



Consumer Involvement In Advocacy Organizations: Action Index in Developmental Disabilities

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PART I

ETIQUETTE OF CONSUMER INVOLVEMENT

Consumer groups exist to promote a broad set of values in their communities. Among the many values consumer involvement groups share are such principles as fairness, equal opportunity, independence, community integration, social acceptance, safety, dignity, and consumer control.

Issues involve the application of these principles in everyday situations. For example, a policy change can have positive or negative effects on the principle of community integration. The general goals of a group are to support positive changes, prevent negative changes, and develop new ways to promote these principles. But the approach your group takes can make a big difference on its success. This lesson describes 10 guidelines that have led other groups to success.

The type of projects your group chooses will contribute to its reputation in the community. Since your group is likely to address many issues over a long time period, its reputation is a vital key to success. The following guidelines have emerged as characteristic of many successful advocacy organizations. This list is not complete. But it can serve as a basis for healthy community involvement.

ACCENTUATE THE POSITIVE. Respond to at least as many positive events as negative ones by complimenting and acknowledging positive actions. It's an easy thing to do, and it will win you friends and build your reputation as being reasonable. Constructive involvement can serve as the basis for many successful projects.

BEGIN BY ASSUMING THE BEST OF OTHERS. Challenging the motivations of other people often produces needless resistance. Assuming a negative act is the result of ignorance or inattention creates opportunities to teach and learn. A corollary to this

argument is to give credit freely for good decisions. Acknowledging the wisdom and vision of others who support you is likely to increase their commitment to your goals.

DO YOUR HOMEWORK AND DOCUMENT EVERYTHING. If your group takes a position or initiates an action based on an error in fact, you stand a very good chance of being embarrassed. Such embarrassment can damage a hard-won reputation. A significant error in fact can also direct attention away from your issues, no matter how important they are. Thus, the first step in developing a position or a project should always involve confirming your information. In addition, you should document everything you do and what others tell you. Documentation protects you from denials and counter-chargers.

TAKE THE HIGH GROUND. When you take a position on an issue, always highlight the general values or principles you are promoting, such as independence, dignity, or safety. The importance of these values and principles is hard for anyone to deny. They serve as a firm basis for agreement on general community goals. They help prevent personality conflicts stemming from disagreements over details of solutions. And finally, positive values lend an air of eloquence to your position that will impress almost everyone.

TAKE A BROAD PERSPECTIVE. Although a consumer group is usually too small to act on every relevant issue, it is wise to spread your attention across different issue types. Various issues are likely to share similarities. A group that focuses only on employment issues will have a narrow appeal to some members and to the public. Addressing different types of issues like housing, insurance, and public education broadens your appeal and generates more opportunities for involvement of potential participants. Pursuing different issues probably increase your chances for success, too.

PLAN MANY SMALL SUCCESSES. Groups are more likely to grow over time, if they have many small successes. One way to facilitate success and growth is to have many small projects rather than one major one. Many successful efforts over time will build the

competency and reputation of the group so that it can take advantage of major opportunities when they arise.

BEGIN WITH THE SIMPLEST STEP. If an issue is personally important, members may want an immediate and strong response. This approach can seriously restrict your options and those of others who might support you. Radical actions should not be used until less intrusive alternatives have been tried without success.

BE PREPARED TO FOLLOW THROUGH. Once you have begun to address an issue, be prepared to follow through with the actions that might be required to complete it. This means you should be ready to acknowledge responsiveness, attend meetings, compromise, or escalate your approach if there is no response. When a situation becomes intolerable, do not avoid conflict at all cost. If you don't follow through on your efforts, others will or may ignore you in the future.

BE REASONABLE. Developing a quality community requires cooperation and compromise among groups with competing interests. Public support is almost always on the side of those who are the most reasonable in their approach and demands. Action that offends interested parties--especially the public--decreases the chances for cooperation and success.

BE PREPARED TO ACCEPT SUCCESS. Success might best be viewed as progress toward an ideal rather than capitulation by the enemy. You should advocate for your own proposals, but you should also keep an open mind about alternatives and compromises offered by others. They, too, have legitimate goals and need control over their situations. Moreover, their knowledge about systems you may not understand might lead to greater success than you imagined. A mutually acceptable solution to a problem is a success for everyone. Your willingness to help others win will contribute to a strong group reputation.

Review Questions

Fill in the blanks. Check your answers with those in the answer key on the following page.

1. Advocacy groups exist, in part, to promote a broad set of values in their community, including such principles as fairness, equal opportunity, independence, community integration, social acceptance, safety, well being, dignity, and consumer control. What values and principles do you feel your group should promote?

_____	_____
_____	_____
_____	_____
_____	_____

2. The general goals of a group are to support _____ changes, prevent negative changes, and develop new ways of enhancing its values.
3. A good reputation is a key to _____.
4. Accentuate the _____. Respond to at least as many positive events as negative ones.
5. Take the _____ ground by referring to the general values and principles you believe are involved in an issue.
6. Plan many small _____.
7. Begin with the _____ step.
8. Begin by assuming the _____ of others.

Answer Key

1. There are no right or wrong answers. You will have to consider each issue carefully and examine your beliefs in relation to it.
2. positive
3. success
4. positive
5. high
6. wins
7. simplest
8. best

PART II

Project Planning Guide

Deciding how to act on an issue involves a complex and creative process. Members must balance the importance of an issue and the values they wish to promote with the potential consequences of a broad range of possible options. The Project Planning Guide is designed to help you make these important judgments. It consists of the Issue/Goal chart, the Goal/Action chart, and 38 project outlines.

The Issue/Goal chart presented on the next page, groups issue types into four general situations. Each situation suggests, in turn, one or more general goals for group action. The Goal/Action Chart groups 38 generic action projects under the goal for which they are most appropriate. These actions are listed roughly in order of least to most complex and intrusive. Finally, each of the 38 action projects summarizes the action, its objective, the resources required to implement it, and a list of some of the potential benefits and costs of taking such action.

To use the Guide, review the Issue/Goals Chart to determine which type of issue your group faces and its goal.

ISSUE/GOAL CHART

SITUATION/ISSUE TYPES

GENERAL GOALS

Positive changes in service, policy, or budget allocation; and potentially beneficial proposals.



Support, encourage, increase, maintain, facilitate, honor.

