

# 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 learning disabilities have been forming themselves into self-advocacy groups.

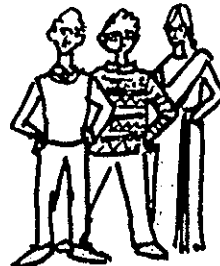
There are already a lot of people who are involved in self-advocacy groups.



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 learning disabilities at your meetings as an advisor or supporter.

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

Often, a lot more can be done if you get help from other people than if you struggle along on your own.

## SOME EXAMPLES OF THINGS SELF-ADVOCATES DO

### TALKING

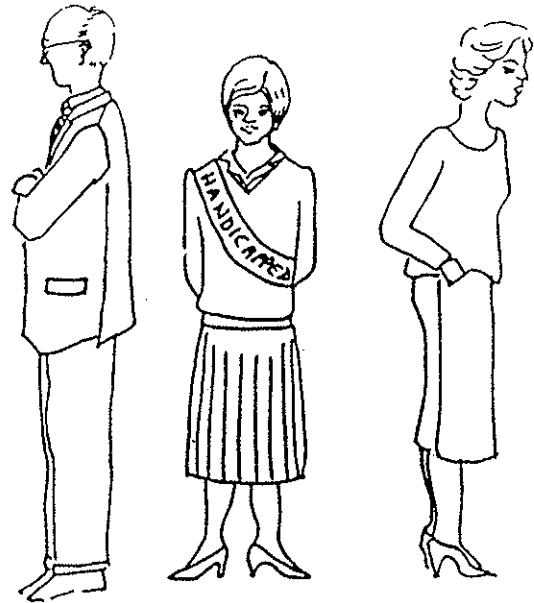
Many people will come to the group wanting to talk about all sorts of things.

Some of these may involve taking action at some stage. Other issues may be things it is 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.

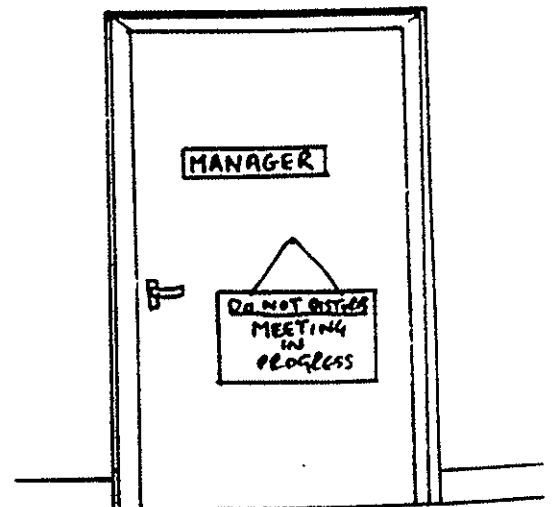
The group will need to talk about what they can actually do to change something.

Some things needing action may involve just one person. Or they may involve the whole group.

Sometimes the group may have a problem which affects all people who are labelled 'handicapped' or 'disabled'.

For example:

One person may have a problem. A review meeting is being held to discuss where she will live. That person has been told she can't go to the meeting even though it's about her life. She wants to go and tell them what she thinks. The group may decide they are going to speak to the people having the meeting and see that she is allowed to tell the people there what she feels.



