Speak Up! Guide

7: Being a Part of the Community

Published by:
STIR – Steps Toward Independence and Responsibility and
Shifting the Power, projects of the
Clinical Center for the Study of Development and Learning, UNC-CH
For further information please call Rebekah Pennell at (919) 966-5171.
This model suggests that:

1. learning begins with the experience or knowledge of participants;
2. after participants have shared their experience, they look for patterns or analyze that experience (what are the commonalities and what are the differences?);
3. to avoid being limited by the knowledge and experience of people in the room, we also collectively add or create new information or theory;
4. participants need to try on what they’ve learned: to practice new skills, to make strategies and plan for action;
5. afterwards, back in their organizations and daily work, participants apply in action what they’ve learned in the workshop.

ACT
Advocating Change Together

 Courtesy of Doris Marshall Institute
The Spiral Model

1. What is the problem?
2. Who else does it affect?
3. Investigate to get information
4. Brainstorm solutions and strategies
5. Just Do It!
   ✧ Choose the strategy
   ✧ Do it!
   ✧ Did it work? If not, try another strategy
CHOOSE IT OR LOSE IT

Time: 30-45 minutes

Goal: to provide a framework for choosing issues.

Materials: blackboard or flip chart and markers.

Description:

This exercise helps participants understand the significance of choosing the right issue for their group. Participants consider the overall makeup of their group and practice selecting issues that address their beliefs as self-advocates and benefit their group in the long-term. In analyzing who they are as a group, participants learn the value of choosing issues that build lasting leadership, on both a personal and group level.

Directions:

Read the following profile of a self-advocacy group: it states who they are, what their goals are, and what issue they are currently working on. (If all participants are from one group, they may choose to use their own group profile for this exercise.) One person from each table must act as facilitator and read the profile aloud. Have participants pretend that this is their group. These are their goals, and everyone must act as if they are working on this issue. When they've gone through who they are and what they are working on, use the Issue Checklist to determine if this issue is a good fit for their group. Ask each group to report their findings to the larger group when they're finished.

Group Profiles

- 12 year old People First group
- Staff support of 10 hours per week through a parent advocacy organization
- Office space at the Arc with access to a photocopy machine, a telephone, and a fax machine
- You have 25 members – some very active, some not
- Your group meets once every week
- You have a track record of success with small issues, such as getting a microwave in your lunchroom at the workshop
- $10,000 annual budget through small grants
- Members participate in statewide self-advocacy every year
- A newer member has personal connections with a local reporter
- Most members work at the workshop or get SSDI
**Goals of the group:**
- Bring in new members
- Make sure everyone feels welcome
- Raise $5,000 through a fundraiser
- Make more connections to the larger disability community
- Break away from the parent advocacy group and become an independent organization
- Have new leaders to work on issues
- Increase visibility in community as a “real” organization
- Do more work together with other social change, social justice, and neighborhood groups
- Have fun!

**Current Issue: Make our neighborhood safer**

Additional information:
- Two members assaulted recently
- Poor lighting on streets
- Bus stop is a hang-out for teenagers
- Drugs being sold at vacant parking lot
- Neighborhood safety group interested in working together
- Media is somewhat interested in safety issue
- Your group has had success at working with city to increase police patrol

Is this a good issue for your group? Why?

**Checklist for choosing a good issue:**

Will the issue:
- Result in meaningful change for people? **YES**
- Give people a sense of their own power and leadership? **YES**
- Build your organization? **YES**
- Change the relations of power? **YES**
- Be winnable in your own terms? **YES**
- Be easy to understand? **YES**
- Involve new people in your organization/group? **YES**
- Be consistent with your values and vision? **YES NO**
Take a few minutes at the end of this exercise to go over the group’s responses. Can participants think of other issues that would be a good fit for their profile? When considering issues for new groups, encourage participants to look for issues that can be realistically achieved. A track record of success, even small successes such as getting a microwave oven at the workshop dining room, will lead to greater success in the future.

