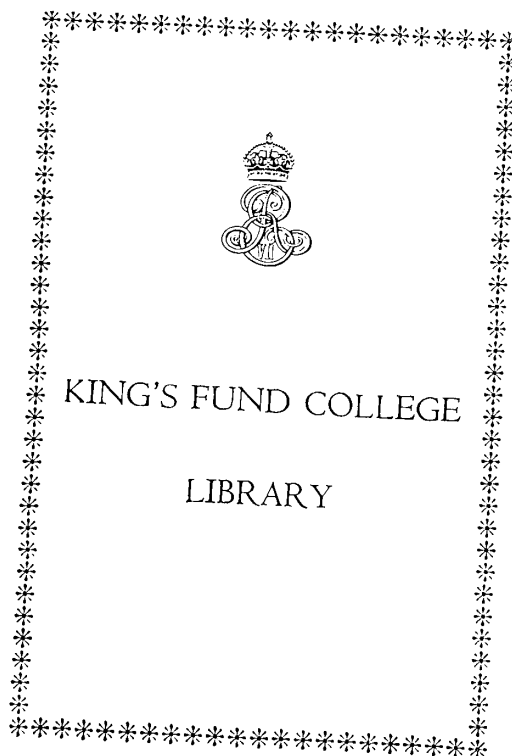




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SUPPORTING SELF-ADVOCACY

**A report of two
conferences held in
June and September 1989
at the King's Fund Centre**

Edited by
Andrea Whittaker

Thank you

To all the conference speakers for co-operating in the writing up and editing of their contributions and for allowing us to base the drawings included here on their original work.

Thank you, too to the willing band of 'conscripts' who took such detailed notes of the small group discussions at both conferences. Without their help, the important section on participants' own experiences could not have been included.

The Community Living Development Team is part of the King's Fund Centre. The team works to promote the development of high quality services for people with long-term disabilities. It supports innovations in service organisations, and encourages the use of good ideas and practice. The team has a particular interest in working with services, user groups and voluntary organisations at the local level, but is also concerned with policy issues and the large-scale management of change. Andrea Whittaker is a member of the Community Living Development Team.

Taking action

Confidence

MAKING FRIENDS

SPEAKING UP FOR YOURSELF

Solving problems

MAKING DECISIONS

SELF-ADVOCACY

Making decisions

Speaking up for yourself

Confidence

Self-Advocacy

Confidence

EMPOWERING

Confidence

EMPOWERING

Taking action

Confidence

Self-Advocacy

Making friends

SOLVING PROBLEMS

Taking action

MAKING DECISIONS

Taking action

RIGHTS AND RESPONSIBILITIES

Rights and responsibilities

Solving problems

SUPPORTING SELF-ADVOCACY

Edited by
Andrea Whittaker

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The King's Fund Centre is a health services development agency which promotes improvements in health and social care. We do this by working with people in health services, in social services, in voluntary agencies, and with the users of their services. We encourage people to try out new ideas, provide financial or practical support to new developments, and enable experiences to be shared through workshops, conferences and publications. Our aim is to ensure that good developments in health and social care are widely taken up.



The King's Fund Centre is a part of the
King Edward's Hospital Fund for London.

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INTRODUCTION

This is the report of two conferences held in June and September 1989 at the King's Fund Centre. They were attended by over 200 people – people with learning difficulties, staff, advisors and parents. The participants were all involved with self-advocacy groups in some way.

Numerous workshops and conferences have been held to discuss what self-advocacy is and why there is a need for it. They have all looked at the history of self-advocacy – particularly in the United States. The two conferences described in this report aimed to go beyond this 'getting to know about self-advocacy' stage and look at groups already in operation, to see how they are progressing. We also wanted to look at what support is needed to help groups run well and bring about changes in people's lives.

The broad questions discussed at these conferences were:

- How are self-advocacy groups developing?
- What successes have they had?
- What challenges do they face?
- What are the best ways of helping advisors and other people directly involved in developing self-advocacy?
- How can we encourage a supportive environment for self-advocacy? What support can people in senior positions provide?

We wanted to hear what people were doing already, why they were doing things in certain ways, seeing how we could build on the good ways people have developed and to learn how we might do some things better.

The report begins with two views of the national scene in the UK – one from a researcher and one from a practitioner. Then there are contributions from four People First groups – each focussing

on a particular aspect of developing self-advocacy, followed by a section on how people in senior positions in services can help. The final section of the report – but a very important part of it – describes the experiences of the conference participants.

At both conferences there were two opportunities for people to meet in small groups. In the morning, participants talked about good things that are happening in self-advocacy and some of the problems. One or two of these problems which seemed particularly important to the group were used in the afternoon discussions.

In the afternoon each of the groups – made up of a mixture of self-advocates, supporters, staff and parents – were asked to divide into two. One half pretended to be self-advocates, the other half pretended to be supporters. Each half discussed their chosen problem from the point of view of the people they were pretending to be. They then came back together as one group and shared their ideas.

Many issues were discussed enthusiastically. A lot of good practical ideas were put forward and questions asked, but, needless to say, you won't find answers to all the questions in this report! However, we do feel there is much to get you started – a lot to set you thinking.