## 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.

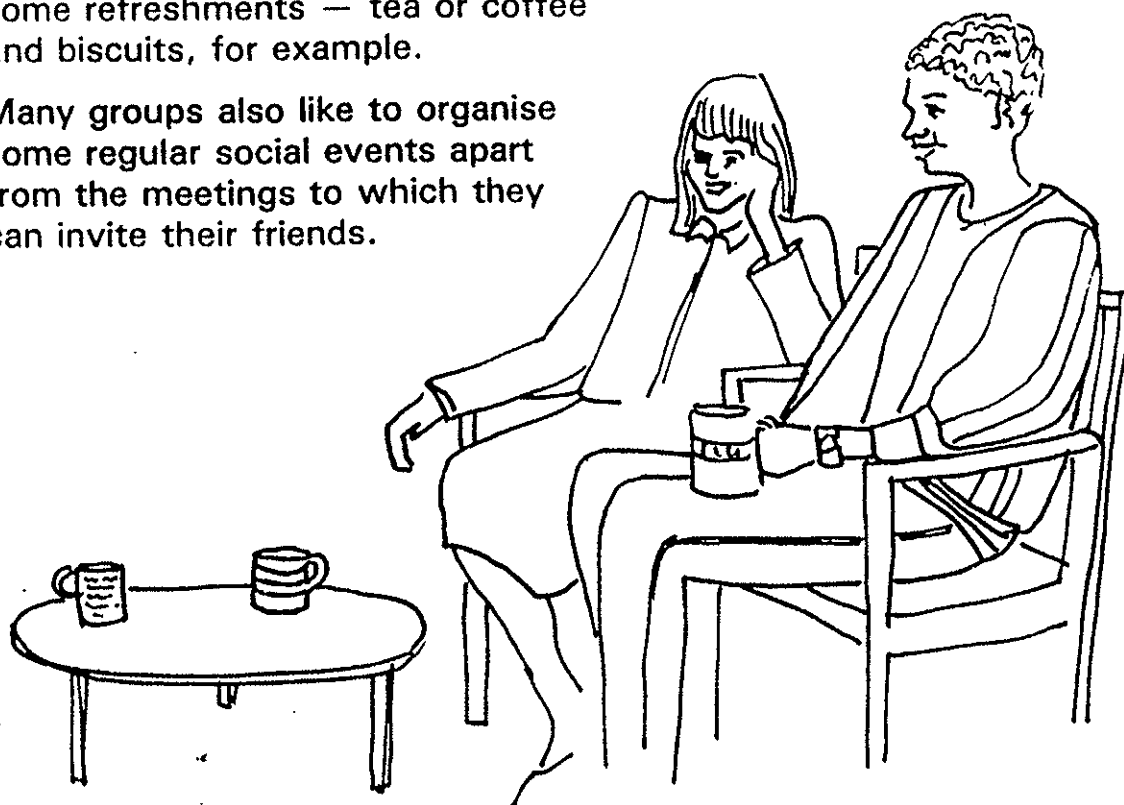
For example:

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 are nervous of talking in the meeting may have a chance to say what they think.

It's usually a good idea to serve some refreshments — tea or coffee and biscuits, for example.

Many groups also like to organise some regular social events apart from the meetings to which they can invite their friends.

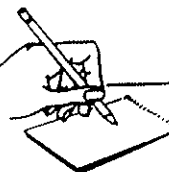


For example:

One group decided to organise a Christmas party. They hired a room in the local community centre and invited along their friends and supporters for the evening.

### **THINGS TO DO**

***Can you think of a list of activities which your group might like to do in the future?***



# WHY DO WE NEED SELF-ADVOCACY?

People often don't know much about people with learning disabilities.

The things that people read about us in newspapers and books, or hear on the radio or see on television, are often negative, unhelpful or simply untrue.

In the past people with disabilities have often been shut away so people have not met us and got to know what we are like or what we think.



As a result people may avoid us, think of us as second-class citizens, or even ill-treat us.

Self-advocacy is a way of letting other people know that:

- People with disabilities are people first
- We are important people; just as important as anyone else in the world.
- Just because we are all different from each other doesn't mean that any of us are less important.
- We want the chance to be full citizens of our community.
- Many of us have shown great courage in overcoming our difficulties.

## **THINGS TO DO**

*Can you think of any other ideas that people have that are wrong and that should be changed?*

*Can you describe the most important things about yourself and other people with handicaps that you know?*

We need self-advocacy to tell people who we are and what we think.