**Action Step:** Working in groups, ask participants to name an issue they have worked on and evaluate it through the Issue Checklist. Have the larger group discuss whether this was a good issue for the group.
ORGANIZING FOR CHANGE

Time: 30-45 minutes

Goal: to give participants experience in choosing issues, developing strategies, and selecting tactics.

Materials: blackboard or flip chart and markers

Description:

This exercise provides scenarios where self-advocacy groups are faced with the need to make important decisions. Through choosing issues, making plans, and selecting tactics, participants are encouraged to consider how their decisions and actions will affect their group, and their community, in the long term. They will also consider the consequences of other groups developing goals and strategies for them.

Directions:

Read the following scenarios and choose an issue that best meets the needs of your group. You may choose an issue from the stories below, or use one of your own. Read the checklist carefully and make sure all group members are comfortable with the issue they choose.

Facilitator’s Tip:

The group should agree on time to be spent on an activity. It is respectful to the group to keep track of this time agreement and let participants know where they are in the allotted time. It is okay to go slightly overtime, but anything more than this should be arranged by group agreement.

Part One: Identifying the Problem and Choosing an Issue

SCENARIO ONE

You work with a disability rights organization that has been around for twelve years. Your group is small but very strong, with a lot of community support. Since your group started, it has helped people learn to speak for themselves and stand up for their rights. For the past three months, you have worked with other community members in making your neighborhood safe. This has been important to your group because two of your members were assaulted over the past year.
Recently, a government agency – the Planning Department – has started providing “self-advocacy training” to individuals with disabilities. Although your organization has a good track record for doing this kind of work, the Planning Department claims that they are better qualified to do this, since they have a large professional staff and financial resources. You know and even like many of the people in the Planning Department, but you feel their new direction may undermine your organization. When your group discusses this concern with the Planning Department, they offer to use a few of the more experienced members of your group in their trainings. They even offer to pay a $25 stipend to each person who assists them.

Some of the members of the group want to work with the Planning Department, especially if it means earning $25. Other members worry about being used by the Planning Department, about being treated as tokens. Larry, a quiet member of the group who usually doesn’t speak much, says “I thought our mission was to help people with disabilities. I don’t care if we do trainings or if they do them, as long as we’re helping people.” But some people disagree with Larry.

**SCENARIO TWO**

Your self-advocacy group has been around for over ten years. There are over 25 members, four full-time staff, and dozens of volunteers. Over the years, your group has had many victories as you’ve responded to problems in the community. You have helped people with disabilities get better jobs, you’ve made the community more accepting of people, and you’ve helped people to take control of their own lives. But now, after all these years, your group is getting a little tired. The same people in your group have been making all of the decisions and the others feel left out.

Recently, there has been a lot of news coverage of people with disabilities working for low wages in workshops. One of your members was even featured in a newspaper article, talking about working long hours and only making $2.00 per hour. Most of the group members are excited about this, but the group leaders – the ones who make most of the decisions – are not very interested, and the others are not comfortable speaking up.

During your last meeting, the group decided to plan what they would be working on for the next year. Some suggestions the group raises are 1. Fighting discrimination against all persons with disabilities, 2. Raising the minimum wage, 3. Closing all institutions in the United States, 4. Creating better job opportunities in the community, and 5. Using technology. Which issue, if any of these, will you choose.

- As a group, describe the problem.
Describe your group: What are your strengths & weaknesses?
What kind of support do you have in your community?
What will happen if you ignore the problem?
What would you like to have happen?
What issue will you work on?

Go through the following checklist for choosing an issue:

Will the issue:

- Result in meaningful change for people?
- Give people a sense of their own power and leadership?
- Change the relations of power?
- Be winnable in your own terms?
- Be easy to understand?
- Have clear goals and objectives?
- Involve new people in your group?
- Be consistent with your values and vision?