One important question which was raised but not answered was: 'How do we reach black people who are isolated?'. Out of all the notes taken of the discussions, this was the only recorded comment relating to people from black and minority groups. While much of what is described in this report will be relevant no matter what a person's cultural or ethnic background, that one lone comment provides us with a challenge for the future. Firstly, the need to include this issue in conference programmes and secondly, the responsibility we all have to make sure that the needs of people from black and minority groups are not forgotten.

Ideas on getting more detailed information about self-advocacy are given in the Appendix. We hope that readers will use this report for discussion and training as well as for information.

SELF-ADVOCACY GROUPS: AN OVERVIEW

To give an overview of what is happening in self-advocacy at the moment we need to think about the future and also take a look back at the past-where we have come from and what has happened in self-advocacy in this country so far.

In 1979, when I was a young student fresh out of college, I was looking for a project. The people I was working with at the time, Ed Whelan and Barbara Speek, had just carried out a study looking at adult training centres. Quite by chance they had come across something called the trainee committee. They did not really know what it was and did not have time to find out more about it. So there was my project; to study more about trainee committees. I had never heard of the term self-advocacy. No-one was using it at that time in the UK – and that is not really a very long time ago.

For this study,¹ I wrote to all the adult training centres (ATCs) in England and Wales and asked them if they had a trainee committee or any other group like it. I was surprised at the number of centres that did have some form of committee or group, but still it was not many – about 22 per cent. In some centres individuals sat in on staff meetings or parents' meetings and had a chance to speak up there.

When I looked in more detail at these trainee committees I found that most of them were led by staff and were more like discussion groups than what we today would call self-advocacy groups. There were only one or two groups (Avro Centre in Southend was notable at the time) involved in activities such as writing to MPs or trying to change their name from 'trainee' to 'student'. They really showed what was possible. Another interesting finding was that having got started some groups had then stopped, and it was difficult at the time to understand why.

So that was the scene in 1979 – not an awful lot going on, but some interesting signs. A lot has happened in ten years. In 1986-7 that study was repeated: we wrote to all training centres in England, Scotland and Wales to see whether anything had changed.² We also

wrote to all hospitals, to see what was going on. We were pleased to discover that things certainly had changed. Over half (about 60 per cent) of the training centres in England, Wales and Scotland had some form of self-advocacy activity – trainee committees, representative group, or self-advocacy group.

What was more exciting though was the change in what the groups were talking about and doing. There had been a real change in the kind of things that people were interested in. Although they were still talking about things like whether or not to have a disco, or planning a day out, lots of groups were talking about more important issues, like what activities should we do in this centre? What policies should we have here? What matters to us as people who have learning disabilities? What do we think about labelling? What do we think about other people's attitudes? Topics which were more meaningful than we had seen eight or nine years earlier and which I think come closer to what we mean by self-advocacy.

We asked people what they thought these groups had achieved since the first study. Many groups had produced real changes in their centres – changes in activities, changes in policies, changes in very simple things like getting rid of the word 'ambulance' on the side of their transport. I remember in one centre it was said: 'We now use the same crockery as the staff use'. That may not seem much, but if you have ever tried to change anything in a hospital or social services environment you will realise it is a fairly major achievement!

But perhaps an even more important outcome was how self-advocates had grown from involvement in these groups. Many people felt that the major achievement of their groups was that the members felt better about themselves, were more confident and could do more. For me that is one of the most important things self-advocacy can achieve – enabling people to feel more confident and happier in their lives.

We also asked groups what problems and difficulties they experienced. One problem was that of members not having the right skills. It was hard for them to run their groups, they said, because it was taking a long time for people to develop the necessary skills to be chairperson, secretary or whatever.

But that is a problem that we can overcome. We can all learn skills. If we have patience and we have the right level of support we can develop.

Another and more serious problem mentioned was a lack of support from staff. The survey showed that if staff within a centre did not support the activity, it was very unlikely that a group could succeed. This makes sense because within our services, the people who have the power are staff and the professionals – the people that get paid for being there. They are the people who make most of the decisions. If the people with power do not agree with what the self-advocacy group is saying, they may decide to close the group down. This is exactly what happened to Avro Centre mentioned earlier. The committee was closed down because some of the more senior people in the borough were not happy with what was being said there.

So that is the situation in training centres. More groups, doing a lot more and achieving a lot more. I think that is a very exciting state of affairs.

What about hospitals? The situation here is not so exciting. They are at the stage training centres were at ten years ago. We found very few groups in hospital settings, and the ones that did exist were really more like discussion groups. So, hospitals still have a very long way to go. In fact, perhaps there is something about hospital settings that does not help self-advocacy groups to flourish. Often self-advocacy groups formed outside of hospitals can be very effective as advocates for people inside hospitals, particularly when the group members are people who have lived in hospitals and have now moved out.

But the most exciting current development is the growth of independent groups like People First. We had no People First in England in 1979. Now People First flourishes, doing all sorts of things – arranging exciting conferences and spreading the word about self-advocacy. And there are many offshoots – local groups of People First setting up.

Where should we be going in the future? For me, the independent groups are really the future of self-advocacy. They are the way forward because they are free. Members of People First are not held back by what professionals think or what parents think. They are free to go the way they want to go, because the group belongs to its members. The more growth there is in those groups, the more real self-advocacy we will be seeing.