This will help to change people's wrong ideas. It will help people to treat us better and give us more opportunities.

Without self-advocacy we will continue to be seen as second-class citizens.

With self-advocacy we will be seen as people first.

## **SUMMARY**

**Self-advocacy is a way of letting people know that we are people first**

**And that we are as valuable as everyone else.**

**Many people have a lot of wrong ideas about people with handicaps.**

**These ideas need to be changed.**

**We need self-advocacy to tell people who we are and what we think.**

# KEEPING THE GROUP GOING

Any kind of group has its ups and downs.

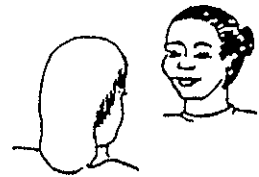
Some meetings are better than others.

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 difficulty 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.**

# MONEY MATTERS

## WHY DO YOU NEED MONEY?

You do not need very much money to start a group.

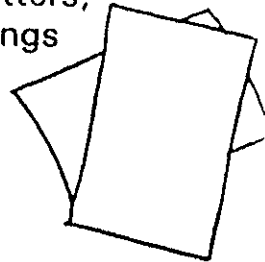
BUT once your group gets going you may need money to help run the group well.

Some of the things you might need money to pay for when you start are:

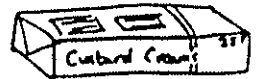


envelopes to send out the letters and notices

writing paper for writing letters, notices and notes of meetings



stamps for letters



tea, coffee and biscuits.

Then, when your group gets bigger and you want to do more things you might need money for

- \* photocopying
- \* printing a newsletter
- \* telephone calls
- \* rent (if you have to pay for using a room or hall).

### **THINGS TO TALK ABOUT**

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

***Make a list of these things.***



## **SUMMARY**

**You need money to help run the group well.  
But you don't need money for everything you want to do.**

**You can get money**      **from your members**  
  
**by organising fund-raising events**  
  
**by asking for a grant from an organisation.**

**Every group needs a Treasurer to look after the money.  
It should be someone who likes doing arithmetic and who can add  
and subtract money.**

**There are two main ways of looking after money —**

**in a petty cash tin (for small amounts of money)**

**in a Bank or Building Society  
(for large amounts of money).**

**It is a good idea to have a rule that two people must sign each  
cheque when money is withdrawn from the Bank or Building  
Society.**

**REMEMBER — don't spend all your time worrying about money!  
Have some fun too!**



# THE AGENDA

## WHAT IS AN AGENDA?

An AGENDA is a list of things your group has decided to talk about at a meeting.

Each thing on the list is called an ITEM.

The AGENDA is a list of these items.

## WHY HAVE AN AGENDA FOR MEETINGS?

An agenda may sound rather unnecessary for a meeting of a group of friends who want to just get together and discuss some things.

BUT there are several reasons why having an agenda is a good idea.

An agenda can

- help people to get through the business of the meeting
- help people remember what the business of that meeting is
- help individuals remember if there are particular items they specially want to speak about.

You can make sure you get through all the business by allowing a certain number of minutes (roughly) for each item on the agenda.

You won't probably 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 which may make up the agenda. They are ones that other groups have found useful.

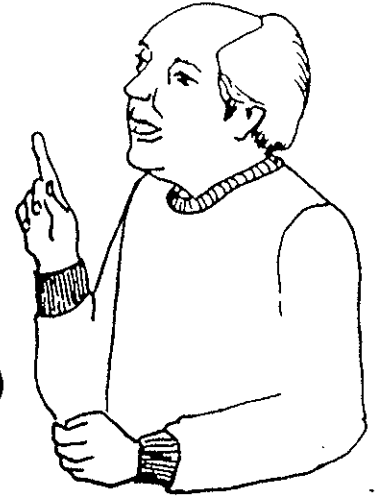
5. Discussion about money.  
The Treasurer's report.