Rumors, complex issues, incomplete or confusing information.



Investigate, study document, clarify.

Unmet needs.



Create or develop new options, programs, or services; improve.

Negative changes in service, policy, or budget conditions; and potentially harmful proposals; unresponsiveness; offensive language or action; discrimination.



Avoid or prevent negative conditions; oppose, stop, decrease, eliminate, reverse.

GOAL/ACTION CHART

if your goal is to:

then you could:

1. **Support, increase, encourage, maintain, protect, honor, facilitate, aid, assist,**

2. **Personally compliment favorable action**
3. **Organize an award/celebration ceremony**
4. **Provide public support**
5. **Volunteer to help**
13. **Request participation**
16. **Remind those responsible**
22. **Conduct a fund-raising activity**
23. **Sponsor a conference**
24. **Offer public education**
25. **Develop consensus between groups**
26. **Build a coalition**
28. **Seek enforcement of existing laws, policies or ordinances**
29. **Seek the enactment of new laws, policies, regulations, or ordinances**
31. **Conduct a petition drive**
32. **Conduct a letter-writing campaign**
36. **Organize public demonstration**

GOAL/ACTION CHART

if your goal is to:

2. Clarify, analyze, understand, study, learn, explore, investigate, probe, review,

5. Volunteer to help
6. Document evidence of a complaint
8. Establish a formal communication mechanism
9. Request formal justification
11. Gather more information
12. Prepare a fact sheet to distribute information about your group on the issue
13. Request participation
14. Watchdog decision process
20. Conduct a study
23. Sponsor a community conference
25. Develop a consensus between groups
26. Build a coalition
30. Organize consumer service audits

then you could:

GOAL/ACTION CHART

if your goal is to:

then you could:

3. **Develop new programs or services;
improve existing programs or services;
innovate;
start;
build;**

2. **Personally compliment favorable action**
4. **Provide public support**
5. **Volunteer to help**
8. **Establish a formal communication mechanism**
11. **Gather more information**
12. **Prepare a fact sheet to distribute information about your group or the issue**
13. **Request participation**
14. **Watchdog decision process**
15. **Provide corrective feedback**
16. **Remind those responsible**
17. **Make an informal complaint**
18. **Seek a mediator or negotiator**
19. **File a formal complaint**
20. **Conduct a study**
21. **Develop a proposal**
22. **Conduct a fund raising activity**
23. **Sponsor a community conference**
25. **Develop a consensus between groups**
26. **Build a coalition**
28. **Seek enforcement of existing laws, policies or ordinances**
29. **Seek enactment of new laws, policies or ordinances**
30. **Organize consumer service audits**
31. **Conduct a petition drive**
32. **Conduct a letter writing campaign**

GOAL/ACTION CHART

If your goal is to:

then you could:

**4. Oppose;
stop;
reverse;
decrease;
eliminate;
avoid or prevent;
escape;
resist;
attack**

- 1. Postpone action**
- 7. Personally criticize unfavorable action**
- 9. Request formal justification**
- 10. Express opposition publicly**
- 12. Prepare a fact sheet to distribute information about your group or the issue**
- 16. Remind those responsible**
- 17. Make an informal complaint**
- 18. Seek a mediator or negotiator**
- 19. File a formal complaint**
- 23. Sponsor a community conference or public hearing**
- 24. Offer public education**
- 25. Develop a consensus between groups**
- 26. Build a coalition**
- 27. Initiate a legal action**
- 28. Seek enforcement of existing laws, policies or ordinances**
- 29. Seek enactment of new laws, policies or ordinances**
- 31. Conduct a petition drive**
- 32. Conduct a letter writing campaign**
- 33. Flood the system**
- 34. Media expose**
- 35. Organize passive resistance**
- 36. Organize public demonstrations**
- 37. Organize a boycott**

Once you have identified the type of goal you would like your group to pursue with an issue, you should review the **GOAL/ACTION CHART**. There are four of these charts according to the 4 main types of goals. Each chart provides a list of actions that could be taken to pursue a given goal. The first step in the planning process is to make a list of potential actions. Once you have the list, then you should review each potential action and consider its objectives, resources required, potential benefits, and costs of taking such action. This information will help you decide which actions you want to recommend your group to follow. After discussing the likely success of various actions, group members can select which actions are most compatible with the group's goals and resources in the particular situation. In most cases, you might want to list what actions your group is going to take first, second, and so on.

For example, your group might be concerned about the failure of some local school officials to facilitate inclusion for children with severe disabilities. After reviewing the **Issue/Goal Chart**, group members might classify this issue as an unmet need. The goal of the group in this situation might be to select one school as a target and try to work with school officials to develop inclusion opportunities for children attending that school. (Note that we try to focus group efforts on just one school, while we develop the experience and expertise to deal with other schools latter). The Goal/Action Chart # 3 lists 24 possible responses to this situation, ranging from personally complimenting favorable action (#2), to establishing an alternative program (#38). From these options, the group might choose first to establish a formal communication mechanism with school officials and other parents involved; second, to gather more information (#11) about the extend of the problem locally and the number of children that are affected by the situation; third, to remind school officials of their responsibility (#16) in order to make them aware of the situation and the rights of the children and their families; fourth, to seek a mediator or negotiator (# 18) in order to widen the support for your issue and increase your visibility; fifth,

to make an informal complaint (#17) and ask school officials for action on the issue; sixth, to develop a proposal (#21) to school officials about an approach that would satisfy the parents' and children's needs; seventh, to file a formal complaint (#19) in case no action is accomplished with the previous step; and eighth, to seek enforcement of existing laws regarding inclusion of children with disabilities (#28).

This planning guide provides an opportunity for all group members to contribute in the planning process. Having a plan helps group members understand their roles and their commitments to a given cause. It also serves to attract other people who might want to help your group once they learn about your plans.

ACTION INDEX

1. POSTPONE ACTION. This involves taking no public action on an issue and waiting to see what happens.

OBJECTIVE: To avoid negative consequences that might result from taking some action prematurely or without adequate resources.

RESOURCES REQUIRED: One or more members willing to track the development of the issue.

Potential benefits

- The situation may get better without having to do anything.
- Someone else might take action you could support.

Potential costs

- The situation may get worse
- Similar things may happen in the future.
- Others will not know how to consider your needs.
- The situation may gain wider acceptance as time passes.
- Silence on an issue may be seen as acceptance and even tacit agreement.