What will be important however, is that self-advocacy groups have time to strengthen and develop properly. In the past, it was often a

struggle just to get going, a struggle to exist. Now, a large number of groups do exist and, more important for the future, is that these groups develop, consolidate, put down roots. Self-advocacy groups need time and support to develop skills, to think about what they want to achieve, decide what really matters to them, where they want to go. If we have strong independent groups, the people who make policies that affect the lives of people with learning difficulties will come to groups like People First and ask their advice about what services should be like. Self-advocacy groups will be strong leaders in presenting the views of people with learning difficulties. I have every confidence that this will happen.

To make that happen we – professionals, parents, friends – have to continue listening and learning from what people with learning difficulties say to us. We have to recognise the power we have to encourage or discourage self-advocacy. Our job is to help promote it and support it. If we stand in the way of self-advocacy groups growing, that is something we are going to have to bear on our consciences for a long time.

Andrea
Whittaker

SOME THOUGHTS ON THE NATIONAL SCENE

What is self-advocacy?

Conference participants had a lot to say about what self-advocacy means to them – speaking up for yourself, gaining confidence, gaining new skills, helping other people, making friends, getting things changed. When asked to choose the most important key words which meant self-advocacy to them they came up with words like rights and responsibilities, power, participation, partnership. Self-advocacy is not only about speaking up for yourself, it is about taking action to get something changed. It is like climbing a ladder – you begin with ‘speaking’ on the first rung and climb up towards ‘doing’.



Taking an overview of what is happening around the country, there is a danger of self-advocacy itself becoming a ‘label’ attached to a variety of activities which may be related to – but are not in themselves self-advocacy. Self-advocacy is much more than social skills, or communication skills, or self-expression – important though all these are in helping people towards independence. Self-advocacy involves creating an environment in which there is a real partnership between people with learning difficulties and all

who work with them. It is about service workers having the courage to share power. It is about helping people to move away from the 'service world' and into the 'ordinary world'.

We need to be clear about the purpose of a group. Is your self-advocacy group still thought of as a subject on a curriculum – something that you do from 2 – 3 p.m. on a Wednesday afternoon? Or is it a focus for activities aimed at making changes for the better in people's lives?

We know that changes are being made where people live and work, but are the only changes being made those that don't cause any controversy? A Canadian advisor, Bill Worrell, puts it this way:

If the group is not focused on initiatives to change the system around it, the members remain passive. When a group functions mainly as a social event, and when it avoids controversy, the real concerns and needs of the members are repressed.

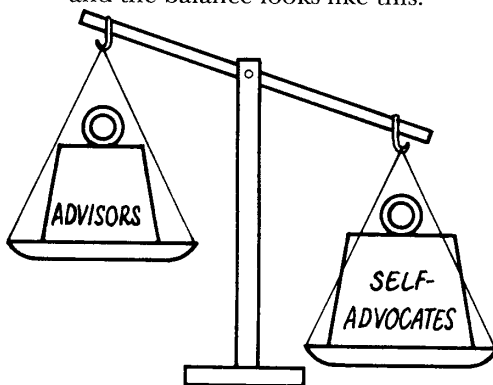
*People First: Advice for advisors*³

Self-advocacy is about changing things for the better. Self-advocacy is not only talking about what people want in their lives but taking action to do something about it.

Sharing power

Even to use the word 'power' in relation to people with learning difficulties can strike fear and trepidation into the hearts of staff, family, parents and even advisors. But if we are talking about genuine partnership with people with learning difficulties, then we must talk about power and face up to this challenge.

At the moment advisors and supporters have most of the power and the balance looks like this:

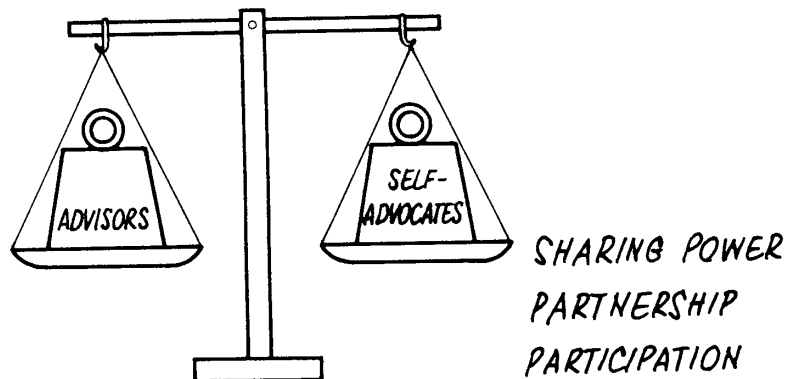


**ADVISORS AND STAFF
HAVE MOST OF
THE POWER**

For self-advocacy to work well, advisors, supporters and staff have to learn to share power. Sharing power means allowing people with learning difficulties to do things themselves – allowing them to take risks and make mistakes. It means working alongside people – recognising that we all have skills to offer and we all have more to learn. Supporters have had much more opportunity of developing skills than self-advocates have – so they are way ahead at the moment. But if we are really working together we can help self-advocates to catch up.

It can be difficult for staff to share power. Sometimes it's because their bosses don't really believe in self-advocacy – they don't want their staff to try new ways of doing things, they won't support staff who allow people to take risks. Often, service structures – inflexible routines, systems of working – can make it difficult to work in partnership. Some staff don't know how to work in partnership – they've done things in a certain way for so many years they find it very difficult to change.