6. Old business.

7. New business.

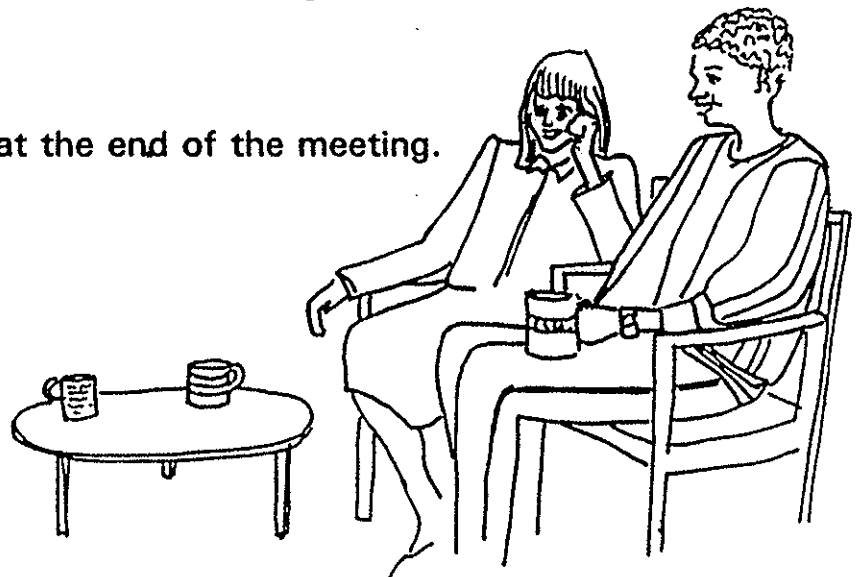
8. Requests for speakers.  
(Your group may have been asked  
to send someone to speak to  
another group about self-advocacy.  
You need to decide who will do this.)



9. Any other business  
(Any business which hasn't been dealt with  
earlier in the meeting.)

10. Date and time of next meeting.

11. Social time at the end of the meeting.



You may also want to add in:-

the name of the person who will introduce each item,  
and  
roughly how much time you will spend on each item of the agenda.

# LISTENING

When someone is talking, there is another very important task to be done by those who are not talking.

This task is to listen.

Listening means paying attention to the other person when they are speaking and trying to understand what they are saying.

It also means trying to understand what someone is 'saying' to you if they are using drawings or signing — or any of the other ways of communicating.



## HOW TO LISTEN

Ways of showing people that you are listening are:

- by looking at the person who is speaking
- by not turning your head away, or moving away, while they are speaking
- by not fidgeting or starting to do something else
- by giving them signs that you agree or don't agree with them — for example, nodding your head, or saying 'yes' or 'Aha' or 'Mmm'
- by asking questions about what the person is saying — for example, 'Can you tell me some more about that, please?'

Sometimes it is difficult to pay attention to people and to listen to them well. This can happen —

- if a person speaks very quickly or very slowly
- if they cannot speak very clearly
- if they use difficult words
- if the person uses sign language and you do not understand it
- if the person cannot use speech or sign language.

## **SUMMARY**

**Listening means paying attention to what another person is saying to you.**

**It is important to be a good listener because**

- it shows the other person that you are interested in them and what they are saying**
- it encourages people to talk to you**
- it shows the other person that you think they are important.**

## HISTORY OF THE SELF ADVOCACY CAUCUS

The Self Advocacy Caucus was started in 1987, but self advocates have been involved in BCACL since the early 1970's. Before we look at the history of the Self Advocacy Caucus, it is a good idea to look at what happened in the ten years before the Caucus was formed.

- In 1976 the first self advocates were elected to the B.C. Association for the Mentally Retarded (BCAMR) Board of Directors. They were Jacquie Hall (Siggs) and Jim Balfour.
- In 1981, BCAMR appointed the Self Advocacy Task Force. It was chaired by Conrad Alberts. A large meeting was held at Hero's Restaurant with self advocates from all over B.C. to talk about the things that were important to them and what people needed to make their lives better. By the end of 1981 the Task Force was named the Self Advocacy Committee - the purpose was to be a link between People First and the BCAMR.