CASE: A group of parents of children with developmental disabilities fear that a recent consolidation of elementary schools in their county may result in less mainstreaming. They wait until they meet with school administration to clarify their suspicions before they begin to take action.

2. PERSONALLY COMPLIMENT FAVORABLE ACTION. This involves personally calling or writing a letter to the individual(s) responsible for some favorable action and thanking them.

OBJECTIVE: To increase the chances that similar action will be taken in the future or to ensure that the particular action will continue.

RESOURCES REQUIRED: A volunteer to write a letter and the chairperson's time to review and approve it. A phone call will take very little time and effort.

Potential benefits

- Visibility for your group.
- Good public relations.
- Increased probability that the same people will take similar action in the future.
- Starts a history of involvement that facilitates future actions by your group.
- Helps ensure that the action will continue.

Potential Costs

- None except the time it takes.

CASE: A group of People First members sent a letter to a local corporation thanking them for initiating a supportive employment work program and thus increasing the employment opportunities for people with disabilities in their community.

3. ORGANIZE AN AWARD/CELEBRATION CEREMONY. This is a way to honor and recognize those that support your cause with the establishment of an award ceremony. This activity might become an annual event and gain publicity and respect for your organization.

OBJECTIVE: To honor those community members and even group members that have distinguished themselves for their support of your cause.

RESOURCES: A number of volunteers will be required to help prepare the award ceremony. Some money will be required to pay for the awards. Additional costs might be added if you have a banquet. You might have to sale tickets to finance the event.

Potential benefits

- Increased visibility in the community.
- Good positive image in the public eye.
- This might become a local tradition.
- You can have some exposure in the local media.
- This is a fun activity for group members.
- Good opportunity to honor and recognize the efforts of your own members.

Potential costs

- Lots of time and effort in planning and preparing the ceremony.
- Money to pay for the awards.
- Only few people might be interested in your activity.

CASE: To recognize the efforts of state representatives who supported the development of family support programs, a community services organization held an award ceremony.

4. PROVIDE PUBLIC SUPPORT. This is similar to complimenting favorable action but is implemented by sending letters to editors of newspapers and to public officials (e.g., city commissioners) who have broad authority to respond to issues. In such letters, your group should express its support for an action and the reasons behind your support.

OBJECTIVE: To increase the chances that an action will occur or continue.

RESOURCES REQUIRED: A volunteer to draft a letter representing the views of your group. The chairperson's time to review and approve it. Someone to type, copy, and mail the letter.

Potential benefits

- Visibility for your group.
- Public education about the goals of your group.
- Increases the chances that your group will be invited to participate in decision making.

Potential costs

- You may offend those who are opposed to the action.
- Time and effort involved in preparing the letter.

CASE: Members of People First deliver hundreds of letters of support to their local senator to thank her for supporting the American for Disabilities Act.

5. VOLUNTEER TO HELP OTHERS. This involves offering individually or as a group to help others complete some project or provide some service.

OBJECTIVE: To help achieve a worthy goal and to build good will with other groups in the community.

RESOURCES REQUIRED: Members of your group willing and able to commit some time to work on the project with others.

Potential benefits

- Good will with other groups.
- Reputation of cooperation in the community.
- Resources for help when you need a favor.

Potential costs

- The time required to help others may of your group.

CASE: The National Association for Down Syndrome (NADS) sends a parent of a young child with Down Syndrome to the hospital to talk to the new mother and father of an infant with this disability. This volunteer often helps these new parents talk about their feelings regarding having a child with a disability.

6. DOCUMENT EVIDENCE OF A COMPLAINT. This involves collecting relevant documents such as policy statements, interviewing participants or witnesses, and otherwise gathering information to establish the facts in a complaint.

OBJECTIVE: To provide a firm basis for initiating some action and to avoid being embarrassed because a group member has misunderstood or misinterpreted information. In general, you should be sure of the facts before taking any other action.

RESOURCES REQUIRED: One or more volunteers to follow-up an issue report to document details. This may entail looking through documents or taking notes during interviews.

Potential benefits

- The act of contacting someone to document the facts in a complaint is often enough to resolve a problem.
- Documenting evidence protects you from later denials.

Potential costs

- The time required to verify information.

CASE: A local parent advocacy group gathers data on per capita expenditures for community services programming in other states in the country to support their complaint of inadequate funding in their state.

7. PERSONALLY CRITICIZE UNFAVORABLE ACTION. This involves personally contacting or writing a letter to the individual(s) responsible for an action considered unfavorable, telling why your group doesn't like it, and suggesting how the situation might be corrected.

OBJECTIVE: To modify the action taken so that it is more to your liking and to decrease the chances similar action will be taken again.

RESOURCES REQUIRED: A volunteer to draft a letter, the chairperson's time to review and approve it, volunteers to type and mail it; someone willing to schedule and attend a meeting to present the complaint.

Potential benefits

- Possible modifications in the action taken.
- Education of those responsible.
- Increased credibility for your group.
- Basis for further actions.

Potential costs

- Disagreements and arguments.
- Denial.
- Retribution.

CASE: A group of family members and people with disabilities visit their local legislator to state their discontent with his lack of support for a recent bill that would have established a statewide system of independent case management.

8. ESTABLISH A FORMAL COMMUNICATION MECHANISM. This involves establishing a regular and frequent meeting schedule or other way of routinely checking information with a particular agency that significantly affects your members.

OBJECTIVE: To provide an easy and personal way to influence policy and practices of an agency and avoid public conflicts by resolving disagreements privately.

RESOURCES REQUIRED: A volunteer willing to attend meetings at the target agency and a schedule for the meetings. The cooperation of the agency might make this process easier, but it is not required since board meetings are usually open meetings. In some cases exchanges of minutes of meetings and/or newsletters might be sufficient.

Potential benefits

- Helps develop a working relationship with agency staff.
- Might help avoiding complaints caused by misunderstandings.

Potential costs

- You may become less assertive in your demands, so as to not to jeopardize the personal relation you've developed.
- The time required to attend meetings.
- The transportation cost for getting people to attend the meetings.

CASE: The Illinois Planning Council for Developmental Disabilities invites the leaders of the developmental disability advocacy groups in Illinois to join a statewide advocacy coordinating committee. This committee helps the various advocacy groups coordinate their lobbying efforts, share advocacy resources, and discuss advocacy issues.

