



National Technical Assistance Center for Voting and Cognitive Access

GUIDELINES FOR BUILDING PARTNERSHIPS WITH SELF-ADVOCACY ORGANIZATIONS

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Funded in part by a grant from the Administration on Developmental Disabilities. The opinions expressed herein are by the authors and do not necessarily reflect those of the funding agency.

In order to work together to improve the lives of people with disabilities, professional organizations and self-advocacy organizations must have relationships that are based on understanding, respect and trust.

These guidelines are provided to help professional organizations, such as Protection and Advocacy agencies (P & As), to form genuine partnerships with state and local self-advocacy organizations.

Contact Your Self-Advocacy Organization



Do you know the name of your state and/or local self-advocacy group?

Who is the chairperson or president?

Who is the coordinator?

Where is the group located and how do you contact them?

Knowing the answers to these questions is the first step in making contact with your self-advocacy organization.

Not Sure?

Many professional organizations don't know how to contact self-advocacy organizations.



To find out, we suggest asking people with developmental disabilities, your State Council on Developmental Disabilities, the Arc or your University Center of Excellence in Disability.

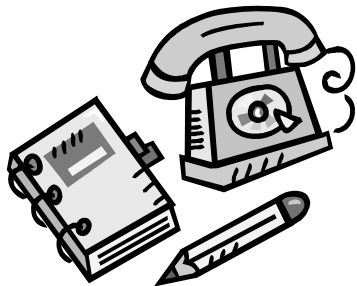
The self-advocacy group may have a website. You can go to the website www.govoter.org for contact information for state self-advocacy organizations.



Use a variety of options: One resource may be more current than another and there may be more than one group in your area.

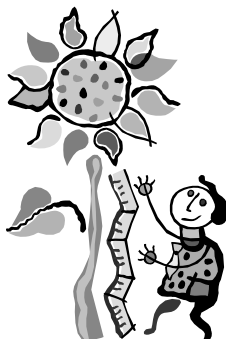
Remember that **all groups don't have the same name**, such as "People First". For example, a group might have "Self-Advocacy" in its name or "Speaking Up"- words that sound like advocacy.

Officers and coordinators may change over time so it's important to keep your contact information updated.



Phone and email the contact person because there are still many people who do not have email or do not use it regularly.

Grow Your Relationship



It is very important to **get to know the leaders** of the self-advocacy organization and give them a chance to get to know you before you begin working on something.

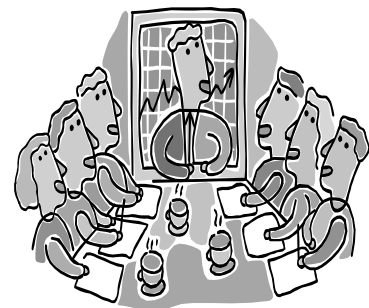
Communication and trust must be developed and it may take several meetings to learn how to work together.

Explain to the self-advocacy group that you would like to come **talk** with them **about what your organization is doing and learn about what they are doing.**

Let the self-advocacy group set the terms for the location, date and time of the meeting.

Be prepared to:

- ★ Fill out a request form to be on the meeting agenda;
- ★ Meet at the time that is convenient for the group;
- ★ Travel to the group; and
- ★ Do whatever else is requested.



Suggest including some informal time before or after the official meeting to get to know each other. You could have “meet and greet” time before a meeting and/or lunch after a meeting.



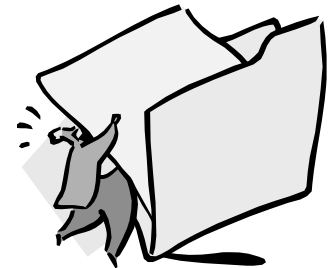
Talk about what your organization does. For example, if your organization is a P & A, clarify that you advocate for the person with a disability even if other people don't agree.

Understanding that the P & A advocates for the person with a disability is a major issue because some self-advocacy leaders are intimidated by lawyers. They think about guardianship, being taking away from their families and others getting into their personal business.



Self-advocacy groups need to know that your organization is on the person's side.

Set ground rules for talking together. Clarify that everyone can talk openly and no action will be taken in response to what people say.



Promise that information shared will not be told to others without permission from the group or individual leaders.

Be sensitive to the fact that, at first, self-advocacy leaders may be reluctant to question things that are said. They may feel like they aren't supposed to challenge "authority", they may feel embarrassed or they may worry that if they bring up concerns, they will not be invited to participate in future meetings or activities.

Sometimes it can be helpful to **invite someone in the group to be the "Keeper of Respect"** The role of the Keeper of Respect is to observe everyone's communication and point out to the group any situations in which someone is not being listened to, is not given the opportunity to participate or is being treated disrespectfully.



Use straightforward language and materials. Explain complicated words and invite people to ask questions.

Ask people if they understand what a word means. Ask everyone, not just the person with a disability - don't put the person on the spot.

Teach one another the meaning of key words that your organizations use. **Avoid using acronyms** and check out the understandability of your materials by trying them out with a variety of people with disabilities. For more information about accessible language, see our *Guide for Creating Cognitively Accessible Language*.

Share your organizations' strategic plans and identify the goals you have in common and what you could work on together. Review your activities and projects. Talk about resources and connections you could share with one another.