Facilitator’s Tip:

It is more important that everyone shares their perspectives than that everyone agrees. If differences of opinion arise, it can be helpful to explore or at least note them. It is important, however, that conflicts not become personal or attacking. If this happens, restate the need for respect of differences or any related group rules.

Part Two: Planning a Strategy and Choosing Tactics

Now that you’ve chosen an issue, you have to plan a strategy to map out where you’re going, and choose tactics in order to get there.

Like planning a trip, planning a strategy begins with the knowledge of where you are and where you want to go. You need to know where your starting point is: the strengths of your group, what skills and abilities you have, what resources you have, and who your friends are. A good strategy involves considering a variety of tactics, or steps, for moving an issue forward.

Begin by thinking of as many tactics as you can. Even if they seem silly or impossible, list as many tactics as you can think of. Sometimes the most creative tactics come from people who have never before organized around an issue.
Now that you have a list of possible tactics, decide which ones are the best fit for your issue and your organization. Use the following checklist to help you pick the best tactics:

- Does our organization have the ability to do this?
- Does it affect a lot of people?
- Does it bring people closer together?
- Does it really involve the people in your group, and others you may join in the issue?
- Do people feel strongly about the tactic?
- Is the tactic simple and easy to understand?
- Does the tactic build your organization? Will working on this tactic in any way help you in the future?
- Is this tactic fun? Will your group enjoy working on it?

After you’ve considered your strategy and picked your tactics, share your plans with the whole group. Tell others how you are going to pursue your issue and what you think it will do for your group and for the community.
Supporting Individuals With Developmental Disabilities And Family Members On Governance Boards

Strategies for Making it Work

By Jill Flynn
Laurie Powers, Ph.D.

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June 1999
Supporting Consumers on Governance Boards

What is consumer governance?
A board makes decisions about the direction of an organization. Consumer governance means that people who receive services have meaningful roles in the decisions made about how services are offered. Consumer governance must include people who might qualify as consumers, or users of that service. As we talk about Self-Directed Supports, consumer board members are individuals with development disabilities or family members who want to be involved in governing the program.

Why have consumers involved in governance?
The word consumer implies a person has choices and some control over the way resources are spent. While we have been using this term for years, the choice of services has not been terribly extensive, and the power of individuals to control how services would be provided has been minimal. Individuals with disabilities and their family members “must have meaningful voices in their own affairs and decisions made for them as citizens” (From Not Another Board Meeting). Any board that serves individuals should include the very people they serve as their members.

One crucial thing to remember is that this will only work if an organization sincerely believes people with disabilities and family members have the right to be at the table and active in discussions. Governing boards which have successfully supported consumer members have set up a “culture of support” which makes meetings more accessible for ALL its members. An organization must sincerely “buy-in” to this goal of creating a culture where members feel respected and safe to speak up. This means that the organization has truly asked itself questions like the following:

“How will we – personally and as a group – continually challenge our own and others’ misconceptions and stereotypes about people with disabilities?”

“How will we improve the way we communicate to all board members?”

“What will our commitment to support individuals with disabilities and family members as group members really look like?”
It is important for us to benefit from the experience of individuals with disabilities and family members. Yet, to benefit from their expertise requires an investment. Whether that is an investment in time, or in dollars for transportation, respite, or personal assistance, the investment will be worthwhile.

Organizations do not have any business inviting people onto governing boards if they are not committed to supporting members who need assistance. This support takes time and is most successful when based on the general roles and responsibilities of being a board member. It is critical to take time to establish a relationship of respect between those staff in the organization who are doing the supporting and those members who require assistance to fulfill their duties.

**QA**

**Quality Assurance**
How can a governing group make sure that they are on track? How can they measure how well they are doing in ensuring the meaningful involvement of individuals and families at the same time they measure how well they are getting their work done? We have put together two tools to help board members measure their progress.

