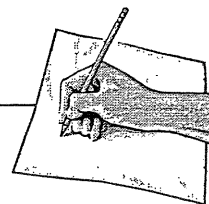


Self Advocacy Group Start-up Kit

**Distributed by the BC Self Advocacy
Foundation, 2001**

This manual has been used by self advocacy groups all over BC.
The author(s) is unknown and we are attempting for identify the
source.

THINGS TO DO



Can you think of other things that you would like to tell other people about people with disabilities?

Do you know of any people with disabilities who have shown courage in overcoming difficulties?

If we speak up for ourselves through self-advocacy, we can change things that people believe about us. Here are some ideas that people have that are **wrong** and should be changed.

- * Some people think our disabilities are the most important things about us.
- * Some people think we are all the same and don't see that we are individuals.
- * Some people label us with words like 'mentally handicapped' or 'epileptic'.
- * Some people think we don't deserve respect or dignity.
- * Some people treat us like children.
- * Some people don't want us near them.
- * Some people think we should be shut away in hospitals or other institutions.
- * Some people don't think we deserve houses, money, work or education.
- * Some people don't think we should have rights and freedom.

WHO ARE SELF ADVOCATES AND WHAT DO SELF ADVOCATES DO?

SELF-ADVOCACY IN GROUPS

Self advocates are people like you who want to stand up and speak for themselves.

Recently people who have developmental disabilities have been forming themselves into self-advocacy groups.

There are already a lot of people who are involved in self-advocacy groups.

There are groups of people who have got together in adult training centres or social education centres, in hostels and hospitals or as groups of friends.

Other groups have members from different places who meet together as a group, usually in the area where they live.

Anyone can start a group if they want to and it doesn't have to be in a place like a training centre.

It may be easier to hold meetings somewhere other than in a place which belongs to people who run services like centres or hostels.

You may feel more independent if you have your own meeting place.

You may decide to have someone who does not have developmental disabilities at your meetings as an advisor or supporter.

Someone who is on your side can be a great help.

Also many people aren't used to talking about themselves in groups of other people and about important matters.

SO DON'T RUSH THINGS

Don't worry if the group doesn't start doing things straightaway.

It's important to really get to know each other well and to get your ideas straight from the start.

If you have decided to have an advisor for the group, you will also want to spend time getting to know him or her.

SOME EXAMPLES OF THINGS SELF ADVOCATES DO

TALKING

Many people will come to the group wanting to talk about all sorts of things.

Some of these may involve taking action at some stage. Other issues may be things that are useful just to talk about together.

For example:

One group spent time talking together about how they felt about being labelled with words like 'handicapped'.

They discussed some newspaper items about people with disabilities and some things people had seen on television.

TALKING LEADING TO ACTION

Sometimes people will come to the group with something that needs action.

decided to write to the bus company and ask them to stop this happening.

LEARNING

Being an effective self-advocacy group involves learning new skills.

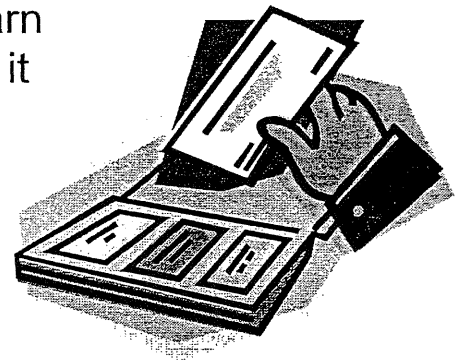
After all, not everyone is good at making decisions, or dealing with money.

Sometimes the whole group may want to learn a new skill. Sometimes only one or two people such as officers of the group will need to learn a particular skill.

For example:

The treasurer of one group needed to learn how to put money into the bank and take it out.

He spent several sessions with the advisor, visiting the bank and learning things like how to use a chequebook.



HAVING SOCIAL ACTIVITIES

Being a member of a self-advocacy group can be very hard work. But groups can make time for social activities too when everyone can relax and enjoy themselves.

For example:

A group may have a break in the middle of the meeting. Or they may decide to have some social time at the end of each meeting.

This informal time together can give people the chance to talk and swap news and ideas for the group. People who

SETTING UP A SELF ADVOCACY GROUP

SUMMARY

- Find out about self advocacy
- Meet with friends to start planning a group
- Ask for help to start the group
- Keep the group small at first
- Visit another active group
- Have regular meetings of the group
- Plan your meetings
- When you are ready, start to recruit more members.
- As numbers grow, have an elected committee
- Continue to involve all the members in the group's work
- Use your Advisor for any help you need
- Keep in touch with other groups
- Keep going, even if you come across difficulties

RECRUITING MEMBERS TO YOUR GROUP

There are a number of different ways you can bring new people into the group including:

- talking to other people about the group
- making posters about the group
- having a newsletter to send out
- holding social events
- having special events or meetings

The next few pages talk a bit more about how you can do this.