9. REQUEST FORMAL JUSTIFICATION. This involves writing a letter requesting a person responsible for a decision to provide a justification, in writing or orally, for making the decision.

OBJECTIVE: To create an opportunity to comment on previously unknown criteria for decision making (i.e., to make an issue out of the justification).

RESOURCES REQUIRED: A volunteer to write a letter. Chairperson's time to review and approve it. Willingness to follow up by commenting on the justification received. You might have to escalate the pressure--by taking additional actions--if you don't get any response.

Potential benefits

- Educate decision-makers to the criteria they use. They may not fully understand all the consequences of their decisions.
- Opportunity to comment and change the criteria.
- Making criteria explicit occasionally leads to a re-negotiation of a decision.
- May help establish evidence for further formal efforts.

Potential costs

- Requires additional work from decision-makers that might be resented.
- Denial of request may create a conflict situation.

CASE: A parent of a child with a disability writes a letter to the school principal requesting justification for the removal of one of the two teacher aid in her son's special education class.

10. EXPRESS OPPOSITION PUBLICLY. This involves publicly stating the opposition of your group to some action through letters to editors of newspapers, in testimony at public hearings, and in letters to decision makers.

OBJECTIVE: The goal is to decrease the chances that a proposed action will occur or to increase the chances that a current condition will be changed.

RESOURCES REQUIRED: One or more volunteers to draft letters or to provide testimony for the group. The chairperson's time to review the comments. Volunteers to type and mail letters. One or more volunteers to present personal testimony.

Potential benefits

- Possible modifications in the proposal or conditions.
- Visibility for your group.
- Public education about the goals of your group.
- Increases the chances that your group will be invited to participate in decision-making.
- Provides a history of involvement of your group in this type of issue.

Potential costs

- You may offend those who support an issue.
- If you haven't done many positive activities, your group could get a reputation for being negative. This could reduce your effectiveness in the long run.

CASE: The chair of the Coalition for Citizens with Disabilities writes a letter to the editor of a local newspaper to complain about the lack of accessible transportation in the city.

11. GATHER MORE INFORMATION. This involves contacting by phone or in person those responsible for the action and asking them to clarify the point(s) you don't understand. Alternatively, it may involve reviewing records and documents.

OBJECTIVE: To gather information that will help you determine what kind of issue is involved and whether it is relevant to you.

RESOURCES REQUIRED: A clear statement of the information to be collected and those who may be able to provide it. One or more volunteers to collect and report the information. You might need access to libraries or to records kept by different agencies. It might also cost you some money to get copies of relevant documents.

Potential benefits

- Information will help you clarify the issue, consider its relevance, and decide whether you should take additional action.
- Helps avoid embarrassment that would result from taking inappropriate action.

Potential costs

- Delays response to possibly important issues.
- Time involved in collecting data.
- Sometimes you might need money to pay for copies of documents.

CASE: A group of concerned family members interviews the staff and clients at a local group home to investigate allegations of client neglect.

12. PREPARE A FACT SHEET TO DISTRIBUTE INFORMATION ABOUT YOUR GROUP OR

THE ISSUE. This involves developing a clear list of statements that describe either your goals or refers to some relevant aspects of the issue at hand.

OBJECTIVE: To increase community members' awareness of the issue or about the existence and purpose of your organization.

RESOURCES: You will need a committee of group members that prepare the fact sheet. You will also need funds to print the fliers, and volunteers to distribute them.

Potential benefits

- Greater visibility for your group.
- You might attract new interested people.
- The fliers could be easily distributed to many people.

Potential costs

- Money required for printing fliers.
- Time for planning and preparing the fact sheet.
- Some people might react negatively after reading the fact sheet.
- In some cities you might be cited for littering.

CASE: Confronted with opposition from community members regarding the development of group homes in their neighborhood, a local service provider develops and distributes a fact sheet which outlines the positive aspects of community living for people with disabilities.

13. REQUEST PARTICIPATION. This involves asking the responsible parties to allow one or more of your group members to participate in the planning sessions of a project.

OBJECTIVE: To influence decisions on the details of a proposal so you can shape the final decision to your liking.

RESOURCES REQUIRED: A volunteer to contact, in person or by phone, those people who can give permission to participate. One or more members willing to attend various meetings. The person(s) should be knowledgeable about the topic or willing to learn. Participant should also be aware of the position of your group in relation to the issue and be willing to make progress reports back to the group. If your request is denied, you might have to escalate your actions.

Potential benefits

- Members of your group who act as representatives will gain valuable experience and contacts.
- The final decision may be one that is more acceptable and more beneficial to your group than the one that may have resulted without your participation.
- Increases your chances of being asked to participate in the future.
- Establishes your group's credibility.

Potential costs

- Your request may be denied, so you might have to plan additional actions.
- The opinions of your representatives may be ignored.
- Effective participation may require a great deal of time and energy.

CASE: A group of family members with children about to age out of the school system asks the Department of Rehabilitation Services (DORS) to involve some of its members in a committee that DORS developed to identify how DORS could better serve the vocational needs of young adults with disabilities.

14. WATCHDOG DECISION PROCESS. This involves sending group members to meetings of other organizations when they are discussing issues of importance to you. This differs from routinely sending a monitor to a group.

OBJECTIVE: To increase the sensitivity of the other organization's members to your group.

RESOURCES REQUIRED: Information about scheduled meetings of the target organization. One or more members willing to attend meetings and observe without making public comments.

Potential benefits

- Greater information.
- Increased sensitivity to the interests of your group.

Potential costs

- Suspicion of your intentions.
- Time and money required to attend those meetings.

CASE: The United Cerebral Palsy Association closely monitors the proposed legislation in each state that could affect the lives of its members. Members are frequently sent to legislative hearings to observe the development of the issues.

15. PROVIDE CORRECTIVE FEEDBACK. This involves writing a letter or personally contacting those responsible for the use of offensive language or action, explaining why it is offensive to your group, and providing instructions and examples on how they can correct their errors.

OBJECTIVE: To correct misconceptions concerning your group and its members, and to teach people, such as newspaper reporters, the proper way they should refer to your group or its members.

RESOURCES REQUIRED: A clear understanding of the offensive nature of the comment or action. A clear understanding of the desired alternative. One or more volunteers to write the letter or make the presentation for the group.