First, board members fill out an evaluation of their board process on how productive they have been and where they need to improve. This gives them the opportunity to look at what they are doing in the big picture, getting away from the details they work with each meeting. The next tool is a checklist of things that should be in place if a consumer board is working well. These Quality Indicators should be reviewed honestly by the board, as a way of evaluating how well the organization is working for its customers. Samples of both tools are found at the end of this document.
Successful Strategies
To Recruit, to Orient & Train, and to Support
Consumer Boards

Recruiting
Recruiting board members who know everything about your organization is basically impossible, so there is always a need to inform people about what it is you do. The best way to do this is to hold regular, informational forums about the organization, a couple of times each year. Invite a broad group of people to attend, making sure to send information about the forum to parents and self-advocacy groups.

Customers of the organization are also a good source for board members. After all, they know what you do and they are likely to be invested in making sure you do a good job. Having customers on the board is not a conflict of interest as long as they act in the best interest of the organization as a whole. This means that they care about the organization, are loyal to the decisions made by the board, and follow the rules of the board process.

To keep a board strong, it is necessary to do ongoing recruitment. Do not wait for vacancies on the board. Instead, build a pool of people who are interested in joining when an opening comes up. To do this requires regular forums, sending information to customers and contacting specific people who you want on the board in the future.

The board members you want are people who are interested in the work of the organization. You want people who can understand the mission, figure out what that means to them and then figure out how they can support that mission for the good of the customers served by the organization. Members must be willing to actively participate in a governing group that is responsible for making sure the program follows its mission.

Many of us have had the experience of being on boards where some people are “token” members. We may even have been those “tokens” ourselves because we have a characteristic, like disability, that is needed on the board, but we are not listened to and we do not actively participate. Boards and their members cannot allow this to happen. Everyone on the board must have responsibilities and the organization must give support to make sure each member has a fair chance to participate and do their jobs as board members.
KEYS TO A SUCCESSFUL RECRUITMENT

1. **Determine what the strengths and weaknesses of your current board are.** Determine what qualities of skills in board members would strengthen the group. If a lawyer or an accountant is something you are looking for, find one who has experience with disabilities, whether through themselves, as a family member, or as a friend or colleague. It may be a customer of your organization whose perspective is needed to round out your board.

2. **Come up with an initial list.** Then be creative and go beyond that first list of potential members, since those people are usually busy already. In every community, there are leaders every group wants to get involved. Keep you eyes open for the budding leaders who, with a little experience, mentoring and support, could emerge as extremely valuable board members.

3. **Talk about the expectations you have for board members up front.** Send potential board members a letter with general information about your organization, the length of a board member’s term, and an invitation to call if they have questions. This, of course, must be done in easy to understand language. Invite them to attend a board meeting to see how it works.

4. **Hold informational meetings or Forums.** Share information about your organization and activities and the expectations for board members. Then invite all still interested to apply. Offer assistance in filling out applications and supply it as needed. Keep the applications simple (see samples). Make these meetings fit the character of your community. In some communities, this has been done as a potluck or a barbecue.
ORIENTATION

Process:
Set up a way of giving an Orientation to new members.
This might look different in various groups.
- One-on-one meetings, or a full day meeting, if a number of new members will come on at the same time.
- Consider filming a video presentation with key information for new members to view.
- Have a consistent policy, with who does what clearly laid out.

Information:
However you do it, there are things to include in your Orientation of new members.
- The mission of the organization and its goals and activities (a brief history of the board, including past minutes and a timeline of events).
- Also, provide a short discussion (and info sheet) on the board’s current or upcoming issues.
- Clarify the role of the board (as a policy making group) and the role of the organization’s lead staff (as manager of the organization). Also, clarify other staff roles.
- An organizational chart, show the board’s committee structure.
- A Who’s Who On the Board info sheet, with short biographies (maybe even photos) of each board member.
- Provide a cheat sheet of acronyms specific to the issues of this governance board.
- Board member responsibilities: attendance expectations, how to handle conflict of interest, legal responsibility as a board member, asking for supports or information when it’s needed, and financial responsibilities and the impact of the board’s fiscal decisions. Provide a Board Member Position Description (see sample).
- It is important the board realizes how what they do impacts the customers served by the organization. This can be done by a series of customer profiles (written or on video), to show how the process works, what it means to different customers, what it is like being a customer coming in for service.
- Don’t forget the basic details like the layout of the office, and where the bathrooms or the coffee are found. How can they get reimbursed for their expenses and when? These questions answered up front will strengthen open communication later.