1981 was also the International Year of Disabled Persons. BCAMR received a grant from the Secretary of State to promote self advocacy. Ludo Van Pelt and Charles Curtis were hired to travel the province and meet with self advocates. Several People First chapters were formed.

- In 1982 the self advocates who were involved with BCAMR worked on developing their public speaking skills. Some self advocates were making presentations in public forums and educational settings. Gordon Fletcher was appointed as chairperson of the Self Advocacy Committee.
- In 1983 BCAMR became British Columbians for Mentally Handicapped People (BCMHP). Many self advocates wanted this change to happen.
  - A Self Advocates conference was held at the same time as the BCAMR AGM and more than 200 self advocates attended.
  - Self advocates made a presentation to the McDonald Commission on Economic Development.

Self advocates from Capitol People First in California were the keynote speakers at the AGM.

The plain language book -"This Book is about Rights" - was published. Rose Fulcher was the first Chairperson of the Caucus.

1988:

Six Caucus members were appointed as ex-officio members of the BCMHP Board.

The Caucus invited Bob Cronin, John Lord, Robin Loxton and Gus Long to speak to Caucus.

An all candidates forum was held inside Woodlands in preparation for the federal election.

Workshops were held in several communities.

Penny Soderena was elected Chairperson of the Caucus.

1989:

Self advocates spoke out in favor of changing BCMHP to the B.C. Association for Community Living. The name was changed at the 1989 AGM.

The Self Advocacy Foundation was formed.

Self advocates worked with Headlines Theatre Co. on the Power Play "And the Walls Come Tumbling Down".

Self advocates participated in the training of MSSH social workers.

The first issue of "The Voice" was published in September, 1989.

A representative of the Self Advocacy Caucus (Phil Allen) met with the Minister of Social Services and Housing, Claude Richmond.

# 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.

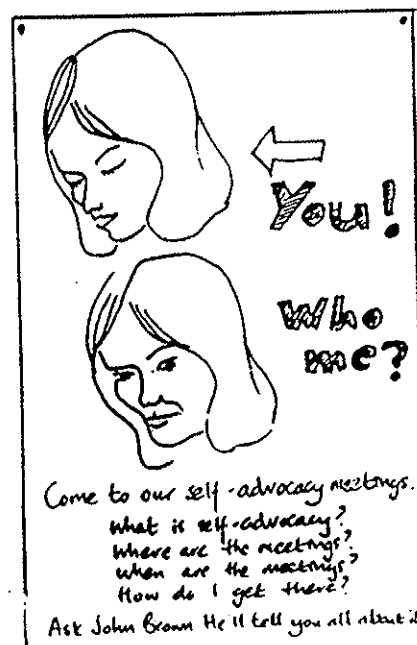
Perhaps you can offer to meet a new member on the day of the meeting and travel there together.

## MAKING POSTERS ABOUT THE GROUP

Posters should be bright so they can be seen clearly.

Posters should give the name of the group, where it meets and when, and briefly what it does.

It is probably also a good idea for the poster to give a name and phone number where people can find out more about the group.



At a place which can be used by people in wheelchairs  
At a time which doesn't clash with other things like Gateway club evening  
At a place which people can get to easily by public transport.

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!