What we need to be working towards is this:

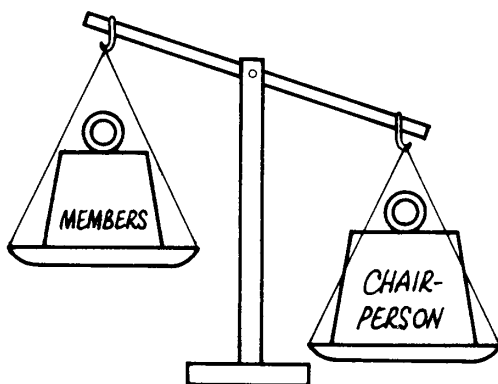


This might seem like an impossible dream, but if we believe in words like partnership and participation, we *can* shift the balance.

Self-advocates need to learn how to share power to

There is also an important point to be made about sharing power within self-advocacy groups. Many people have now gained a lot of skills in speaking up for themselves and have become leaders of groups. This is a very exciting feeling – to take the lead – to be in control. People who have never known what it is like to be a leader, deserve the chance to enjoy that feeling. But then they need to watch that this does not make them too bossy in a group. They can end up dominating other members of the group and not giving them the same chances as they themselves enjoyed.

Self-advocates too, can find it difficult to share power. A group will not work well and achieve what it sets out to do if its leaders don't learn about sharing power.



*SELF-ADVOCATES
NEED TO LEARN TO
SHARE POWER TOO*

Advisors

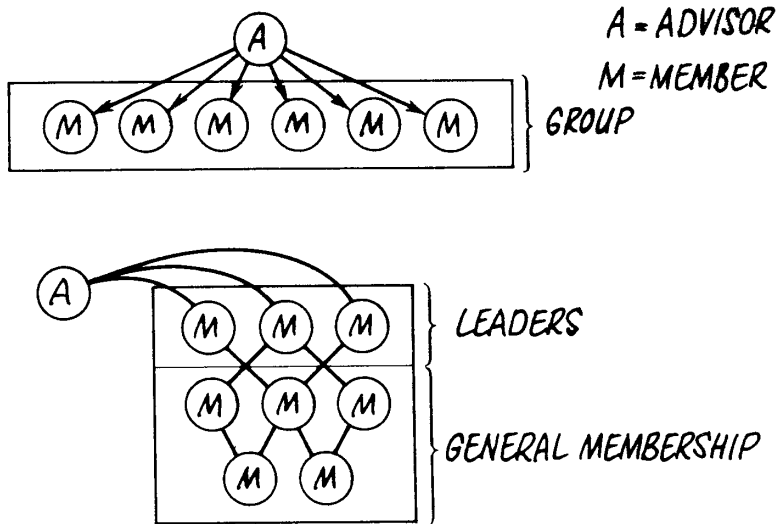
When asked to describe what the advisor's role is, participants came up with words like support, advice, listening, teaching, being a friend. An advisor tries to do all these things. Advisors are constantly asking themselves questions such as:

- Am I helping too much, or too little?
- Am I being too quiet, or talking too much?
- How do I help people make choices involving risk?
- What if it goes wrong?

Being an advisor can feel as if you are walking a tightrope!



Advisors can feel overwhelmed with the task of being a good advisor. Again, Bill Worrell is helpful in clarifying this challenge of seeing so much potential in people, knowing you can't help everyone. Bill's way of putting it is to say, in effect: 'Advisors are there to develop leadership – not to develop groups'.



This is the only way advisors can begin to stand back and gradually allow self-advocates to take over. Unlike a teacher for example, who retains an overall responsibility for each member of the class, an advisor is always trying to hand over responsibility to the group and decrease the amount of help and support as group members gain skills and independence.

Groups and individuals need consistent support from advisors

There is concern about lack of continuity in the support self-advocacy groups receive. Too often groups start well and then stop because advisors leave before the group is firmly enough established to act on its own. Enthusiastic attempts have been made by self-advocates to start a group, but because of inadequate help these have failed leading to disappointment and disillusionment.

Advisors need support, too

Setting up a self-advocacy group seems to be a favourite 'project' to give students – on a six month placement! It takes time to promote genuine self-advocacy. For example, it might take six months or more for a small group of people who have never before had the chance to speak up for themselves, just to start to work together as a group.

This is not to blame these 'short-term' helpers – perhaps it is better to try and do something in only six months than not to do it at all. But we must recognise and take steps to avoid the dangers of this practice.

There is too much reliance on already over-committed staff who can't give sufficient or regular time. We need to be aware also, that the majority of staff who act as advisors for self-advocacy groups do so in their own time.

One way forward here is to try and get more than one person supporting the group. It is also another good reason for getting an independent person involved – someone who is free from the constraints of being a staff person and who is not going to move on when their 'placement' is over.

Advisors need support, too

Many advisors are working in comparative isolation, often with only tokenistic support from immediate colleagues, let alone any active support from people 'higher up'. We are now able to point to individual examples of areas where there is a broad commitment to self-advocacy through all layers of the services, but we have a long way to go before we can say this is general practice.