A special note on Orientation & Training: Organizations may need to make extra efforts to increase the meaningful involvement of consumer members in these two areas of key responsibility:
• Budget discussions. 
  Make this mean something to members.
• Strategic planning for the group

TRAINING

All boards can benefit from training now and then. Staff to consumer boards need to spend additional time in this area, in order to give individuals and families more background information or training in skills which they may not have had the opportunity to learn yet.

Consider these training sessions for all or some of the board members:
• Simply, “How Meetings Work” – not everyone will be familiar with the rules to follow in meetings or with meeting etiquette. This can be a formal training or a facilitated discussion.
• A discussion about what supports are or are not working (general and personal supports).
• How to be more assertive.
• Interpersonal communication, or Communicating when you disagree.
• Dealing with the media: who does it and when? What is each board member’s responsibility?

Build in opportunities for board members to get involved.
• Giving board members opportunities to build upon their skills and information is one of the best ways to make them effective and motivated members of the board. Many consumer members have not had access to diverse opportunities.
• Have board members attend workshops or conferences where they can learn new information and act as a representative of the organization.

Supporting Board Members
Every board member has support needs, and each person (not just those who have disability labels) is responsible to let their support needs be known. The organization, in turn, is responsible for making sure that board members get the support they need to actively contribute to the board. Support needs take different amounts of time, energy and attention by the person who is doing the supporting.

The group must build a culture of support, one in which ALL members feel free to ask for the assistance they need, and one in which ALL feel responsible to help each other. By building a “culture” on your board where people support each other, all members can be more effective.

On the following pages are some strategies which can be used to promote this “culture of support”. These are suggestions which have worked exactly as written in some cases. In others, variations were made when it made sense for
the individuals who requested support or for a particular board’s way of doing things. Be flexible.
WAYS TO PROMOTE A CULTURE OF SUPPORT:

- Pair new members, or those who need more support, up with a mentor, another board member who can assist them when they have questions.
- Provide orientation, in the form of materials and training.
- Hold pre-meetings for those who want to spend extra time to understand the agenda topics or organization’s activities, so that everyone can feel more confident in the meeting.
- Go through the “Support Needs Checklist” with every new board member, and review it from time to time. (From Not Another Board Meeting: Guides to Building Inclusive Making Groups)
- Use easy-to-understand language: in materials and during board discussion, all members should avoid using jargon without explaining what it means (including acronyms). It is amazing the effect this can have on ALL involved in enhancing meaningful discussion around the table.
- Have frequent phone calls with board members, and have one-one meetings with them occasionally, as this is where mutual respect and contributions might become apparent.
- Think about ways to make the actual meeting more accessible.
  - Record the meeting on a cassette, so it could be reviewed at home.
  - On a flip chart, write key words of discussion topics during the meeting, so people can follow the train of thought.
  - Put the budget into an image (like a gas tank) so a general idea of the organization’s money can be grasped before getting to the specifics. (See sample.)
  - Before a vote on a serious issue, go around the table, one by one, and give everyone a chance to ask a question, express a concern, to bring up a point for others to consider when voting. This can slow the tempo of the meeting down enough to let everyone put a word in. It also supports educated decision-making, which is a responsibility of every board member.
- Frequently ask (both individually and as a group) board members these questions: (see sample board evaluation)
  “Are you receiving information in a way you can understand?”
  “Are you confident in your skills as a board member or are there areas you need more training in?”
  “What’s working for you on the board, and what’s not?”
- Get the agenda, minutes and materials out in a timely manner. (Using consistent symbols or colors of paper might assist non-readers)
- Provide time for board members to get to know each other and learn more about their individual interests and experiences.
WHAT DOES IT TAKE?