Potential benefits

- Public education.
- Public awareness.
- Opportunities for members of the group to become involved in making some important but often easy changes.

Potential costs

- Your feedback may be ignored.
- May embarrass the target of your your group, its members, or continue to be offensive but less publicly.

CASE: A group of concerned persons with disabilities write a letter to their local newspapers to complain about their usage of terms such as "the retarded" and "the handicapped". They ask, instead, that the newspaper remember that all individuals are people first, and that they use terms that signify this, such as "a person with mental retardation".

16. REMIND THOSE RESPONSIBLE. This involves contacting someone who has failed to perform a duty, respond to a suggestion by your group, or come through on a promise within the agreed upon time. You must remind them of their obligation.

OBJECTIVE: To elicit a formal response and to increase the chances that the person will take appropriate action.

RESOURCES REQUIRED: A promise from the person to do some favor or acknowledge that he or she has a responsibility to take an action. An agreement on what is to be done and a timeline for acting. A reasonable delay in completing the action. A volunteer willing to phone or write a letter to the person responsible and remind him or her of their promise or responsibility. If your request is ignored, you might have to escalate your actions.

Potential benefits

- Gives those you are dealing with the benefit of the doubt.
- Gives you a reputation for reasonableness.
- The person may have forgotten. Reminding them is one way of getting the job done.
- The person may have run into problems in taking the agreed action and might be able to use your help in some way.
- Reminding someone of their responsibility gives you a basis for taking stronger action.

Potential costs

- Delays action by some time.
- The responsible person may ignore your request.

CASE: A local community service provider asks the family members of its clients to contact the Director of the Department of Mental Health and complain about the ending of funding for the Community Integrated Living Arrangements (CILA) programs, a program that the Department of Mental Health promised would be continued into the late 1990's.

17. MAKE AN INFORMAL COMPLAINT. This involves directly contacting the individual(s) responsible for an action and/or their supervisor, explaining why you believe an action is a violation of some agreement, policy, or law, and describing the change you would like to see.

OBJECTIVE: To rectify some clearly improper action without starting a public fight or without exposing/jeopardizing individuals.

RESOURCES REQUIRED: One or more members who will discuss the details of the complaint and clarify the interests of the group. One or more members willing to schedule a meeting and present the complaint.

Potential benefits

- Helps avoid embarrassing public complaints.
- Gives your group a reputation for reasonableness.
- May achieve a resolution of a complaint without the extensive work required by more formal complaints.
- May resolve a dispute faster.

Potential costs

- Conflict over facts.
- Denial of complaint or remedy.

CASE: The members of a local People First Chapter contact the Executive Director of the sheltered workshop where most of them worked to complain about the restricted access to meeting rooms for their group.

18. SEEK A MEDIATOR OR NEGOTIATOR. This involves asking a respected person not connected with your group to help resolve a problem you have with some other agency or organization.

OBJECTIVE: To resolve a disagreement without increasing the risks and costs to the parties involved.

RESOURCES REQUIRED: A clearly stated complaint. A demonstrated/documentated effort to resolve the dispute in some other, less intrusive manner. A respected person willing to act as a mediator. Volunteers willing to help the mediator collect information and discuss the issue with the other party.

Potential benefits

- A witness to your reasonable effort.
- A witness to unreasonable actions of others.
- Resolution of conflict outside of formal channels.

Potential costs

- Delays in resolving the dispute.
- The right person may be difficult to find.

CASE: A parent that is just starting school for her child with disabilities comes to the first IERP meeting accompanied by an experienced parent who has attended many such meetings at the school.

19. FILE A FORMAL COMPLAINT. This involves filing a formal, written complaint with an administrative body which has authority to resolve disputes or with those in a position of authority who can rectify the actions of subordinates.

OBJECTIVE: To rectify a clearly improper action when those responsible have been unresponsive to more reasonable efforts. A second, important goal is to increase the responsiveness of those responsible to future requests by your group.

RESOURCES REQUIRED: One or more persons who have suffered from a law, policy, or procedure willing to act as the complainant. Documented evidence of the action and resulting suffering. A volunteer to prepare the complaint and evidence in writing. An advocate with experience in formal (i.e., administrative) procedures willing to act on the case--such advocates might exist within your group or may be found through other organizations such as Legal Aid.

Potential benefits

- Fair hearing of grievances.
- Improvement in conditions.
- Public record of findings.
- Accentuates the seriousness of the complaint.
- Allows you to follow formal grievance procedures.

Potential costs

- Efforts required to document your case.
- Angry respondents and confrontation with the unresponsive parties.
- Denial of request or case.
- Retribution.
- Delays in reaching a resolution that can tax your energy and resolve.
- If the conclusion of the case is not satisfactory you may have to try legal action in the end.

CASE: A person in a wheelchair files a complaint with the Equal Employment Opportunity Commission because where she worked lacks accessible bathrooms. In her written complaint, she cited recent legislative rulings (ADA) that requires organizations to adapt their buildings to accommodate people with disabilities.

20. CONDUCT A STUDY. This involves forming a study committee to carefully review the facts and history of an issue, document the existence of a problem, analyze the situation, and develop recommendations for action by your group or others.

OBJECTIVE: To increase understanding of a complicated situation and develop options for action from which you and others might choose.

RESOURCES REQUIRED: Three or more volunteers from your group willing to organize and coordinate the study. Access to sources of information. A clear statement about the purpose of the study and the intended audience of its results. Participants in a study group from other organizations, as appropriate.

Potential benefits

- Gives your group a reputation for considered action.
- Provides a firm basis for public education and other actions.
- Increases your understanding of the issue and contributes to the resolve of your group in addressing the issue.
- Gives you an opportunity to include a number of members of your group in an important task.

Potential costs

- May delay important action.
- If the project becomes large, your group may lose control of it.
- It may be time consuming.
- It might require some expertise that members of the group lack.

CASE: To help determine the need for residences for persons with disabilities in your city, your group conducts a study to determine the number of adults with developmental disabilities currently living at home with elderly parents.

21. DEVELOP A PROPOSAL. This involves preparing a written document that describes the methods and procedures you or others who are responsible can use to address a problem, the resources needed to implement the method, and who is responsible for taking actions needed.

OBJECTIVE: To provide a workable alternative--where none existed before--for improving services or meeting needs you have identified.