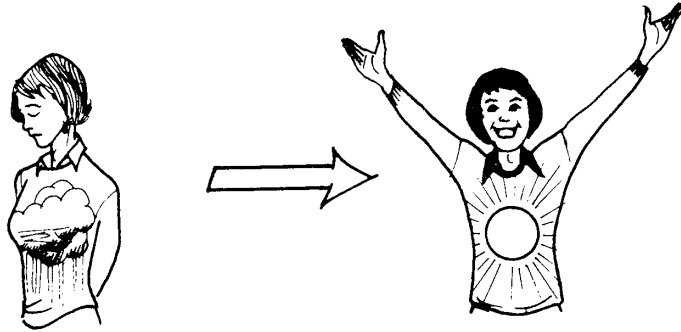
Self-advocates can help here. It is one of their rights to have good support from an advisor. Perhaps the responsibility that goes with that is to think what they can do to support their advisor. Self-advocates have skills and advisors have skills; we can learn from each other.

We will help to ensure the success of self-advocacy for individuals and groups if we build in appropriate support for advisors and for self-advocates right from the start.

Celebrating achievements

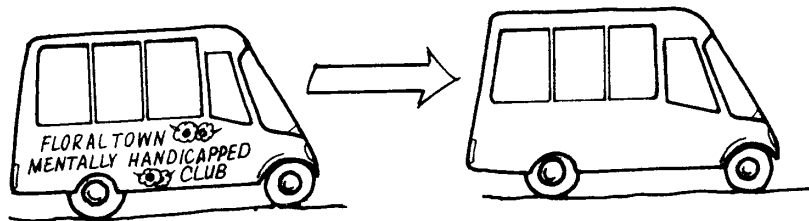
We have much to celebrate in the changes that have come about in the comparatively short time since self-advocacy began in the United Kingdom.

There are many hundreds of people with learning difficulties who now speak up for themselves with great skill, they feel good about themselves and are forging ahead, gaining more independence and control over their lives.



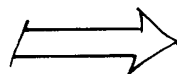
We have made great progress on the question of labelling. Although not all the battles have been won, the term 'mentally handicapped' is fast fading into history, and the more acceptable term 'people with learning difficulties' is in fairly common use. Let us hope that we will continue progress until one day we do not need any labels at all. Many self-advocates have succeeded in changing images of people with disabilities, for example by getting labels taken off mini-buses, a more acceptable design for bus passes, or persuading local newspapers to present more positive images of people with disabilities.

~~MENTALLY HANDICAPPED~~ \Rightarrow PEOPLE WITH LEARNING DIFFICULTIES



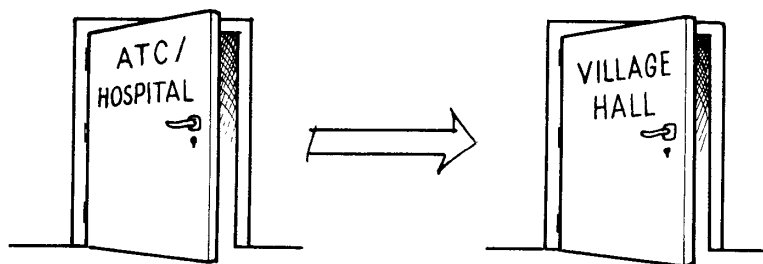
People are campaigning successfully on more difficult issues like stopping wages being cut or getting an increase in wages at centres.

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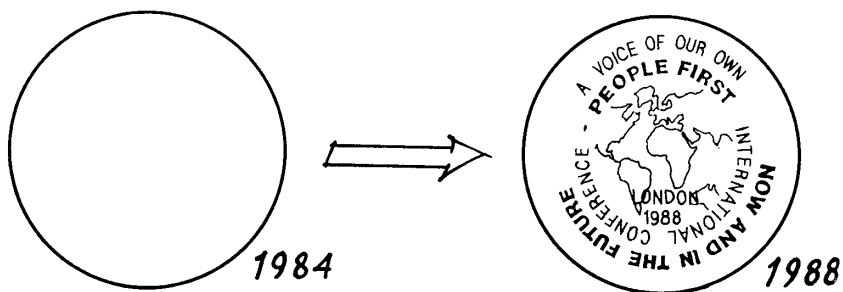
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More and more groups are moving away from meeting in service establishments to meeting in ordinary places in the community. This is another positive step towards becoming independent.



The tremendous response to these conferences is itself a sign of progress. The large number of service users who have been able to attend shows a greater commitment by services to helping self-advocates get relevant training. Services are recognising that people with disabilities as well as professionals need to attend conferences, and are providing the necessary resources.

The self-advocacy movement has come a long way in a very short time. In 1984 there was no national focus for self-advocacy in the United Kingdom. People First started in October of that year and began to make links with other groups around the country. Organising and running the second International Conference successfully in 1988 was a great achievement after just four years. We have laid some of the foundations. Now we need to strengthen these and start building the walls.



Westminster People First

Sue Charles

– Chairperson

Annette McDonald

– Advisor

TRAINING: HELPING GROUP MEMBERS TO LEARN NEW SKILLS

Sue Charles began by describing briefly how Westminster People First started and the aims of the group.

How Westminster People First started

I knew about People First because I went to City Lit. (F.E. college) and met other people who were part of London and Thames People First. I decided that it would be a good idea to start a group in Westminster. A number of people were living in hostels in the area and I wanted to give them the chance to express themselves and to talk about their problems and the way they were living.