## **MAKING NEW MEMBERS WELCOME**

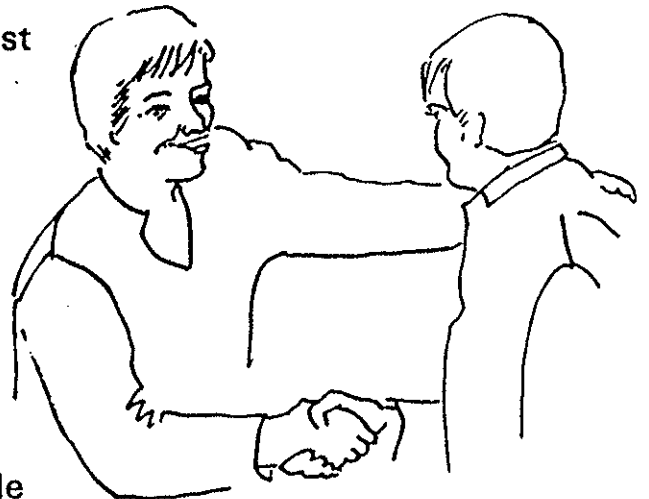
Probably everyone can remember what it felt like to go into a room where there were a lot of people you didn't know or where you knew only one other person.

So it is important that people coming to your group for the first time are made to feel welcome.

Otherwise they may not come again!

When anyone comes into the meeting, make sure they get a friendly welcome.

You might want to make one member of the group responsible for this. They could stand at the door and welcome people.



Introduce new members to other people in the group.

Make sure new members have the chance to speak — if they want to.

Make sure new members know what is going on in the group. It can be hard to understand what is going on the first time you go to a meeting.



# MAKING THE MOST OF EVERYBODY'S SKILLS

Self-advocacy can involve many different skills.

Some of the most important ones are:-

- getting your message across clearly (communication)
- paying attention to other people (listening)
- making choices (making decisions)
- finding answers to questions (solving problems)
- feeling confident about yourself and speaking up (being assertive)
- giving everyone a chance to take part.

This may sound like a very long list of skills. When you read it, you may feel it is too difficult for you!

## BUT REMEMBER

You don't have to be good at all of these skills to take part in self-advocacy.

To make the most of self-advocacy, make sure that everyone uses the skills they have, and find help when you need it!

Here are some ways to do this:

### 1. SHARE OUT THE JOBS

Everyone is good at doing some things.

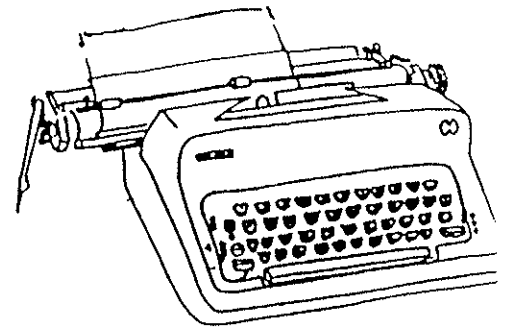
We call these a person's strengths.

In any group, different people will have different strengths. 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.

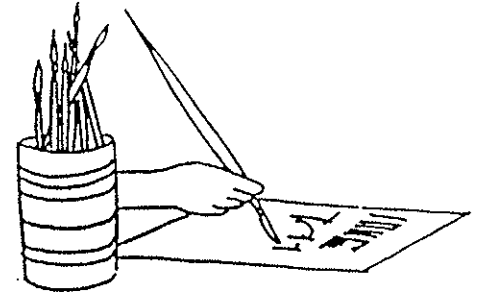
If you are part of a self-advocacy group, your advisor may be able to help you. If you are not in a group, a friend, member of staff, or one of your family may give you a helping hand.



You may need help from a person with a particular skill:

For example:

- from a secretary to do your typing
- Or from someone who is good at art to draw a poster
- Or from a person who understands about money if you want to open a bank account.



You may need help from a person who can give you information or advice.



For example:

- If you need to know about what benefits you are entitled to, a local Welfare Rights Officer or the Citizen's Advice Bureau should be able to help you.
- If you need information about the law, a policeman may be useful.
- If you need to know more about money, a bank manager may be able to answer your questions.

Don't be afraid to ask for help.

**Remember —**

**we all need help at times.**

**Ask for it when you need it.**

### 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 practise speaking into if you have to give a talk.

# **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.

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