

Front cover

SELF-ADVOCACY SKILLS TRAINING

Report of two workshops held between April and September 1987

by Alison Wertheimer

Front cover includes four photos taken at the workshops

THE KING'S FUND CENTRE

Title pages

King Edward's Hospital Fund for London is an independent charity founded in 1897 and incorporated by Act of Parliament. It seeks to encourage good practice and innovation in health care through research, experiment, education and direct grants.

The King's Fund Centre for Health Services Development has a particular role in promoting advances in policy and practice in relation to problems of health and related social care. It offers a forum for informed debate, provides an information service and organises a range of activities designed to support local strategies for service development.

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"I have gained confidence and I can help other people get confident."

"Some people are still a bit scared about speaking up for themselves. We can help each other by going out with another person to, say, college or swimming, to get confidence and not to worry about people laughing at us."

"Staff should tell us what goes on in the meetings. We're not allowed to go to them."

"Why do letters to the group all have the advisor's name on them and not mine?"

"People feel really good when things succeed."

"You learn to think for yourself."

Foreword

Historically, it has been the practice for other people to advocate for people with learning difficulties. It is clear however, that, given the opportunity to acquire the appropriate skills, any people can advocate for themselves, make choices and decisions, and take the responsibilities that go with those decisions. What is more, they want to speak up for themselves and take responsibility for running their own lives.

Moves towards enabling this to happen began in Britain in the early 1970s with the development of trainee committees in day centres and the organisation of various participation events and conferences. Over the past four years there has been a tremendous increase in interest in self-advocacy encouraged partly by the activities of the self-advocacy organisation, People First. Many people are now learning how to speak up for themselves whether it be in a social skills class at their local training centre or FE college, as a speaker at a self-advocacy conference, or as a member of a self-advocacy group.

But self-advocacy is more than just being able to speak up for yourself. It is about making decisions, knowing about rights and responsibilities, solving problems, knowing how to take action about things that concern you. It is not only about getting the things you want, but learning how to handle disappointment and frustration when you don't get what you want. It is also about working with staff, advisors, family and friends in such a way that you get as much help as you need - but not too much!

For staff and other supporters it is understanding that self-advocacy is much more than social skills - or communication skills - or self-expression; it is more than just another subject on the Centre curriculum to be 'taught' from 2.00-3.00 on a Monday afternoon. It is about learning how and when to reduce your involvement— how to take a 'back-seat' role— as an individual or group learns more skills and takes on more responsibility. It is about learning the very difficult skill of being a good listener. It means working in partnership with people so that there is a real sharing of power.

Clearly, self-advocacy is a challenging concept, not only for people with learning difficulties but for their families and for services. So— how can we support the many people who are already committed to the ideas in principle but are searching for good ways of putting these principles into practice?

We can learn from looking at how other self-help groups work. We can also learn from the

experience of countries like the United States where self-advocacy has been a part of people's lives for over fifteen years now. But here in Britain we are just beginning. We don't yet have much written or visual material to help us. Many people are asking for practical help with such questions as:

How do we get a group started? And keep it going?

We've got a group going, but how do we get beyond the 'talking together' stage?

How can advisors and self-advocates work together better?

At these workshops we began to tackle some of these questions. You will not find all the answers in this report! But we hope you will find some good ideas and perhaps be encouraged to organise a workshop in your own area. The King's Fund Centre is very interested in developing ways of helping consumers and services work together better and we would welcome your comments and suggestions.

Andrea Whittaker

Project Officer, King's Fund Centre

Advisor, People First

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Introduction

The workshops

Between April and September 1987, the King's Fund Centre held two two-day pilot workshops for self-advocates with learning difficulties and for advisors. Under the title "Helping your self-advocacy group to grow", the workshops aimed to help people increase their own skills and those of other members of their group. People attending the group already had a basic knowledge of self-advocacy and were involved in existing groups.

Participants were asked to come as teams of four, at least two members of each team being active self-advocates. A total of thirteen groups attended the workshops and their names and addresses can be found at the end of this report.

Each group attended two one-day workshops. There was a two-month gap between each of the two days, when participants went back to the groups and worked on specific tasks which they had set for themselves. After the first day, the workshop organisers were able to build the second day around issues which participants had said they would like to spend time on when they returned for the second workshop.

The workshops were organised and run by :—

Gary Bourlet, Self-advocate and President of People First

Jan Porterfield, Mental Handicap Advisor to the Joseph Rowntree Memorial Trust

Andrea Whittaker, Project Officer, Long Term Care Team, King's Fund Centre and Advisor to People First of London and Thames

The content and structure of the report

During the four days, a great many interesting things were said. But to have included absolutely

everything would have resulted in a report that was too long, so this publication attempts to:

- describe the main content of the four days;
- explain how various skills were taught;
- share the most important issues which arose;

- discuss some of the practical issues involved in setting up the workshops.

Setting up and running the workshops: Some practical issues

Deciding the content of the workshops.

All three workshop leaders had considerable experience in self-advocacy and the content of these workshops was decided by them on the basis of their knowledge and experience. With hindsight though, it would have been a good idea to involve more self-advocates in the planning stages and anyone thinking of running their own workshops should consider having a planning group with, perhaps, equal numbers of self-advocates and other people. Allow plenty of time at this stage, as self-advocates may, for example, want to go back and consult their groups before final decisions are made about the workshop content

We found it particularly useful to have the second day some time after the first one. This enabled us to think about what we had learned from the first day and to try and plan the second day taking into account the things participants said they would like to know more about. Also, people seemed to enjoy the chance to come back for a second day, meet up again with the same people, and get to know each other better.