RESOURCES REQUIRED: Developing a proposal usually requires the results of a study that recommends the action by carefully documenting its need. Two or three members of your group to organize and do the work. Collaboration from other organizations, where appropriate.

Potential benefits

- Opportunities for group members to participate in project and gain important experiences and contacts.
- Visibility for your group.
- Presenting a clear, well developed proposal requires others to carefully consider your perspective.

Potential costs

- May require expanding your group to include other organizations or types of individuals which could result in a dilution of your group's specific objectives.
- Lots of time and hard work.

CASE: The Illinois Planning Council for Developmental Disabilities submits a legislative proposal to the Department of Mental Health to enact a family support cash subsidy program in Illinois.

22. CONDUCT A FUND RAISING ACTIVITY. A large number of activities could be conducted to raise funds for the group. This involves the careful planning and implementation of an activity with the purpose of generating revenues for the group.

OBJECTIVE: To conduct an activity that would generate funds for the group.

RESOURCES: Depends on the type of activity selected. Some fund raising activities like bake sales or raffles require volunteer participation of as many members as possible. Raffles usually require the group to make an investment in a service or good to be raffled, unless you get a donation.

Potential benefits

- Having some money to fund group activities gives the group flexible options.
- Increased visibility in the community.

Potential costs

- Lots of time and effort.
- Some fund raising activities generate very little income compared with the effort involved.
- Fund raising might detract members from focusing on the issues.

CASE: A local service provider holds an annual theater benefit to help finance respite services for families with children with developmental disabilities.

23. SPONSOR A COMMUNITY CONFERENCE OR PUBLIC HEARING. This involves finding an accessible public meeting place that can be used by the group and preparing a program with speakers or discussants to deal with your issue.

OBJECTIVE: To increase community awareness about your group and its goals. To promote open discussion of the various implications to all community members of your campaign.

RESOURCES REQUIRED: An accessible meeting place, a number of volunteers to help prepare the meeting and publicize the event in the community. You might need one or more people willing to speak at your meeting. You might also require some funds to pay for using the meeting place.

Potential benefits

- Increased awareness of your group goals.
- You might be able to recruit some new members.
- Increased visibility in the community.
- Open dialogue of the issues at hand.
- If you are able to recruit a well known person to speak at your meeting, you might get additional attention in the media.

Potential costs

- Time and effort involved in preparing the event.
- You might draw individuals who want to disrupt the meeting if they strongly oppose your cause.
- You might get little turnout.

CASE: To address the shortage of supportive employment programs in their community, a local self-advocacy group organizes a conference for local business owners, state legislators, and service providers on the benefits of supportive employment.

24. OFFER PUBLIC EDUCATION. This involves implementing an organized plan over a course of time to provide important information to the general public through the media and presentations to community groups.

OBJECTIVE: To make the general public and important decision makers more responsive to your needs, programs, and proposals.

RESOURCES REQUIRED: A reasonable understanding of what you want to communicate to the public. Three or more volunteers to develop a plan. The willingness of all of the members of your group to carry-out a number of educational activities.

Potential benefits

- Public awareness and acceptance.
- Opportunities for members of your group to gain exposure in public settings.
- Opportunities for members of your group to gain valuable experiences.

Potential costs

- Requires careful planning.
- Effects may not be easily observed.
- Lots of time and effort.

CASE: People First of Illinois sends members to area high schools where they help the high school students examine their attitudes toward people with disabilities during special classroom presentations.

25. DEVELOP A CONSENSUS BETWEEN GROUPS. This involves bringing representatives of differing viewpoints together to discuss an issue and try to reach agreement on how to address it.

OBJECTIVE: The goal of this response is to develop common agreement on an issue that is not well understood or where there has been little cooperation in the past, so that efforts might be organized to address it.

RESOURCES REQUIRED: One to three volunteers to organize a discussion of an issue between interested parties.

Potential benefits

- Recognition of your group as a skilled organization.
- Visibility for your group.
- Increased ability to accomplish a difficult task.
- Resolved differences between groups and greater amount of common ground.
- Your group might be able to recruit new support.

Potential costs

- A considerable amount of work.
- Often difficult to forge a consensus on an issue, and there may be some arguments along the way.
- There may be legitimate differences that can not be reconciled, and extended discussions can accentuate them.

CASE: A local Independent Living Center brings together family members, persons with disabilities, and human service professionals to discuss their differing opinions regarding how services are and should be provided. The Center attempts to help these three groups develop a common advocacy agenda.

26. BUILD A COALITION. This involves establishing cooperative arrangement with other organizations to work on some project.

OBJECTIVE: To expand the resources available to work on difficult issues.

RESOURCES REQUIRED: An issue affecting you and other organizations or a proposal that could benefit you and others. Several members willing to organize a meeting between interested parties.

Potential benefits

- Increased ability to accomplish a difficult task.
- Establishes a reputation for cooperation on important community issues.
- Your position gets broader support.

Potential costs

- May require compromising some of the specific objectives of your group to the common objectives of the coalition.
- Quite a bit of work in meetings to plan mutually agreeable actions.
- Building the coalition is just the first step. Then, you have to invest time and energy implementing its plan.

CASE: Several service providers and disability advocacy groups formed a coalition to propose to the Illinois Department of Mental Health the development of independent case management services in Illinois.

27. INITIATE LEGAL ACTION. This involves retaining legal counsel (i.e., a lawyer) for advice on how to proceed in filing legal action.

OBJECTIVE: To rectify some condition, receive compensation for unjust treatment, or establish a binding rule that will govern the actions of others in similar situations in the future.

RESOURCES REQUIRED: One or more individuals who have suffered some harm willing to act as the complainants. A lawyer willing to take the case. Time in searching for the lawyer who will take the case at a cost you can afford-- sometimes free legal counsel can be retained but it might be difficult to find. Time in preparing the case with the lawyer and appearing at various hearings.

Potential benefits

- Simply contacting a lawyer and beginning legal action may make those responsible for the offensive action more flexible in order to avoid a costly, time consuming legal action.
- A legal resolution is binding on all parties.
- Justice is often served.
- A precedent may be set.

Potential costs

- Legal action can be costly if you can't get free legal assistance, or if a lawyer is not willing to take the case on some percentage of settlement basis.
- There may be repeated delays in reaching a resolution that can drain your energy and resolution.
- The legal action can distract you from conducting other important business.
- Legal action may require a great deal of time from a few members.

