES MAY CHOOSE TO EXPLORE

The members decide what matters to them. Topics might include:

- Disability rights and responsibilities
- Self-determination
- Supported decision-making
- Employment and career goals
- Education
- Transportation
- Housing
- Health care
- Friendships and relationships
- Voting and civic participation
- Speaking up during meetings and service planning
- Safety and personal boundaries
- Consent
- Privacy
- Money management
- Community inclusion and accessibility
- Leadership development
- Public speaking
- Community service
- Changing unfair policies or practices
- Connecting with other self-advocates

CHECKING PROGRESS

Self-advocates should have opportunities to evaluate their own group.

Questions members might ask include:

- Are we discussing things that matter to us?
- Are self-advocates making the important decisions?
- Do members feel comfortable sharing different opinions?
- Can everyone participate in a way that works for them?
- Are our elected leaders actually leading?
- Are we taking action on the things we discuss?
- Are we becoming more connected to our community?
- Are members developing new leadership skills?
- What should we do differently?
- What support do we want from our facilitator?

A CHECK FOR FACILITATORS

Facilitators should also regularly examine whether their support is strengthening or unintentionally replacing self-advocate leadership.

After a meeting, consider:

- Did self-advocates lead the meeting?
- Did members make important decisions?
- Did I ask before helping?

- Did I provide access without taking control?
- Did I allow enough time for people to communicate?
- Did I explain options without steering the decision?
- Did I speak directly to self-advocates as adults?
- Did members communicate with one another, or did everything go through me?
- What leadership did self-advocates demonstrate today?
- What support did members ask for?
- What can I do less of next time so self-advocates can do more?

SELF-ADVOCACY MEANS ACTION

Self-advocacy is not a program that professionals provide to people with disabilities. It is people with disabilities speaking for themselves, making choices, developing leadership, supporting one another, and working for change.

Strong self-advocacy groups create opportunities for people to have real authority and real responsibility. Self-advocates should have access to understandable information, effective communication supports, meaningful choices, leadership opportunities, and connections to their communities.

Facilitators and supporters have an important role, but that role is to make participation and leadership more accessible, not to take the lead.

The measure of a strong self-advocacy group is not how well the facilitator runs the meeting. It is how much self-advocates are leading it.

Their voices. Their choices. Their leadership. Their group.