Preparation for group leaders

We did no specific preparation for people who were group leaders or who were taking part in the role-playing. This was mainly due to lack of time and anyone planning similar events would do well to allow more time for planning and preparation than we did. On reflection we feel this might have been useful as it would have given people the chance to think a bit about the small discussion groups before they came to them. As it was, advisors tended to chair these groups, rather than the self-advocates themselves.

Using role-play

We used role-play with both groups of participants to explore the issue of how the chairperson can deal with “unruly” meetings. It seemed to be a useful exercise but more preparation for those who actually performed the role-play would have been helpful. We were only able to organise it on the morning of the workshop: we asked particular people to take part and gave them a very short ‘briefing’ on what we wanted them to do. This was not enough preparation time. Also it would have been useful to have a script -

with lines written out like a real play. This would have made it easier for the people taking part who could read, and it would have reduced the amount of 'improvising' that had to be done.

Using video

Most of the sessions were video-recorded, and we found this useful because:—

- We could play back the recording of some sessions immediately to reinforce information which had been given or skills which had been taught (eg. how to get quiet people to participate in meetings).
- We replayed parts of the first day's workshop when people came back for the second day and this helped people to remember some of the things we had talked about.
- Many participants commented that they enjoyed being videoed and seeing themselves on the screen when it was played back. (Remember though, you really need a large screen – or monitor to play it back on in order for everyone to be able to see it properly).
- There may be some parts of the video material which could be edited and used more widely for teaching about self-advocacy

Separate sessions for advisors and self-advocates— a good idea or not?

We tried both! Though after the first two days we decided not to have separate groups in future. You will probably want to make up your own minds about this one. Some self-advocates wondered what the advisors were saying about them when they weren't present— and some advisors weren't too happy talking about self-advocates in their absence. It's something people have different views about but we felt that anything advisors had to say should be said in front of self-advocates and we would not recommend having separate groups.

Timetable for the day

Although we had a written timetable for each of the workshop days, in practice it was useful to be flexible and regard the timetable as only a rough guide. We put in extra short breaks, for example; we also found that some sessions didn't need as much time as we'd allocated, but others needed more.

Equipment for the day.

It is useful to be able to write or draw things for everyone to see and so we did some 'wallpapering' during each workshop. For those not familiar with the idea, the 'wallpaper' is actually long strips of the sort of paper which newspapers are printed on; these are fixed to the wall with masking tape you can then write on them with felt-tip pens (BUT have a double layer of paper to make sure the pens don't mark the walls!). If you don't want to use this method, then flip charts are another (but more expensive!) way of writing or drawing information to share with everyone.

We also had a map of Britain and marked on it with pins where each group came from. This meant that people could see where the other groups were if they were thinking of going to visit them. It also meant that we could see where groups were "clustered together" and might form a network to meet together in future.

Starting the day

Sharing information about the groups

As each team arrived, they were asked to write up the answers to the following questions on large sheets of 'wallpaper'. (An example of what this looked like is on the next page.):-

WHAT IS YOUR GROUP CALLED?

WHAT ARE YOUR NAMES?

HOW MANY PEOPLE ARE THERE IN YOUR GROUP?

WHAT DATE DID YOUR GROUP START?

WHY DID YOU START?

WHERE DO YOU MEET?

HOW OFTEN DO YOU MEET?

Introducing the day and setting the ground rules

The workshop leaders introduced themselves to the participants, and suggested the following rules' for the day:-

- Although this is a workshop for self-advocates and advisors to work and learn together, we need to remember that self-advocacy is about people with learning difficulties speaking for themselves. We hope that advisors, therefore, will let that happen today, by allowing self-advocates to control the day themselves as far as possible. Of course advisors may talk but please don't take over!
- If you feel uncomfortable about joining in any part of the day, don't feel you have to. You are free to opt out if you want to.
- Silence is OK. Some people may need time to say something so if that means some silence - that's OK.
- We're all here to learn today and to share skills. There are no experts in self-advocacy, so let's share things and learn from each other.

Getting to know each other— Some “Getting To Know You” Games

We used two different games for getting to know each other.

(1) Working in pairs:

- Each person chooses a partner— preferably someone they don't know.
- Each person tells the other person their name, where they come from and if there's time, a bit about what they do
- After everyone has done that in pairs, go round the whole group and each person introduces the person they were listening to to the rest of the group.

- Although it can be quite hard for people to remember what the other person said, it's a good way of practising listening to other people and trying to remember what they said.

(2) Working in a big group:-

- Everyone sits round in a circle
- Each person takes it in turn to go into the middle of the circle
- They say their name and something they like. For example: "My name is David and I like football"
- The whole group repeats: "His name is (David) and he likes (football)"
- Go round the group until everyone has had a turn.

Another way of playing the game is for each person to go into the centre and say their name followed by something they don't like. For example: "My name is Jane and I don't like getting up in the morning".

In the workshops this not only reminded us of everyone's name but we learned about some of the different things people like (pop music, computers, tennis, holidays) and some of the things they don't like (violence, tapioca pudding, discrimination).