TALKING TO OTHER PEOPLE ABOUT THE GROUP

This is one of the best ways of getting new members to join you.

Talk to friends, people at the centre and others you know. Tell them about:

- how important it is to speak up for yourself
- why you meet together regularly to do this
- some of the things you talk about in your group.

You can ask them to come along to one of the meetings.

People are often happier to join a group if they know someone who is already a member of that group. Perhaps you can offer to meet a new member on the day of the meeting and travel there together.

At the end of a special meeting, make sure you have the names, addresses and phone numbers of the people who came along. Make sure they know when the group meets so they can come along to the next meeting.

CHECKLIST OF THINGS TO REMEMBER WHEN PLANNING A SPECIAL EVENT TO RECRUIT NEW MEMBERS

1. Start planning well before the event. Setting up special events ALWAYS takes longer than you think it will!
2. Send out letters and/or posters about the event to as many people and places as you can think of.
3. Tell as many people as you can about the event.
4. Make sure you have the event –
 - At a place which can be used by people in wheelchairs
 - At a time which doesn't clash with other things like a club evening
 - At a place which people can get easily by public transportation.
5. Make sure you have checked with the place where you are holding the event that they are expecting you at the right time and on the right day.
6. If you are going to need any equipment make sure that it is there and that someone knows how to use it. For example, if you are going to show a video make sure there is video equipment there and make sure someone has agreed to operate it.
7. Try and start and finish at the times planned
8. If you get stuck – don't forget you can ask your advisor for help!

SUMMARY

Recruiting new members to your group means you get more people involved in self-advocacy.

Having more members can mean the group can get more things done.

You will probably want to meet as a small group first though, before you start recruiting lots of new members.

Remember that a group doesn't have to be large to be successful.

There are several ways you can recruit new members to your group: -

- Talking to other people about the group
- Putting up posters
- sending out a newsletter
- writing a leaflet about the group
- writing about the group in other people's newsletters
- Holding social events
- Holding special meetings like film shows.

Some people will be good at some skills while other people will be good at other skills.

To make self advocacy work well, make sure that everyone has the chance to use their strengths.

So when there are jobs to be done, get people to do the things they are good at.

For example:

- if two people in the group can write, get them to do any writing that needs to be done.
- if several people can read, share out the reading
- you may think one person is very good at thinking up ideas, while another person is good at thinking out what would be involved in trying out these ideas
- some people will be good at making tea and coffee
- others will be good at listening
- and so on...



Everybody is good at something.

Make sure you make use of all the skills whatever they are.

In this way, everyone can get to take part in self- advocacy.

2. GET OTHER PEOPLE TO HELP YOU

We all need help at times.

Sometimes we can get stuck in self advocacy because

- we don't have a particular skill
- we don't have a particular piece of information
- or we may be unsure about something and need advice.

3. MAKE USE OF EQUIPMENT

Sometimes, simple pieces of equipment can be very useful in self advocacy.

For example:

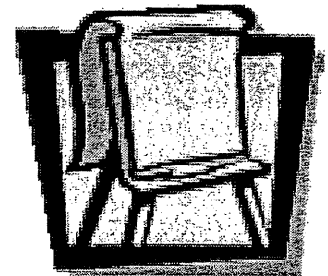
- Tape recorders are useful if writing is difficult. You can get a helper to write out what you have recorded.

Tape recorders can also be useful to practice speaking into if you have to give a talk.



- Large sheets of paper and coloured pens are very useful for writing the list of topics to be discussed.

Or for making a note of ideas that come up. Stick the paper to the wall, using Bluetac or masking tape (so you don't take the paint off the wall).



- Make use of photographs, pictures from magazines or drawings to communicate if you have difficulty speaking or if you are talking to someone who doesn't understand speech very well.
- You may be able to borrow video equipment to make a video of your own about self advocacy. You can show the video to others so that they can find out about self advocacy.

4. LEARN NEW SKILLS

Although you may not be good at all of the skills in the list when you first start being involved in self advocacy, one thing is certain – being involved in self advocacy will help you improve your skills.

One way of doing this is to set aside a regular time in your self advocacy meeting to work on one skill.

SUMMARY

Self advocacy involves many different skills.

Although these skills are helpful, you don't have to be good at all of them to be involved in self advocacy.

There are ways of making the most of self advocacy without all of these skills

These are:

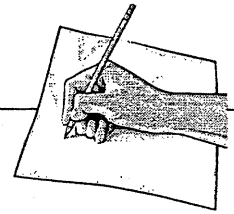
- sharing out the jobs**
- asking for help**
- using equipment**
- learning new skills.**

Remember -- everyone can be involved in self advocacy.