• Hold meetings when individuals with developmental disabilities and family members can attend.

• Provide reimbursements for Transportation, Personal Assistance or Respite Care so individuals and families are able to attend meetings.

• Have a specific contact person on the staff to provide general support, in addition to the mentor pairings.

• The sincere belief that it can work.

• Time.
RESOURCES:


TOOLS:

- Application for board membership. Two samples of easy-to-understand applications are enclosed.

- “Checklist of Support Needs” from Not Another Board Meeting, a walk-through tool to use as you set up a support relationship with a board member, to determine what they need assistance with and what they will do themselves.

- Chart for Board room of Mission and main goals/tasks of board, see example, which is blown up and posted onto the wall of the board room for easy viewing.

- Visual image to help explain general budget information (see example of gas tank).

- Board self-evaluation, to be filled out at least yearly, so that board members and staff can see where they need work and can address problems in their governing process.

- Quality Indicators: a checklist the board can go through to measure how well they are overseeing the work of the organization.
SELF-DETERMINATION RESOURCES, INC.
APPLICATION FOR THE BOARD OF DIRECTORS

If you need assistance to apply for this Board, please contact
Jill Flynn or Mary Anne Seaton at (503) 364-9943

Name_________________________________________________________
Address_________________________________________________________________
City/State/Zip____________________________________________________________
Home Phone ________________________ Work Phone _________________________
Email ______________________________ Fax ________________________________

1. Are you a family member representing a ☐ child ☐ adolescent, or ☐ adult?

2. Are you a person with a disability? ☐ yes ☐ no

3. Why are you interested in being on this Board?

____________________________________________________________________

4. Please check which areas interest you.

_____ ☐ Policy Development. Set up policies to make Self-Determination
Resources, Inc., an organization that really helps people to control their lives and
get the support they want.

_____ ☐ Financial Operations. Develop the budget for the organization and
oversee how the money is spent.

_____ ☐ Community Resource Development. Develop plans for the
organization to educate customers about directing their supports, to educate
other people about the best ways to help customers, and to get more people in
the community involved.

_____ ☐ Quality Assurance. Monitor the quality of services the organization
is providing to customers and set goals to improve the services.
5. Please list organizations that you are currently or have been involved in (for example, neighborhood associations, school boards, People First, fraternal organizations).

______________________________________________________________

______________________________________________________________

Are you now or have you ever been a member of a board of directors?

☐ yes  ☐ no

What is/was your role on the board?

______________________________________________________________

6. What types of skills and experiences would you bring to this Board?

______________________________________________________________

7. What is your paid or volunteer work? What do you do?

______________________________________________________________

8. Are you a customer or user of developmental disability services?

☐ yes  ☐ no

If yes, what services do you receive?

______________________________________________________________

9. Do you see yourself as a future customer of this organization?  ☐ yes  ☐ no

10. Can you make a commitment to attend one or two Board meetings every month and to do committee work?  ☐ yes  ☐ no

If yes, which days couldn't you meet?

______________________________________________________________

During the development of the board and activities related to the brokerage, limited funds for family support services or personal assistant services and mileage or transportation costs will be available to allow board members full participation at scheduled meetings.

Additional Information/Comments

______________________________________________________________

______________________________________________________________
SELF-DETERMINATION RESOURCES, INC.
BOARD OF DIRECTORS
APPLICATION FOR APPOINTMENT

Please type or clearly print information and return form to:
SDRI, P.O.Box 82746, Portland, OR 97282

Name: ____________________________
Occupation:__________________

Address:
_____________________________________________________________

Home Phone: ______________________ Work Phone: ______________________

Reason for applying:
______________________________________________________________
______________________________________________________________
______________________________________________________________
______________________________________________________________
______________________________________________________________

Availability for meetings:
______________________________________________________________

Membership Category:  
Circle One)  Parent  Professional  Other

Applicant’s Signature     Date

Do Not Write Below This Line – Board Use Only

Date Received by Board of Directors:

Appointed by the SDRI Board of Directors on

Board Signature:
SELF-DETERMINATION RESOURCES, INC.
MEMBERSHIP CRITERIA FOR THE BOARD OF DIRECTORS

The Board of Directors consists of people with disabilities, active family members and community members. People with disabilities and active family members comprise at least 51% of the Board. The following criteria guide the selection of the Board of Directors.