Example of wallpapering done at the start of the workshop

WHAT IS YOUR GROUP CALLED?	YOUR NAMES?	HOW MANY MEMBERS?	STARTING DATE?	WHY DID YOUR GROUP START?	WHERE DO YOU MEET?	HOW OFTEN
HUDDERSFIELD PEOPLE FIRST	Joyce Kershaw Kevin Richards Alan Le Broc Sheila Ireland	22	August 1986	We want to be more independent	At the co-op	EVERY TWO WEEKS
RAVENSWOOD PEOPLE FIRST	Naomi M Jshin Michael Banbury Jeni Shaw John Griffiths	7	January 1987	People wanted the opportunity to change things	In the training centre	MONTHLY

Learning the skills for self-advocacy

Being a chairperson

What we did

We learned about this in several different ways:-

Gary Bourlet who is president of People First and chairs their meetings gave a talk to everyone.

Other people who also chair their groups shared their experiences with other participants.

Some of the small group sessions discussed the role of a Chairperson.

What people said

Here are some of the things people said about being a Chairperson:-

- The Chairperson must be elected to do the job and should know what it involves before taking it on.
- They should be there well before the meeting starts to make sure everything is ready and that there is an agenda for the meeting
- The Chairperson is a leader but must not dominate; each group member must be responsible for him or herself.
- They must listen to the group and try and find out what the group wants.
- The Chairperson should make sure that everyone gets a chance to speak if they want to. You can go round the table and ask people if they want to say something
- The Chairperson must not tell the group what to do.

- They must keep the meeting in order (see below for more about this) and make sure that only one person talks at once.
- If a meeting is arranged on a date you can't be there, you must make sure that the Vice-Chairperson can be there instead of you

- The Chairperson has to help the group keep “on track” and not wander off the subject being discussed.
- You can have two Chairpersons (like one group which has one person who can read and one who can't).
- Chairpersons have to do quite a lot of work outside the meetings like making phone calls, writing letters and representing the group at other meetings.

Other officers in self-advocacy groups

What we did

We spent some time in small groups talking about the roles of the various officers in self-advocacy groups and the sorts of things they need to learn to be good officers.

What people said

The Secretary

The main jobs of the Secretary are to

- keep a record (the notes) of the meeting;
- help the other officers decide the agenda for meetings (see sample agenda on page);
- write letters for the group;
- keep an up-to-date list of names and addresses of group members

People talked about how self-advocates could learn to keep a record of meetings. Here are some of the ways people suggested the Secretary could do this job;

- The Secretary and the advisor could both take notes. Afterwards they can compare them and make sure all the important points have been noted
- The Secretary could take notes of only one or two items on the agenda and let the advisor do the rest. Gradually, the Secretary can do more and more as they get better at the job, and the advisor can do less.
- Two or three self-advocates could share the job; they can divide up the agenda between them and cover two or three items each. At the end of the meeting they can put their notes together.

- The Secretary could use a tape-recorder in the meeting. Afterwards the advisor and the Secretary could write the notes from the tape-recording. But the tape will record everything that is said and writing notes this way can take a long time.

People also talked about how the Secretary can help other people who can't read. A tape-recorder can be useful here as the Secretary can read the notes on to a tape. The tape can then be played back for people to listen to. The Secretary could also draw pictures on the agenda and on the notes to help people who can't read very well.

Doing the Secretary's job involves learning quite a few skills and the person who does the job will probably need a fair amount of help from their advisor — at least at first.

The Vice-Chairperson

They will need to make sure they can be at any meetings which the chairperson is unable to attend so that they can chair the meeting instead.

The Treasurer

This person will need to be able to handle money; it is likely to involve jobs like going to the bank and writing cheques.

General points

- Before you volunteer for a job make sure you know what skills you need (or what skills you should be prepared to learn) before you put yourself up for the job.
- Some jobs (like Chairperson or Secretary) involve a great deal of work and it might be worth considering whether the group should ask two people to share the work between them.

Most of the discussion at these workshops was about the roles of the Chairperson and the Secretary. However, anyone wanting to find out about these roles and about the roles of other officers like the Treasurer and the Vice-Chairman can find this information in the Learning About Self-Advocacy materials (published by CMH, 12A Maddox Street, London W1R 9PL).

People First of Chard and Crewkerne

This is a typical agenda for one of our meetings

Meeting on Tuesday June 16th

AGENDA

1. Refreshments
2. Apologies for absence
3. Minutes of the last meeting
4. Subscriptions
5. Talking about ourselves
6. How to contact your social worker
7. Any other business
8. Next meeting date and context
9. Transport home

Having good meetings

What we did

As well as talking generally about the work of the Chairperson, participants spent time working on how to ensure that the Chairperson keeps control of the meetings so that the group discusses the items on the agenda and gets through the business.

We did a role-play about a meeting where the Chairperson was having a hard time keeping control.

The story for the role play was this:-

Members of People First are having their meeting.

They are discussing plans for the leaders' weekend.

Bill Jones is chairing the meeting.

Two other people are also trying to chair the meeting!

Several self-advocates are not taking part at all.

Some of them are having private conversations with their neighbours.

One person gets up and goes out to fetch a cup of coffee.

They come back with coffee and someone else goes to get themselves coffee too.

The Chairperson is trying to lead the discussion but no one is taking any notice.

No one is doing anything about it.

UNTIL

The advisor says -“Hold on a minute! This is a very strange meeting. All these people walking in and out of the room. We can't hear what's being said. Shouldn't we be concentrating on talking about the leader's weekend?”

Afterwards we went into small groups and discussed what had been going on. We tried to answer these questions:-

Did the advisor do the right thing?

If “Yes” why was it right?

If “No” what did the advisor do wrong?

How could the advisor have best helped the group?