Look for an opportunity to work together – something that you both care about.

Be sure that both groups have the time and resources to truly work together on the issue.

Do not “burn your bridges” the first time you work together by making commitments that you can't meet.

Make a Formal Agreement to Work Together



It is very important to **allow each group to keep their own identity** while you work together. We suggest developing a written agreement that says the groups respect one another's independence.

That means they won't tell each other how to think or what to do. **They won't use the other group's name or publish material developed together without representatives of each group reviewing and approving it.** They won't plan things without talking them over together. **They won't make agreements involving other groups without talking with each other first.** Each group must have their autonomy respected.



Build Your Partnership Over Time

It is important to maintain ongoing communication and work closely on every step along the way. **Work together on an issue from the beginning.** Avoid inviting self-advocacy leaders to join in after decisions have been made. Make sure that the leaders have a chance to give real input.

Show that you are paying attention to what self-advocacy leaders are thinking by taking time to listen, including their suggestions in your plans and offering them key roles. Talk to the self-advocacy leader, not his or her support person.

If self-advocacy leaders don't respond right away to your questions or plan, do not assume that this means they don't have something to say. They may be busy (remember they are volunteers) or sometimes leaders need more time to think things through before they respond. Seek out the group's input and give them enough time to think it over. **Ask the leaders if they understand or have anything else to add.**



Involve self-advocacy leaders at all levels of planning activities, carrying them out and evaluating their success.

Don't assign self-advocacy leaders limited roles like telling their personal stories or greeting officials. Instead, review all the roles that are needed for the activity and invite the leaders to take on those roles that they want. **Encourage leaders to take charge of something.**

After each person's role is decided, clarify the support that each person needs and make arrangements for providing it. **Ask if support is needed rather than just providing it.** Often several members of the team – those with and without disabilities – need different kinds of support. Identify what each person needs and make agreements to follow-through in making sure it is provided.

Support may include help with scheduling, transportation, personal assistance or letting people know ahead of time if lunch will be provided at a meeting. If a person needs support, let him or her choose the person to provide it. While it may be easier for someone on the team to provide the support, the team member who needs it may feel most comfortable getting support from someone else.





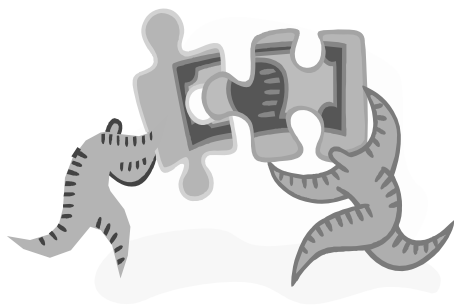
Talk about who may be available to help so the person can make an informed decision. Then respect and support the person's choice.

In addition to having specific people work together on activities, invite other representatives from each group to attend each other's meetings and to share information so that everyone knows what's going on.

Invite members to observe one another's board meetings and then to join, if they want. If a self-advocacy leader reaches out to a professional organization, welcome him or her and invite the person to get involved.

Ask the person to help build connections between the professional organization and his or her self-advocacy organization. Share telephone numbers and email addresses.

We suggest that the president and coordinator of the self-advocacy group and the director and chair of the professional organization **share their personal telephone numbers** so they are able to reach one another at any time.



While most professional organizations have more funding than self-advocacy groups and can more easily cover the cost of activities, we believe that it is important to share costs in some way to help keep the relationship equal.

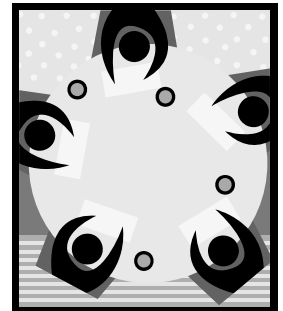
Depending on the sizes and budgets of the groups, work out a plan for each group to contribute in some way.

Help One Another Build Bridges

Be a bridge to help each group get connected to others. For example, P & A's can ask Help America Vote Act (HAVA) groups to invite self-advocacy representatives to participate in meetings and activities.



Self-Advocacy and professional organizations can suggest that representatives from one another's organizations be invited to meetings where they aren't represented.



Representatives can collect and share information that would be helpful to each other.

Group representatives can advocate with other organizations for their meetings to be accessible so that everyone can participate. Meeting accessibility is improved by:



- ★ Using name tags;
- ★ Scheduling a "prep meeting" to review the agenda and discuss issues that might come up";
- ★ Reviewing materials for understandability ahead of time;
- ★ Meeting at a place that is physically accessible;
- ★ Providing alternative formats, interpreters, support and other accommodations that are needed;
- ★ Explaining words during the meeting; and
- ★ Appointing a "Keeper of Respect".

Don't Give Up!



Building relationships among organizations takes time, commitment and patience.

Use these guidelines as a roadmap. When questions or problems come up (we guarantee that this will happen from time-to-time in any partnership), use the opportunity to honestly discuss them and creatively come up with answers and strategies.

Admit when you don't know the answer and seek it out together. Use your resources and trust that each group has good intentions.

There are many problems that people with disabilities and organizations are facing. By working together we can truly make a difference.