1. Commitment to promote the mission of Self-Determination Resources, Inc.

2. Willingness to regularly attend Board and Committee meetings and to actively participate in decision-making.

3. Current or potential customers of Self-Determination Resources, Inc.

4. Consumer members that represent people of diverse ages and disabilities.

5. Geographic representation from the various neighborhoods and communities in Multnomah County.

6. Cultural and ethnic diversity.

7. Community representatives who are active in education, employment, and community living programs that involve people with disabilities.

8. Community representatives who are involved in community employment, housing and recreation activities aimed at the general community.

9. Community representatives who have technical skills, such as accounting, law, fundraising or public relations.
HOW’S OUR BOARD DOING?

Our Mission and Goals

1. The overall mission or purpose of our board is clear to members.
   _____ Yes
   _____ No

2. We are making progress in achieving our goals.
   _____ Yes
   _____ No

3. Our meetings are productive.
   _____ Always
   _____ Sometimes

4. Our Board is strong.
   _____ Yes
   _____ On our way
   _____ No

What could be done to help clarify or move forward the mission and goals of our board to make our board stronger?
Program Management

5. We understand what our Program does for individuals and families.
   ______ Yes
   ______ No

6. Our program policies are adequate.
   ______ Yes
   ______ Some, but not others
   ______ No

7. We are able to adequately oversee and guide the work of the Brokerage Manager.
   ______ Yes
   ______ No

Suggestions for ways to improve our Board management of our Program:
**Community Education/Systems Change**

8. Our board is helping to educate the community about the needs of families and individuals with developmental disabilities.

_____ Yes

_____ Somewhat, but I wish we could do more

_____ Not really

9. Our Board is helping to influence services for individuals and families in our community.

_____ Yes

_____ Somewhat, but I wish we could do more

_____ Not really

**Suggestions for improving our ability to do community, education and advocacy.**
**On a Personal Level**

10. I feel good about my contribution to the Board.
   - _____ Yes
   - _____ No

11. I feel like the effort I put into the Board is worth it.
   - _____ Yes
   - _____ No

12. I have the information I need to fulfill my Board role.
   - _____ Yes
   - _____ No

13. I have the skills I need to fulfill my Board role.
   - _____ Yes
   - _____ No

**What do you need to increase your effectiveness/satisfaction on the Board?**
CONSUMER GOVERNANCE

Self-Directed Support Programs are led by a governing group of community leaders, at least 51% of whom are individuals with disabilities and family members. The governing group is responsible for making sure that the Self-Directed Support Program does its job of helping customers to determine and direct their supports. The governing group oversees the quality of the Program’s work in carrying out each of its functions, and develops goals and policies to improve the Program.

This checklist describes the key features of consumer-led governing groups. It can be used as a guide to organize and evaluate such groups.

<table>
<thead>
<tr>
<th>Key Activities</th>
<th>Is it Happening?</th>
<th>What will we do to make it happen?</th>
</tr>
</thead>
<tbody>
<tr>
<td>The focus of the governing group is to oversee and maintain the mission of the Self-Directed Support Program.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>The governing group does careful planning for the Program’s future.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>The governing group develops policies and reviews the performance of the Program Director or Manager.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>The governing group regularly reviews how well the Program is doing its job and decides what needs to be improved.</td>
<td></td>
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<tr>
<td>The role and authority of the governing group is well-defined.</td>
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<tr>
<td>If the Self-Directed Support Program is part of a larger agency, there is a direct link between the governing group of the Program and the governing body of the agency (ex. a member of the governing board of the Program is a member of the governing body of the agency).</td>
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</tr>
</tbody>
</table>