What people said

- Most people thought it was the Chairperson’s job to control the meetings and stop things like people walking in and out.
- If the Chairperson isn’t doing this, perhaps the advisor should quietly suggest to them that they need to call the meeting to order.
- Some people thought the advisor could best do this by sitting next to the chairperson.
- Other people thought this might not be a good idea because the advisor might look as if she or he was controlling the chairperson. They thought it was better for the advisor to sit away from the chairperson.
- The advisor's job is to help people do things— not control the meetings directly.
- If people need tea or coffee, the group could have a break in the middle, and have a jug of water and glasses on the table during the meeting; but people shouldn't walk in and out.
- People should talk one at a time and speak to the whole meeting. They shouldn't have private conversations with people next to them.

Voting

What we did (1)

We started off by looking at what the word “voting” means

What people said

Voting is about

going to the polls in elections

putting your vote in a ballot box

voting for something at a meeting

a way of coming to an agreement about something

electing the officers for the group

deciding about something

choosing something

What we did(2)

We talked about how groups voted in their meetings.

What people said

We put our hands up.

We talk about it and then ask who agrees.

We have two boxes— a “yes” box and a “no”box— and you put a piece of paper in the one you choose. We talk about the issue amongst ourselves. Sometimes there are big decisions and sometimes small ones.

So there are lots of different ways of voting.

What we did (3)

We learnt one way of voting which has SEVEN STEPS:

STEP 1: PROPOSING THE MOTION. Someone says, for example, “I propose (or “I move”)

that we send a team to the King’s Fund workshop”.

STEP 2: SECONDING THE MOTION. Someone says “I second the motion” which means “I want to talk about that too!”

STEP 3: TALKING ABOUT THE MOTION. Everyone has a chance to discuss the idea if they want to. It's important that everyone has the opportunity to do this.

STEP 4: VOTING. Choose two people to count the votes. Remember only one vote per person

You can't vote yes AND no.

STEP 5: VOTING “YES”. Everyone who think it's a good idea to send a team to the workshop

raises their hand.

STEP 6: VOTING “NO”. Everyone who thinks it's not a good idea and wants to vote “No” raises their hand.

STEP 7: ANNOUNCING THE RESULTS. The Chairperson announces the results of the vote. (For example: “Twelve people voted ‘yes’ and three people voted ‘no’. So the ‘yes’ vote wins, and we will send a team to the workshop. The motion is carried”

Voting in secret or not?

Although it's OK to vote by a show of hands, sometimes people may want to vote another way which is in secret (for example, by putting a vote in a box) because they don't want everyone to know how they voted

Useful things to remember

It's important to remember that you can only vote once; so once you've voted, you can't change your mind and vote again. Vote the way you want to; if the person next to you or a friend votes differently, don't feel you have to copy them. Make sure that the proposal gets discussed thoroughly so that you're clear what it is you're being asked to vote about. If you can't make up your mind, remember, you don't have to vote (this is called 'abstaining')

How to practise voting

We practised voting by having seven cards which each had one of the SEVEN STEPS (see above) drawn on it. Seven people each take a card and stand in any order. Everyone else tells them which is the right order for voting.

Listening and taking turns

What we did (1)

We started off with this game;

- Six people go outside the room and wait
- The workshop leader explains to the others that she will be giving the six people a subject to talk about.
- The rest of us will watch and try and answer the following questions:-
 - who talked most?
 - who talked some of the time?
 - who didn't talk at all?
 - were people listening to what people were saying? or
 - were people just saying what they wanted to say?
 - did people stick to the subject or talk about other things?
 - did someone try and be the Chairperson even though they had not been elected to do that job?
- The six people come back into the room and are asked to discuss this story:-
Michael has been living with his mother at home. She has died. Where could Michael go and live now?
- We used the video here and played it back straightaway afterwards so we could see again what had happened

After we had played the game, we discussed what had happened; we saw that lots of different things had happened in the small group. Some people had talked a lot, for

example, and some people had hardly got a word in edgeways! Some people also felt that the men had been doing too much talking and the women didn't get enough chance to speak!

What we did (2)

We played another game to practise listening—

Andrea, Adrian and Brian showed us how to play it, and the rest of us watched.

Andrea told Adrian a story (about where she lives, how many rooms there are, what she grows in the garden, and so on). Adrian then had to repeat back to Andrea as much as he could remember. Brian listened too and he then told Andrea anything that Adrian had forgotten to mention.

We then split into groups of three and practised this with each other.

What we did (3)

Lastly, we played a game called Chinese Whispers which is yet another way of seeing how good we are at listening to what people are saying

Everyone sits round in a circle

One person starts by whispering something to the person on their left.

They then repeat it to the person on their left.

This goes on right round the room until it comes back to the person who started off.

Our game started with someone whispering "weather forecast" to the person next to them. By the time we had been right round the room and everyone had had a turn, the words had turned into "red box"!

What people said about listening

You have to concentrate hard on what the other person is saying.

It helps to remember what they are saying if you look at them while they are talking.

The listener should look interested in what the other person is saying.

The person who is talking feels good if the listener looks at her.

Helping quiet people to take part in meetings

What we did

Gary and Naomi showed the rest of us how we can help quiet people to speak up. Gary is used to speaking up in self-advocacy groups and he showed us how he would help Naomi to speak up.

We also talked in some of the small groups about how we can help “quiet people” to speak more easily in groups.