THINGS TO TALK ABOUT

Can you think of other things your group might need money for?

Make a list of these things.



THINGS TO DO

- 1. Make a list of the things your group might need money for.
Which are the most important?
Which can be left until later?***
- 2. Choose any two ways of raising money
Talk about what you would need to do to raise money in these ways.
Will you get more money from one than the other?
Will one be more fun than the other?***
- 3. Invite someone to your meeting who can talk about different ways of raising money.
This might be a Treasurer from another organization, or the Treasurer of a near-by self advocacy group,***
- 4. Make a list of the things your group wants to do.
Which things can you do without money?
Which ones would you need a small amount of money for?
Which ones would you need a large amount of money for?***

KEEPING THE GROUP GOING

Any kind of group has its ups and downs.

Some meetings are better than others.

Sometimes

a lot of people turn up



and other times

only two or three people come.



SUMMARY

There may be several reasons why you are having difficulties keeping your group going:

You don't have enough members

You have quite a lot of members but they don't come to the meetings

You don't feel you are achieving very much

BUT REMEMBER

all groups have ups and downs

being self advocates is hard work

a self-advocacy group is there to solve problems
SO face up to them!

By facing up to problems your group will grow stronger.

You probably won't stick to it exactly but it will give you a rough idea of how many minutes you have for each item.

WHAT GOES ON THE AGENDA?

Your group will have its own ideas about what you want to talk about.

BUT here are some ideas for the sort of items that may make up the agenda. They are ones that other groups have found useful.

1. Introductions and welcome to new members.

(It's a good idea to welcome new members. It will help them feel good about coming to the meeting.)



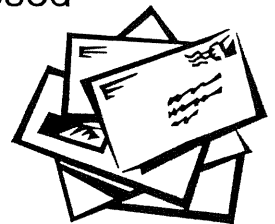
2. Apologies for absence.

(From people who can't come)

3. Notes of the last meeting.

(This will remind you of what you discussed at the last meeting)

4. Letters to be dealt with and phone calls to be made.



5. Discussion about money.
(The Treasurer's Report)



6. Old business

SUMMARY

An agenda is a list of items which the group wants to discuss at its meeting.

The group's officers should work out an agenda before the meeting.

Other members of the group should be able to add items to the agenda at the beginning of the main meeting.

Put the agenda up on the wall before the meeting starts.

Add pictures so those people who don't read will be able to follow the agenda.

Ask someone to read out the agenda at the start of the meeting.

REMEMBER don't make the agenda too long or you won't be able to talk about all the items.

- if the person uses sign language and you do not understand it
- if the person cannot use speech or sign language.

At these times, you need to listen very carefully and ask the person to help you understand – for example, by saying:

‘Could you speak more slowly, please?’ or

‘Could you say that again, please?’

Or explain that you are having difficulty in understanding for example by saying:

‘I am sorry, but I don’t understand Makaton’

or ‘I am sorry, but I don’t understand what you are saying’

or ‘Could you explain that a bit more for me please?’

If people do not listen when we speak, it makes us feel that they are not interested in us or we are not important.

If you are good at listening to other people, they will feel comfortable talking to you.

It is important to be good at listening as it encourages other people to talk to you.

WORKING WITH AN ADVISOR

Advisor

A person who helps your group work better without taking over. The advisor or helper can give ideas about how to run the group, can support the work of the group and can teach the group how to work around problems. But the advisor should never become the group leader or tell the group what they have to do.

What are some things to look for when you are trying to find an advisor?

- A person who believes in self advocacy and what your group wants to do.
- A person who believes that all people have abilities and have something to offer and that all people grow and change through their experiences.
- A person who believes that all people should have the chance to participate in community life and that people have the right to whatever support they need to make that work.
- A person who knows something about disabilities and about services for people with developmental disabilities in your community.
- A person who is willing to spend time with your group without being paid if that is what is needed.

What are some ways to find an advisor for your group?

Many groups already have an advisor when they start. Sometimes the advisor is from a service program or a special "citizen advocacy" program.

Sometimes there are groups in your town like the Association for Community Living or the Association for the Developmentally Disabled. They might help find an advisor for you. If there are other clubs or groups who help people, you could ask them for ideas.

If there is a college in your town, you could call the special education or the education program and ask if they have a teacher or student who could be your advisor. Also ask if they know of anyone else who could help.

Sometimes, churches are a good place to look for a person who could help you. Keep trying and talk to others for ideas of where to look in your town.

What can you do if your advisor does too much or too little of the work for your group?

If your advisor does too much or too little for your group, the first thing to do is to talk to the advisor. Have a meeting so the group can tell the advisor not to take over or not to sit back so much. Make it clear what it is you want. If things do not change and you have given the advisor a chance, ask that advisor to quit and find a new advisor.