I talked to a friend about this. We thought that the first problem would be where to meet. Many of the hostels in Westminster have been set up by Westminster Mencap so I contacted the director who suggested we might be able to meet at Croxley Road, one of the society's projects. Then I wrote to the co-ordinator at Croxley Road, asking if I could hold a meeting about People First, and he agreed.

At first there were only four people in the group – friends of mine who lived in Westminster Mencap hostels and went to day centres. Then I wrote to other places, asking if anyone else wanted to come, and the group began to get bigger.

Aims

The aims of Westminster People First are:

- to help one another get along and make friends
- to get to know one another and share ideas
- to understand other people's problems and try to help them to learn about themselves and other people

- to give everybody a chance to speak and express themselves.

We are learning about being independent, looking after yourself. People learn this by seeing and talking to other people: talking about their problems, about their own life and about their rights and responsibilities. Often people do not know what their rights and responsibilities are and this is part of the reason we decided to have some training.

Self-advocacy training sessions

We discussed the idea of training over several meetings and decided that it would be good to do it and that we would all benefit from it, especially if we ever became chairpeople, because through training we would have the skills to run a group.

Then we had to find out how to get a trainer. We asked our advisor about this. She knew someone who worked as a trainer and who might be interested in working with us.

We invited this person to one of our group meetings and he talked to us about the kind of training he could offer. At our next meeting we had to decide if we wanted to take up his offer, how many sessions we should have and for how long. We decided to have ten sessions that would last for an hour each and take place after our main meeting, every other Thursday.

So far we have had training sessions on:

- criticism
- supporting each other and solving problems
- consideration and understanding
- feeling good about yourself
- how to say 'no' for yourself
- standing up for yourself and speaking up for yourself
- compliments.

We have done a lot of discussion and some role plays.

Everybody feels happy about the training sessions and feel that they are getting a lot out of them. The sessions help to build people's confidence in their ability to stand up for themselves and to deal with problems in their everyday lives. Everybody gets a chance to join in and the trainer often goes over what we have done the week before so that everybody understands what is going on.

We have asked our trainer if we could do some sessions about interview skills, filling in application forms and how to look, behave and speak up at an interview. We have also talked about doing some officer training in the future.

Self-advocacy training: an advisor's view

The role of advisor is a very difficult one to define and can differ from group to group. When Westminster People First decided that some sort of training would be valuable to them I had to decide whether this was part of my role or not. A trainer, although taking a lead from the trainees, plans and follows a specific agenda. He or she is seen as an expert who is passing on his or her knowledge. The trainer has a powerful leading position in the group. For me to take on this role would promote my position as 'an expert'. It would compromise my existing role, which is to assist the members as an equal skill-sharing member of the group. Hence the decision to contact a professional trainer, allowing me to take an equal part in the training session.

After a couple of months we reviewed the training sessions and talked about the idea of doing officer training. We discussed the difference between this and the training that we were already doing. Officer training would be based on organisational skills. We looked at two possible ways of doing officer training: the trainer would work with all the members; or the trainer would work with the group leaders who would then have the skills to train the other group members.

The first way would mean that the skills of all the group members would be increased but it would not create a leadership within the group and could reinforce the idea of the advisor being the leader.

The second way would allow the emergence of group leaders who would, in their turn, become the experts. This would create valued role models in the group and prevent the idea of the advisor being

the only source of assistance in the group. We decided on the second way and will start the training soon.

From an advisor's point of view, since we began the training sessions I have observed people thinking seriously about what we are learning and beginning to relate and apply it to our everyday lives. We all consider that the training sessions are fun. We are all learning something, and that includes me.

Hillingdon People First

Trevor Reynolds

– Member

David Stephens

– Member

Pat Essex – Advisor

BECOMING A MORE INDEPENDENT GROUP: HOW SOCIAL SERVICES CAN HELP

History of the group

We began about three years ago as a self-advocacy group. Then six of us began to attend the People First meetings at the King's Fund Centre. After about six months we decided to set up a People First group in Hillingdon.

We meet once a month on Saturday afternoons. At first we met in the Clifford Rogers Centre. But we kept looking for somewhere else to meet, somewhere that had nothing to do with social services, and somewhere more central as Hillingdon is a large, sprawling borough. After a couple of months two members of the group found and booked a room in Christ Church, a community centre in Uxbridge, and we have been meeting there ever since.

Help from Social Services

We have been fortunate in Hillingdon in that our team managers, divisional manager and director are all committed to the 'ordinary life' principles, self-advocacy and clients' rights. They have encouraged our meetings and been present at our day conferences. Social services pay for the hire of the room we use for our monthly meeting.

Last year we were given a grant of £500 from the borough – a committee meets annually to award grants to voluntary organisations. We used this money to enable some people to go to the People First International Conference at Twickenham in September 1988. This year we have received another cheque for £500.

When we decided to run a day conference ourselves last October the director gave us £100.

Contact with the training department

The training department runs an induction week twice a year for new staff. One day of that course is given over specifically to self advocacy (although self advocacy as a theme runs throughout the week). When we first introduced People First into this we would show the video 'We can change the future'⁴ and then we would talk about People First and our experiences. Now we have changed this; we bring a group of people from the Centre, we have lunch together, we watch the video and then we carry out some of the exercises together.

Two day conferences have been held. The first, in October 1987, about getting jobs, was set up by the training department and the work experiences unit. David Stephens and Trevor Reynolds were speakers at that conference.