What people said

- Talk to the person about things which they are particularly interested in or enthusiastic about
- Sit or stand close to them so that they feel supported.
- Look straight at them, so they know you're listening
- If people find it hard to start talking, say something like “take your time”, so they don't feel pushed into talking.
- Give them plenty of encouragement with comments like ‘your voice is becoming much clearer

Involving people with more severe learning difficulties in self-advocacy

What we did

This is a difficult issue for self-advocates and we spent some time sharing our ideas about how we could better help people who, for example, can't speak or who have other difficulties

We did this by "brainstorming". Brainstorming is a useful way of solving problems in a group It's particularly useful when the problem has no easy answers. In a brainstorming session, someone starts off by saying what the problem or issue is. After that, anyone can throw in an idea of how to solve it. The more ideas the better! It doesn't matter how wild the ideas may be. At the end, you can go back through the whole list and decide which ideas are the most workable

What people said

Here are some of the ideas which people came up with

- People with severe learning difficulties may really need to stand up for their rights.
- Other self-advocates could learn sign language to communicate with people who can't speak.
- Someone may have a special friend (or 'buddy') who can interpret their views to the rest of the group.
- If not everyone learns sign language, then one person could act as interpreter to the rest of the group.
- People who use wheelchairs or who walk with difficulty will need ramps to get into buildings and lifts to get upstairs.
- Speaking is only one way of being a good self-advocate. People need to be good listeners too and someone who can't speak very well may be a good listener.
- Don't believe it if other people say that they think someone is "too handicapped" to be a self-advocate. We heard about one woman who came to meetings; no one outside the group thought she had any idea about what was going on, but she does and she's begun to make her own contributions to the meetings. She still has a lot of difficulties because she's lived in hospital so long, but she benefits from being a self-advocate and is learning to put over her point of view

Putting over your point of view

What we did

Two people showed the rest of us how to have a discussion about something on which they disagree and how both can put their own point of view forward to the other person. We also talked in groups about how we can do this.

What people said

- It's OK for people to have different views about the same issue and to disagree with one another in the group.
- You have the right to your own opinions.
- You can still be friends with people even if you don't always agree with them.
- Your group won't fall apart because you don't all agree with each other all the time (though you may need to vote sometimes to make decisions).

Achieving your aims in self-advocacy groups

Participants had very many different things they wanted to achieve, and at the end of each workshop, the teams wrote down some things they hoped to do when they got back to their groups.

When people came back for the second workshop day and we looked at how far the groups had got in achieving their aims, we realised that:

- Some aims are very big and may be difficult to achieve.
 - EXAMPLE: getting more housing for people with learning difficulties
- Sometimes things can take a long time to change. You may need to gather a lot of information, talk to many people and persuade them to support you.
 - EXAMPLE: find more jobs for people as an alternative to adult training centres
- Some aims can be achieved quite quickly.
 - EXAMPLE: getting the labels taken off the minibuses.
- Some aims can be achieved very quickly.

- EXAMPLE: telling others how important self-advocacy is to you.
- Sometimes other things happen which 'take over' and mean that the group has to postpone its work on a particular objective.
 - EXAMPLE: summer holidays!

Participants had lots of ideas about how to achieve changes and here are some of the things they said:-

- There are all sorts of ways of negotiating for change. Some are informal (like going to have a chat with the centre manager) and some are more formal (like going to meetings and putting over your point of view)
- Self-advocates need to feel comfortable about going to meetings and speaking up.
- If one sort of negotiation doesn't work, try another way! Don't give up!
- There are some things which we can't change and it can be hard when we talk about those things.

Here are two EXAMPLES of how groups managed to achieve their aims:-

Hillingdon People First decided they wanted to have a coffee machine in their ATC. They talked about it and elected three members of their group to represent them. They arranged a meeting between the centre manager and the three people. The manager agreed with their proposal and the machine was installed

Ravenswood self-advocacy group discussed the labels which were on their minibuses and decided they wanted them removed. They talked about this with their advisors who approached the head of their department. The Board of Trustees of Ravenswood were approached with a written request from the self-advocates and it was agreed that the labels would be removed.

Working with advisors

What we did

During the four workshop days, there were two sessions when advisors met together to discuss their role in self-advocacy. The discussions ranged far and wide and at times people talked about issues not specifically related to their particular role. (Advisors aren't always very good at keeping to the subject either!).

What did emerge, though, is that advisors are looking for advice. But none of us is an expert in self-advocacy, we are all learning 'on the job', so what the discussions did was to point to some of the issues which we all need to think about and work on further together.

Although there were these separate discussion groups attended by advisors, some participants thought there should not be separate meetings

What was said

To start with — what do self-advocates say they want from their advisors?

An advisor:

- is someone who listens carefully;
- guides but does not lead;
- helps when asked to:
- helps when we need it but not too much;
- should not boss you around;
- must have confidence in people;
- tries to understand how self-advocates feel;
- helps people to say what they feel;
- helps people gain confidence in themselves.

From this list, it seems that advisors are there to “help” and “guide” but not to “do self-advocacy” for people.

From the many issues which were raised during the advisors' discussions, here are some of the concerns which were raised most frequently.

Power, control and manipulation: advisors were aware of the need to avoid abusing their position and exercising too much power over self-advocates; this could be difficult at the beginning when groups needed help with thinking through ideas and issues about self-advocacy. They were conscious of not wanting to manipulate self-advocates by 'planting' ideas but, on the other hand, self-advocates were not always aware of what the issues were. Allowing self-advocates to take risks was another issue which concerned advisors who sometimes found it hard to stand back and let people take risks.

The changing role of the advisor: a great deal of constant involvement and support was needed when groups were starting up and simply leaving self-advocates "to get on with it" did not usually work. However, it was important for advisors to constantly review their level of involvement to see whether they could reduce their input to the group (for example, by only being present for part of each meeting).