CASE: Law suits are filed on behalf of parents seeking the placement of their school-age children with developmental disabilities into the least restrictive educational environment.

28. SEEK ENFORCEMENT OF EXISTING LAWS, POLICIES OR ORDINANCES. This involves identifying those who are responsible (at the highest level) for enforcing a law that does not appear to be enforced well enough and contacting them to propose and negotiate better enforcement procedures.

OBJECTIVE: To improve the conditions the law is designed to create or maintain, secure the rights specified for those protected by the law.

RESOURCES REQUIRED: A copy of the written law or rule. Evidence that the condition covered by the law or rule has not improved. Evidence that the law or rule has not been strictly enforced. Information about the person to contact. Volunteers to schedule a meeting with the key policy-maker/administrators and to discuss changes in enforcement.

Potential benefits

- Laws are rarely enforced strictly. It is likely that the key persons will respond to a complaint with at least a crackdown for a temporary period and this might improve the situation for some time.
- Laws enacted should be enforced, or citizens will lose respect for all laws.

Potential costs

- Your complaint may be rejected or action on it may be insufficient.
- Even enforced laws don't always succeed.

CASE: The Coalition for Citizens with Disabilities contacts the board of the Chicago Public Transit Authority (CTA's) to complain about the CTA's failure to comply with federal regulations regarding the accessibility of subway stations.

29. SEEK THE ENACTMENT OF NEW LAWS, POLICIES, REGULATIONS, OR ORDINANCES. This involves drafting and proposing new rules to those with authority to adopt them and require their implementation.

OBJECTIVE: To establish a rule that governs the actions of a large number of people in a manner that is favorable to your group.

RESOURCES REQUIRED: Documentation of the existence and status of a problem condition. Evidence that other efforts have been attempted but have failed or that there is no other more appropriate approach. A draft of a law that you want passed. Evidence of its acceptability to as many constituencies as you can get. Demonstration of your efforts to involve others in the development of the draft law. A decision maker willing to introduce your proposal and support it. Constituents willing to support it by writing letters to officials, editors of newspapers, and providing personal testimony at public hearings. Good will within the community. A willing coordinator.

Potential benefits

- The rule will affect a large number of people.
- Your efforts to pass the law will generate publicity for your group.
- Efforts to pass laws often improve conditions through public awareness they create, even when the law proposed is not passed or is weaker than desired.

Potential costs

- Enacting legislation requires a great deal of time and effort.
- Controversial proposals may generate strong opposition and resentment by some.

CASE: A group of advocates lobbies the Department of Mental Health to require every organization that receives its funding to include at least one person with a disability and one family member on its Board of Directors.

30. ORGANIZE CONSUMER SERVICE AUDITS. This involves groups of consumers of various services systematically reviewing the quality and usefulness of services they receive and providing both positive and corrective feedback to service providers.

OBJECTIVE: To use the strength and knowledge of the group to improve and maintain quality services.

RESOURCES REQUIRED: Several group members who receive services from other agencies frequently. A regularly scheduled meeting to assess agency service.

Potential benefits

- Visibility for your group and good will from those receiving positive feedback.
- Improvement or maintenance of quality services without the risks to individuals who may attempt to advocate for quality services individually.
- Invitations by some service providers to provide training to staff.
- A firm base of involvement in consumer affairs.
- Information about the quality of services in town that may be shared with other consumers.

Potential costs

- Resentment of your group by service providers who receive bad marks.
- It may be time consuming.
- Service providers may disregard your audit.
- Service providers might refuse or reduce services to group members.

CASE: The Illinois Planning Council for Developmental Disabilities organizes a team of persons with disabilities and family members to visit and evaluate the group homes in Illinois. These evaluations are then shared with the relevant service providers and the group home residents and their families.

31. **CONDUCT A PETITION DRIVE.** This involves preparing a statement of conditions your group wants to bring about and getting a large number of citizens in your community to affirm their agreement with the statement by signing their name to a petition.

OBJECTIVE: To demonstrate the extent of community support for or opposition to an issue. Facilitate public awareness about an issue.

RESOURCES REQUIRED: One or more volunteers to draft the affirmative statement. Time during a group meetings to review and approve the petition. Several volunteers to type, copy, circulate, and return the petitions. One or more volunteers willing to present the completed petitions to the press and relevant decision makers.

Potential benefits

- Even attacks on the credibility of the signatures generate public awareness.
- Broad support for the issue.
- Visibility for your group.
- Increased community awareness about the issue.

Potential costs

- There is no guarantee that the petition is going to have an effect.
- Many people may not sign the petition.
- Collecting a large number of signatures is complicated and takes lots of work from many people.

CASE: A group of family members who would like the state to increase its funding of family support services, such as respite, creates a document that outlines this request and asks interested family members, community members, and human service professionals to sign the petition.

32. **CONDUCT A LETTER-WRITING CAMPAIGN.** This involves encouraging large numbers of people to write letters to the editors of newspapers or to public officials expressing their support or opposition to some proposal.

OBJECTIVE: To demonstrate the extent of constituent support for or opposition to an issue. In addition, encouraging people to write letters facilitates public awareness about an issue.

RESOURCES REQUIRED: A clear statement of the type of message your group wants to convey. A clear idea of who should be written to and their addresses. Several volunteers (at least three) willing to organize an effort to encourage people to write letters.

Potential benefits

- Public awareness possible.
- Exposure of group issues in the local media.
- It may prompt officials to contact your group.
- An easy way to involve group members.

Potential costs

- Requires careful planning.
- Some people may have difficulty writing letters and may require some help.
- Getting people to agree to write a letter is easier than getting them to do it. You may be disappointed if you expect a mass response, so never make a public declaration about a campaign until it is over.

CASE: Parents for Inclusive Communities asks its family members to write a letter to the local Mayor to complain about the recent Township ruling that would allow day care centers to deny services to children with developmental disabilities for safety reasons.

33. **FLOOD THE SYSTEM.** This involves a concentrated effort to comply completely with the letter of an unworkable system during a short period of time.

OBJECTIVE: To flood the system and expose its failings.

RESOURCES REQUIRED: A large and reasonable need for the services of the system. Many individuals willing to use the system all at the same time.