The following year Hillingdon People First members decided they would like to run their own day conference. They enlisted the help of the training officer, Charlotte Douglass, and formed a committee with Charlotte, six people from People First and Max Wide (from VOX, our local employment agency for people with disabilities). They booked a Centre, decided on subjects, booked speakers, booked Andrea Whittaker as chairperson for the day, arranged the catering. About 80 people attended the meeting – including the Director of Social Services. It was a very successful day.

Recently, People First Hillingdon held an open afternoon, talking about People First, showing videos and serving tea. Thirty people came.

Our future

Well, things are likely to change. We have a new Director of Social Services, a new training officer, and a new advisor. But we still have financial help and the new advisor/facilitator is very committed to self-advocacy. We want to do more to find transport for those unable to travel by themselves.

Kidderminster People First

Joan Bennett – Member

Matthew Fields

– Chairperson

Sylvia Lacy – Advisor

Margaret Smith

– Advisor

INDEPENDENT FROM THE START

To start with a 'big meeting' was called in Kidderminster and a lot of people from training centres, hostels, lodgings and people living with their families came along.

How we got going

We have been meeting now for nearly three years. Our committee has fifteen members. We vote for a chairperson and treasurer.

How we got our advisors

An advertisement was put in the local paper asking for people who lived in the community to help form a self-advocacy group. Six people responded. Two of them were husband and wife and had a person with learning difficulties living with them. One person was a housewife, one an occupational therapist, another worked as a secretary and the other was caring for an elderly mother at home. There was one man and the others were women.

The committee met them all. The applicants spoke about themselves, telling who they were, what they liked doing and why they wanted to be advisors. They were then asked questions by the committee members. After interviewing them all, the committee talked things over and voted for who they wanted.

The members are still hoping more advisors may be interested and would especially like more men. This is what they say they would like the advisor to be: somebody nice – caring and helpful – someone with a lot of go!

Where we meet

We started off in a small room at the Community Health Council.

Very soon more people wanted to come to our meetings. The committee talked about this and decided that we needed a bigger room that did not cost a lot of money as we had no funds at this time. Some of the committee went to look at other places to meet. We decided on a community centre which is in the centre of town and easy for everyone to get to. It was used by many other local groups and we could have it free of charge. It was also large enough to hold our 'big meetings'.

How we organise our big meetings

We try to have two or three a year, so that we can invite everyone with a learning difficulty to attend and tell them about speaking for yourself. We invite them to join our committee. Our 'big meetings' take place in the evenings and last about two hours. Sometimes we have a social as well, after we have finished our talking.

In April 1989 we organised a whole day conference about speaking for ourselves. We talked in small groups about things like where we want to live, names we do not like being called, jobs we would like to do and places we would like to go.

One year later, with help from funding from the health authority, we made all our talking into a booklet and published it. The booklet is called *Speaking for Ourselves*.⁵ On the day we launched the book, we invited service providers so that they could know how we feel and what we are saying. We also made a video film of the day.

Our achievements

Since we began to meet we have managed to do quite a lot. We raise our own funds by sponsored walks and carol singing. We also applied for and received two grants – one from Telethon (£1,250) and one from Community Development Fund (£350). This money has paid for a video camera and for holding 'big meetings'. We hope to use the video to film our meetings and to practise speaking for ourselves, to give us confidence. We can also film conferences like the day we launched our booklet.

We have taped a talk for BBC Radio 4 'Does He Take Sugar?' Three of our group attended the People First International

Conference in London. We regularly attend regional conferences to learn from and listen to others speaking for themselves.

Some of our difficulties

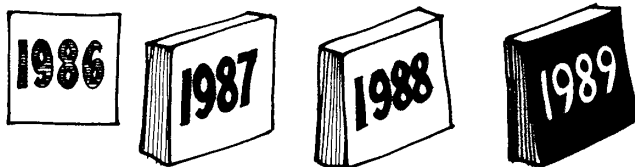
The committee have had to learn about what to do if they are unhappy with any of the members. One example of this was the treasurer. Eventually, by voting we asked him to leave. He did not want to go, and it was a hard thing to do. In the end he realised that the committee no longer wanted him to do this job and he decided to leave.

We are trying to give opportunities for people in our group with speech and learning difficulties that make it hard for them to speak for themselves. We want to give everyone more time to speak and get other members to help them. This seems to work better if the fifteen committee members split into two small groups with an advisor in each group.

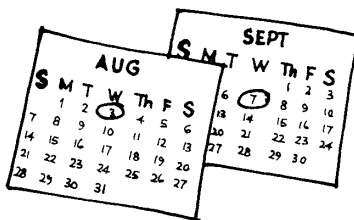
We are trying to work out how to organise the meetings differently to encourage *everyone* to speak for themselves to help them learn what self-advocacy means. We ask each member if they have anything that they would especially like to share with the group and make sure that everyone *listens*.