Teaching self-advocacy skills: advisors thought this was an important issue but that skills-teaching needed to take place outside the group's meetings as a separate activity. With the right sort of skills, self-advocates could do a great deal for themselves with minimal support from advisors. Problems often arose simply because people had not been allowed to do things for themselves in the past and so had not learnt necessary skills

Support for advisors: advisors often felt quite isolated, particularly if there was not a great deal of support for self-advocacy from other people such as staff or parents. Having two advisors for a group was one way of not only sharing the work involved, but of providing some mutual support. Setting up advisors support groups would be another way of helping advisors.

Relationships with 'outsiders': the level of support for groups varies, but some advisors felt that there was little support for self-advocacy from, say, other staff in ATCs or hostels. On the other hand, there was sometimes a danger that management would promote 'self-advocacy' in order to seem 'trendy' or forward-looking but without being really committed to it; perhaps advisors should be looking for more independent allies outside service settings?

The independence of advisors: nearly all the advisors at the workshop were also working in services to people with learning difficulties. This could sometimes result in a conflict of interest, for example, where the group wanted one thing and the service manager — the advisor's manager — wanted something different. Two of the advisors at the workshop worked in services elsewhere so were not in day-to-day contact with the self-advocates in their group. This could be seen as one step further along the road towards having an independent advisor. We realised though, that we still have a lot more work to do in finding really independent advisors for groups.

Finishing the day

What we did

At the end of the first day of each workshop, teams were asked to write up on wallpaper the answers to these questions (An example of what this looked like is on the next page):-

WHAT WILL YOU TRY AND DO BEFORE THE NEXT WORKSHOP?

WHAT WOULD YOU LIKE TO TALK ABOUT AT THE NEXT WORKSHOP?

WHAT DID YOU LIKE ABOUT TODAY?

WHAT COULD HAVE BEEN BETTER?

At the end of each of the second days, teams were asked to write down the answers to these questions:-

- What do you hope to do as a result of being here?
- What ideas do you have for future workshops?
- What did you like about today?
- What could have been better about today?

Asking people what they did and did not like about the workshops helped us plan the following days and avoid mistakes we had already made. If you are planning your own workshops they may help you to avoid making some of the same mistakes as we did!

Although we don't have the space here for all the answers, here are some of them

What people said

What could have been better?

We would have liked more preparation for the role-playing.

We think some people may have been put off by the video camera.

Some people found it hard to eat without a table (it was a buffet).

We would like more time in small groups.

We'd have liked a longer workshop!

It was difficult when more than one person at a time was talking.

Some things should have been explained more clearly.

What did you like about the day?

- Meeting people from other self-advocacy groups and making new friends.
- The role-play about listening
- The lunch — and choosing what we ate.
- Talking in small groups.
- Seeing ourselves on video.
- Self-advocates and advisors discussing things together.
- Sharing our problems with a bigger group of people.

Asking people to write down what they planned to do after the workshops gave people some definite things to aim for, and here are some of the things people said they were going to try and do:-

- Go back and tell other people in the group about the workshop.
- Try and involve more people in the group.
- Practise how to vote in meetings with our group.
- Learn some more signs for communicating with people who can't speak.
- Start a self-advocacy group at one of the centres in our area.
- Give more people the chance to practise chairing meetings
- Try and stand up for ourselves more.
- Get the labels taken of the minibuses
- Have a conference to tell people about self-advocacy.
- Contact other self-advocacy groups.
- Find out more about welfare benefits and about housing

And finally, here are participants' ideas about topics for future workshops:

- How to set up a self-advocacy group outside a training centre.
- More work on how to listen and how to take turns
- How to help people who are 'less able'.
- How to organise meetings with other groups.
- How to be more assertive.
- How to encourage more people to be leaders in self-advocacy so that it isn't just left to a few people who may become rather tired because they have to do everything.
- How to change the power that staff sometimes have over our lives
- How to spread the self-advocacy movement more widely

Example of wallpapering done at the end of the workshop

	BARNET	CREWKERNE	LUTON	HILLINGDON	WESTMINSTER
WHAT ARE YOU GOING TO TRY TO DO BEFORE THE NEXT WORKSHOP?	Elect new members	Get labels off minibuses			
WHAT WOULD YOU LIKE TO TALK ABOUT AT THE NEXT WORKSHOP?				Work experience	Hostel staff
WHAT DID YOU LIKE ABOUT TODAY?		Well organised	Meeting other people		
WHAT COULD HAVE BEEN BETTER?		More small groups		Nothing!	

Appendix A

The workshop programmes

Workshop One — Day One (24 April 1987)

10.00 Coffee and wallpapering by groups

10.30 Welcome and Introduction to the day

10.40 Getting to know you exercise

11.15: Learning what other groups do and what people have gained from self-advocacy

11.30 The skills needed for being a Chairperson.

11.50 Short break

12.00 Learning how to vote in meetings.

1.00 Lunch

2.00 Self-advocates group: how to put your point of view across; involving the “quiet” people in your group; other issues which concern self-advocates.

Advisors group: the issues which concern advisors (power, control; the role of the advisor etc.)

3.00 Advisors and self-advocates report back to each other on their sessions. Play-back of part of video of self-advocates session.

3.35 Deciding what we will try and do before the next workshop; comments about the day

4.15 Tea and Depart.

— Day Two (3 July 1987)

10.00 Coffee

10.30 Welcome and Introduction to the day.

10.40 Introducing ourselves again to each other (using a different game)

10.50 Watching parts of the first day's video.

11.00 Feedback on tasks which teams had set themselves after the first day.

11.30 Role-play about how advisors work with self-advocates in meetings.

11.50 Small group discussions about the role-play and other aspects of the relationship

between the group and the advisor.