(Consumer Governance, continued)

<table>
<thead>
<tr>
<th>Key Activities</th>
<th>Is it Happening?</th>
<th>What will we do to make it happen?</th>
</tr>
</thead>
<tbody>
<tr>
<td>More than 25% of the members of the governing group are individuals with disabilities and more than 25% are family members of individuals with</td>
<td></td>
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</tbody>
</table>
disabilities.

<table>
<thead>
<tr>
<th>The governing group matches the diversity of the community.</th>
</tr>
</thead>
<tbody>
<tr>
<td>The governing group meets regularly and has a structure (ex. chair, president, secretary, etc.)</td>
</tr>
<tr>
<td>The governing group has a pool of people who are interested in being members.</td>
</tr>
<tr>
<td>There is an orientation program for new members.</td>
</tr>
<tr>
<td>Information and written material for the governing group is presented in straightforward language, pictures, etc. to make it understandable. Pre-meetings are held for members who want more time and assistance to review the agenda and the last meeting’s minutes, and to figure out their viewpoints and questions for the upcoming meeting. Assistance is provided to increase the participation of members in meetings (e.g. yes/no question-asking, taking time to review hard to understand information, notes on an easel, using straightforward language, etc.). Support is given to make sure that members can attend meetings (e.g. respite, transportation, personal assistance).</td>
</tr>
<tr>
<td>The governing group regularly evaluates its leadership and support for members.</td>
</tr>
<tr>
<td>Members have opportunities to take part in activities to increase their knowledge, and leadership skills.</td>
</tr>
</tbody>
</table>
WHAT'S OUT THERE?

Churches
Libraries
Civic Groups
Town Council
County Board
Neighborhood Associations
Hospitals
JOINING A GROUP OR COMMITTEE

Find out who can attend the meetings.

Find out when and where the meetings are held.

Attend several meetings as a visitor to decide if you want to be a member of the group.

Find out how to become a member.

Become a member.
NEXT STEPS

What is the thing you would like to do for yourself or your community?

Write down what you’ve decided to do.

Figure out the first steps you should take (talk with your group to figure it out).

Share your goal and steps with others.

Decide if you would like our team to call you to help with ideas to reach your goal.
HERE ARE SOME GENERAL STEPS TO HOW LAWS ARE MADE:

LAWS are rules that everyone has to follow.

1) An idea for a LAW goes to the State House

2) The idea is present as a Bill and gets sent to a Committee

3) The Committee hears the Testament of anyone who wants to talk about the bill

LIST SOME WAYS YOU CAN TELL THE COMMITTEE HOW YOU WANT THEM TO VOTE ABOUT A BILL:

____________________________________
____________________________________
____________________________________

4) The Committee votes on the Bill

VOTE

NO = stops the bill

YES = Bill goes to full House and Senate
5) The House and Senate vote on the **Bill**

**VOTE**

NO = bill does NOT become a law

YES = bill goes to Governor

6) If the Governor votes NO it is called a **VETO**. A vetoed bill does NOT become a law.

If the Governor votes YES, the bill becomes a law.

**Bill**

**VETO**

**Law**

**LIST SOME WAYS YOU CAN TELL THE GOVERNOR HOW YOU WANT HIM/HER TO VOTE ABOUT A BILL:**

________________________________________  ____________________________________

________________________________________  ____________________________________

________________________________________  ____________________________________

Developed by Deb Griffin Kney, PAL, for Partners in Policymaking-RI
Funded by the RI Developmental Disabilities Council
COMMUNITY
Location: Self-Advocacy Group
Situation: Discuss how to be involved in your community
Role play: How can you help your community?
What kind of things do you think you would like to see change in your community?

Activity in Chapter 7, pg. 35