Potential benefits

- Group action of this sort can be fun for the participants.
- It is a way to demonstrate the errors of a system.
- You may get the attention of administrators.

Potential costs

- Requires a fair amount of planning.
- You will probably need the cooperation of many people.
- If the flood occurs only for a short period of time, administrators may disregard the incident.

CASE: A local service provider asks the family members of all of its service recipients to fill out an application for emergency cash subsidy funding from the state to demonstrate to the state leaders the inadequacies of their proposed cash subsidy lottery system.

34. **MEDIA EXPOSE.** This involves providing information that may embarrass someone to reporters.

OBJECTIVE: To publicly embarrass those who have been flagrantly unresponsive and unreasonably biased against your group or its members. The goal is to punish these individuals and increase their responsiveness to you.

RESOURCES REQUIRED: Substantial information concerning misconduct by individuals within an organization. Access to media reporters that may be interested in the story. A spotless record of your own.

Potential benefits

- It is a way to get the attention of the local media.
- Increased public awareness.

Potential costs

- The press may not be any easier on you than on the target of the expose.
- You can quickly lose control of the story, when others with interest to protect get involved.
- Your group may get a reputation as radical and vicious.

CASE: People First contacts newspapers to expose the attempts made by a local service provider to prohibit the development of a self-advocacy group in its group homes.

35. **ORGANIZE PASSIVE RESISTANCE.** This involves members of your group refusing to comply with a law, regulation, policy, or procedures they feel to be unjust.

OBJECTIVE: To make the enforcement of the rule difficult or embarrassing by organizing a large number of people who will ignore it publicly and frequently.

RESOURCES REQUIRED: A community generally sympathetic to injustices--one that is relatively well-to-do. A large number of people willing to ignore a law publicly. One or more committed organizers who can hold the group together by their words and examples. Access to the media or to the events/places in which passive resistance will occur.

Potential benefits

- If you are able to get people to follow the plan, this alone will establish your group's authority and influence with your constituency.
- Even if you don't succeed, others may be more flexible and responsive to your demands in the future -- especially if you have demonstrated a number of other types of involvement over a period of time.

Potential costs

- The sanctions associated with the rule may be applied for some time before they are changed.
- Those who are punished may not be reinstated.
- You may be unsuccessful in changing either the rule or the sanctions.
- The general public and important decision makers may be embarrassed or offended.
- There may be retribution.
- The press may not portray your protest in the same light in which you view it.
- If your group has any official status, it

CASE: A group of persons in wheelchairs barricaded the entrance to a theater that refused to create an accessible entrance in their community.

36. ORGANIZE PUBLIC DEMONSTRATIONS. This involves organizing a large group to make a public routine (e.g., applying for a job at the employment service or picketing in a public area) against an agency or business that poses an obstacle to your group or is detrimental to the members of your group or in support of your cause.

OBJECTIVE: To demonstrate publicly the commitment of your group for reaching a fair resolution to the problem. Demonstrations might be used to draw media attention and educate the public about your issue without attempting to disrupt the normal functioning of a system, or can be intended to actually disrupt and paralyze a system.

RESOURCES REQUIRED: Several volunteers to plan and coordinate the demonstration. A relatively large number of people who can be persuaded to participate in the demonstration. Frequently, a permit from local authorities (e.g., police) might be required.

Potential benefits

- Broad public awareness.
- Solidarity among the members of your group who participate.
- Increased sense of power.
- It may generate greater public support.
- The action might also increase group members' commitment with the cause.

Potential costs

- You may be arrested for obstructing public access.
- It takes a lot of work to organize a successful demonstration.
- Using demonstration tactics can give your group a radical reputation, even if you are involved in a number of different projects.
- The use of such tactics may make it more difficult to deal with some organizations on other issues.
- The use of such tactics can split your group between those who are willing to demonstrate/disrupt and those who are not.

CASE: A group of service providers, angry with the proposed decrease in funding for residential services, organize a sit-in with their group home residences, their family members, and other interested community members on the steps of the State House Building in Springfield.

37. **ORGANIZE A BOYCOTT.** This involves a large group of consumers refusing to purchase a particular good or service from a provider until certain conditions have been met.

OBJECTIVE: To remove economic gains from someone who is hurting your group or its members until they change their ways.

RESOURCES REQUIRED: A just cause resisted by financial interests. A provider of goods or services who can be financially or politically harmed, if a large number of people refuse to buy his or her goods or services. Several people willing to organize and coordinate the boycott. A large number of people who are sympathetic to your cause, or who can be made sympathetic, and willing to do without the good or service. Protection for the coordinators may be needed. Access to legal counsel to protect the coordinators and your organization. Continuing access to the media to present your case and encourage participation in the boycott.

Potential benefits

- Similar targets may learn that learn that they should be responsive to your group before their relations with you reach this point.
- Broad public awareness of the issue.

Potential costs

- It may be difficult to organize a boycott of sufficient size to achieve success.
- You may offend economic interests that support your group directly or indirectly.
- You may be branded as radicals.
- The work required to maintain and publicize a boycott can easily distract all of the efforts of your group from other important issues.
- Economic sanctions may produce a strong and even violent reaction.

CASE: A group of family members organize a boycott of their local school district's segregated special education program by refusing to send their children there.

38. **ESTABLISH AN ALTERNATIVE SYSTEM OR PROGRAM.** This involves implementing a program designed to resolve some problem or provide a service yourself.

OBJECTIVE: To respond to a problem others do not have the responsibility to address or the resources to solve.

RESOURCES REQUIRED: A plan of organization and development. A location from which to work. Funds to purchase supplies and staff time or donations and volunteers. A defined clientele. Recognition as a corporation.

Potential benefits

- Developing your own program give you control over what is done, how it is done who does it, and when it is done.
- There can be a great deal of satisfaction in creating and operating a program.
- Often, those who experience a problem are the best ones to try to solve it.
- Members of the community will respect your group for their effort to help yourselves--and thereby help the community.

Potential costs

- Establishing a program requires a great of work and some money.
- Once a program is started, maintaining it takes a great deal of work.
- The more successful the program becomes, the more often others try to regulate or influence it. This puts pressure on those involved.

CASE: Due to the lack of recreational programs for adults with disabilities in their community, a group of families organize a recreation cooperative, where each family organizes one group activity for all of the member families once every week.