12.30 Feedback to each other from small group discussions

1.00 Lunch

2.00 Small group discussions: how can advisors and self-advocates work together to help other people believe in self-advocacy?

3.00 Feedback to each other about the small group discussions

3.15 Tea

3.30 Sharing information on "How we run our group"

4.00 Wallpapering by each group of what they hope to do in their groups after the day

4.15 Depart.

Workshop Two — Day One (11 June 1987)

- 10.00 Coffee
- 10.30 Welcome and Introduction to the day
- 10.40 Getting to know you exercise.
- 10.50 Sharing “What we do in groups and what we talk about”
- 11.20 Being a Chairperson — what it involves. Sharing the experiences of workshop participants. Helping “quiet” people to take part in meetings.
- 11.40 Small groups on: being a chairperson; the role of the Secretary and the Treasurer; a small group for “quiet people”.
- 12.00 Feedback to each other from small groups.
- 12.25 Lunch
- 12.45 Learning how to vote in meetings.
- 1.00 Session for self-advocates on topics of their choice.
Session for advisors on topics of their choice.
- 2.00 Feedback from the previous sessions
- 2.35 Tea
- 2.45 Teams decide what they will try and achieve in their groups before the next workshop; recording comments about the day. 3.15 Depart.

— Day Two (2 September 1987)

- 10.00 Coffee
- 10.30 Welcome and Introduction to the day.
- 10.40 Getting to know you again exercise (using a different game).
- 10.50 Feedback on tasks which teams had set themselves after the first day.
- 11.20 Role play about how advisors work with self-advocates in meetings.

- 11.40 Discussion in small groups about the role-play and other aspects of how advisors work with groups.
- 12.25 Feedback to each other from small groups.
- 1.00 Lunch
- 2.00 Brainstorming session on how people with special difficulties(for example, not being able to speak) can be involved in self-advocacy groups.
- 2.35 Learning about listening and taking turns in groups.
- 3.20 Tea
- 3.45 Writing down what people hope to do back in their groups after this second workshop day. Comments on the day.
- 4.15 Depart.

Appendix B

King Edward's Hospital Fund for London

King's Fund Centre

126 Albert Street 18 March, 1987

London NW1 7NF ;

Director: Ms Barbara Stocking

HELPING YOUR SELF-ADVOCACY GROUP TO GROW

Developing self-advocacy skills with people with learning disabilities A two-day training workshop

WHERE? King's Fund Centre, 126 Albert Street, London NW1 7NF (Camden Town)

WHEN? Thursday, 11 June and Wednesday 2 September, 1987. 10.00 - 4.00pm each day.

COST? £80 per team of four people. This is the total cost for the two days, including coffee, lunch and tea. Applications are invited from teams of up to four people, of whom at least two must be self-advocates actively involved in a self-advocacy group.

This is the second two pilot training workshops for self-advocates and advisors. It is for people who have already started a self-advocacy group and are looking for opportunities of increasing their own skills and those of other members of their group. It will assume that people who want to take part in the workshop already have a basic knowledge of what self-advocacy means and are already committed to helping people with learning disabilities in this way.

It will be a very practical, skills-based workshop.

Numbers will be kept small to allow maximum participation.

The days will be divided into various sessions - some when everyone is together and some when advisors and self-advocates will have their own sessions.

At the end of the first day we hope you will have chosen at least one objective or aim to work on back in your local area before returning for the second day in July.

We want participants to contribute their own ideas on topics which they would most like to talk about at this workshop but it is probable that some of the following will be included:

providing opportunities for making choices

growing slowly

risk-taking

getting support

managing time

keeping the group going

listening

chairing a meeting

how to involve everyone in the group

People helping with the workshop will include:

Gary Bourlet President, People First

Jan Porterfield Policy Studies Institute

Andrea Whittaker Advisor, People First

APPLICATIONS CLOSE TUESDAY, 26 MAY, 1987

If you have any queries about the content or administration of the workshop, please get in touch with Andrea Whittaker at the King's Fund Centre - tel.267 6111.

Appendix C

HELPING YOUR SELF-ADVOCACY GROUP TO GROW

Developing self-advocacy skills with people with learning disabilities Thursday, 11 June and Wednesday, 2 September, 1987

APPLICATION FORM

Names and designations

(block capitals please)

Address for correspondence

We would like to attend the self-advocacy training workshop and enclose the fee of £..

(Please make cheques and money orders payable to King Edward's Hospital Fund for London)

OUR SELF-ADVOCACY GROUP

Please tell us in a few words about your group. e.g. How long have you been going? How many members? What sort of things do you do?

SHARING GOOD THINGS ABOUT OUR GROUP

Is there some particular project/event - something your group has done - that you would like to tell the other people at the workshop?

SHARING PROBLEMS/LEARNING NEW THINGS

Are there any particular problems you are having/skills you would like to learn?

Appendix D

HELPING YOUR SELF-ADVOCACY GROUP TO GROW

Wednesday, 2 September, 1987

PROGRAMME

10.00 Coffee

10.30 WELCOME AND INTRODUCTION

REPORT BACK FROM EACH TEAM ON WHAT YOU HAVE DONE IN YOUR OWN GROUP SINCE THE FIRSTDAY

Did you do what you said on the first day you would try to do?

11.30 ROLE PLAY ABOUT HOW ADVISORS WORK WITH SELF-ADVOCATES

We will talk about things like:

How can advisors be sure they are helping enough without helping too much?

What do self-advocates think are the best ways for advisors to help?

Can you think of a 'helping situation' in your own group when advisor and self-advocates worked well together?

Can you think of an occasion when you all found it more difficult to work together?

WE WILL GO INTO SMALL GROUPS TO TALK ABOUT THESE THINGS

12.30 REPORT BACK FROM SMALL GROUPS

1.00 Lunch

2.00 SHARING IDEAS (BRAINSTORMING) ABOUT HOW TO HELP PEOPLE WHO ARE LESS ABLE

2.30 MORE SELF-ADVOCACY SKILLS –

LISTENING

TAKING TURNS

MAKING DECISIONS

3.30 Tea

3.45 WRITING DOWN WHAT YOU HOPE TO DO BACK IN YOUR GROUP AS A RESULT OF THE SECOND DAY.

IDEAS FOR FUTURE WORKSHOPS

4.15 Finish.

Appendix E

SELF-ADVOCACY GROUPS WHO CAME TO THE WORKSHOPS.

Acton Self-Advocacy Group

Acton Adult Training Centre

Stirling Road

London W3 8DJ

Tel. 01 992 5812

People First of Yeovil

c/o Fiveways Adult Training Centre

Ilchester Road

Yeovil

Somerset

Tel. 0935 20925

South West Surrey People First

c/o Mencap Development Office

Hydestile Hospital

Salt Lane

Godalming

Surrey

People First of Chard & Crewkerne

c/o Don Archer
Somerset Social Services Department
County Hall
Taunton
Somerset
Tel. 0823 333451

L'Arche (Five-Year Group)
9-13 Norwood High Street
London SE27 9JU
Tel. 01 761 4860 or 01 670 6714

Adult Education Self-Advocacy Group
12 Frances Greeves House
Henbury Road
Bristol BS10 720
Tel. 0272 507088

Barnet People First
Broadfields SEC
Springwood Crescent
Edgware
Middlesex
Tel. 01 958 3442

Ravenswood People First
Centre for Continuing Education

Ravenswood Village

Nine Mile Ride

Crowthorne

Berks.

Tel. 0344 771212 ext. 233

Greenwich Group Homes Project Team

24A Hervey Road

London SE3

Tel. 01 319 4335

Hillingdon People First

Clifford Rogers ATC

Acol Crescent

South Ruislip

Middlesex

Tel. 01 841 7270

Huddersfield People First

clo Joyce Kershaw

33 Netherroyd Hill Road

Cowclitfe

Huddersfield

HD2 2LW

Tel. 0484 541486

Talking Together

73 Russell Rise

Luton

Beds

LU1 SET

Tel. 0582 459412

Westminster People First

18 Croxley Road

London W9 3HL

Tel. 01 960 2848

Appendix F

Where to get more information on self-advocacy

Books and videos for learning about self-advocacy

American Self-advocacy Pack Materials from People First of Washington, USA. Covers: why we need self-advocacy groups; steps to starting a group; officers handbook; and ways to support a group over time and have successful meetings. 1986. Available from CMH

Learning About Self-advocacy Set of five booklets Introduction to self-advocacy Getting going Running a group What next? Basic skills that help Available from CMH— summer 1988

Let's Work Together Book and video produced by members of the Mencap London Division

Participation Forum with the co-operation of the Central Council for Education and Training in Social Work (CCETSW). To hire or buy from: Mencap London Division, 115 Golden Lane, London EC1Y 0RT

We Can Change the Future A staff development resource pack for staff interested in self-advocacy for people with learning difficulties. Book and video. Details from NBHS.

We can Speak for Ourselves by Paul Williams and Bonnie Shoultz. Describes the growth of

self-advocacy in Britain and the USA, and offers practical advice to those who want to support self-advocacy. Available from CMH

People with learning difficulties speaking about their lives

Beginning To Listen. a study of the views of residents living in a hostel for mentally handicapped people. D. Brandon & J. Ridley, CMH, 1985.

Listen: A report of one of CMH's early participation events when people with learning difficulties and others came together for a weekend of shared discussion and other activities. CMH, 1973.

My Life Story E. Wildey, NBHS, 1987. (Also available on tape).

Now What Can We Do All Day? Report of a conference organised jointly by Hackney Action for Mentally Handicapped People and Hackney Social Services, 1985. Available from: HAMHP, The Huddleston Centre, 30 Powell Road, London E5 8DJ

People First— Day Services— Users' Account Report of a conference organised by South Western Regional Core Group Day Services Working Group. Exeter, 1986. Available from: Christine Elliott, Exeter Health Authority, Dean Clarke House, Southernhay East, Exeter EX1 1PQ

Play Back the Thinking Memories... by members of "Something to Say"— a groupwork project for young women with moderate learning difficulties Available from National Children's Bureau, 8 Wakley Street, London EC1V 7QE

Useful organisations

People First, 126 Albert Street, London NW1 7NF tel: 01-267-6111 Full Membership— self-advocates; Associate Membership— professionals, advisors, parents and other supporters. Produces a newsletter. Runs conferences and Open Days. Links with self-advocacy groups around UK.

CMH (campaigning for people with learning difficulties) 12A Maddox Street, London W1R 6PL

tel: 01-491-0727

NBHS (National Bureau for Handicapped Students)

336 Brixton Road, London SW9 7AA

tel: 01-274-0565

National Self-Help Support Centre, 26 Bedford

Square, London WC1B 3HU

tel: 01-636-4066