KIDDERMINSTER FIRST GROUP

IS THE NAME WE CHOSE FOR OUR SELF ADVOCACY GROUP —
WE HAVE BEEN MEETING FOR 3+ YEARS



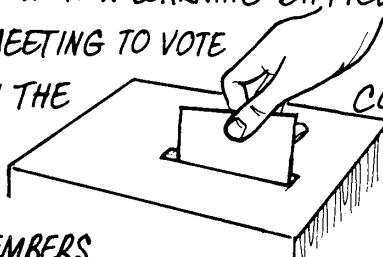
WE MEET AT A COMMUNITY CENTRE ON THE
FIRST WEDNESDAY
OF EVERY MONTH



THE COMMITTEE IS MADE UP
OF 15 PEOPLE



WE ASK EVERYONE WITH A LEARNING DIFFICULTY TO COME
TO A BIG MEETING TO VOTE
THEY WANT ON THE FOR WHO
COMMITTEE



THE COMMITTEE MEMBERS
SPEAK UP FOR PEOPLE WHO LIVE IN HOTELS AND LODGINGS,



WITH PARTNERS
OR PARENTS



OR ON THEIR OWN



HOW WE GOT OUR ADVISERS

AN ADVERT WENT INTO
THE NEWSPAPER



6 PEOPLE WANTED TO HELP



3 WERE CHOSEN BY A VOTE

WE WANT OUR ADVISERS TO BE

FRIENDLY,

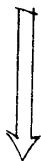
KIND, SUPPORT US,

AND HAVE A LOT OF GO!

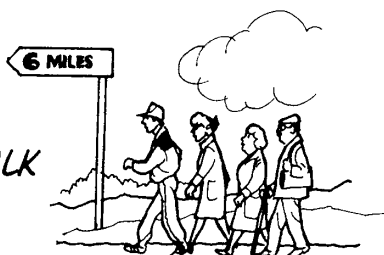


SOME OF THE THINGS OUR
SELF ADVOCACY COMMITTEE HAVE DONE

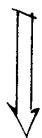
FUND RAISING ££££



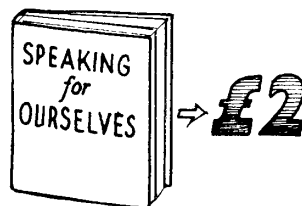
SPONSORED WALK



CAROL SINGING

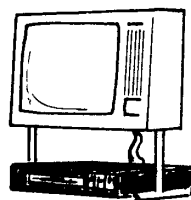


SELLING OUR BOOK



WE HAVE TAKEN PART IN 'DOES HE TAKE SUGAR?'
ON RADIO 4

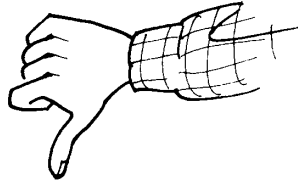
AND GOT GRANTS TO PAY
FOR A VIDEO



WE GO TO CONFERENCES LIKE THIS AND 3 OF US
WENT TO THE INTERNATIONAL 'PEOPLE FIRST' CONFERENCE 1988

SOME OF THE **PROBLEMS** IN OUR
COMMITTEE

PEOPLE WHO DO NOT DO THEIR JOBS
PROPERLY



THINKING OF WAYS TO HELP PEOPLE WITH
SPEECH DIFFICULTIES



MEETING
ONE EVENING EACH MONTH AND NOT HAVING
ENOUGH TIME TO PLAN ACTIVITIES



Colwyn Bay People First

David Roberts

– Member

Paul Hosker

– Advisor

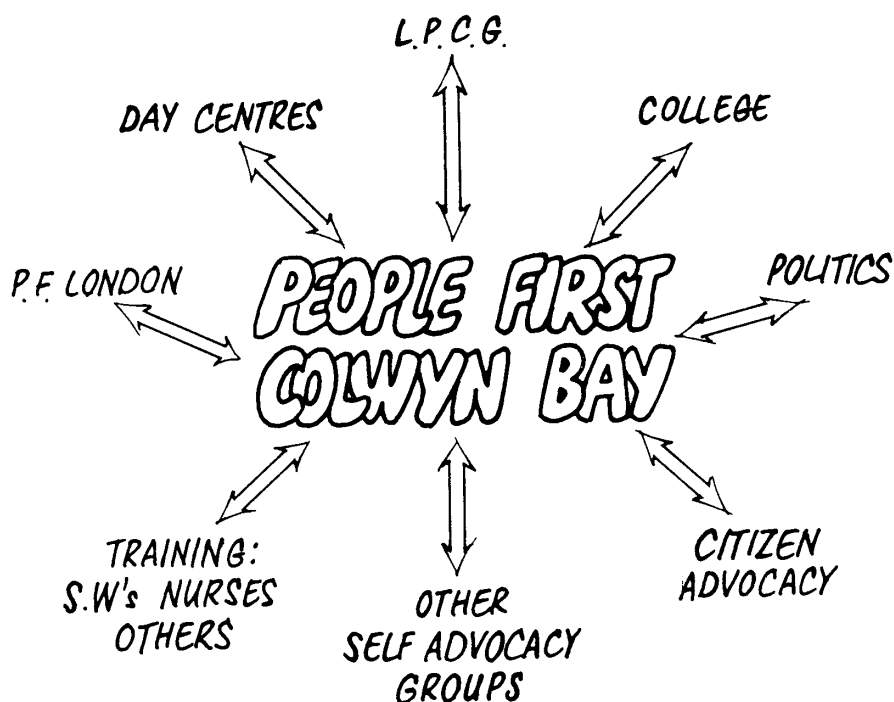
HAVING A VOICE IN SERVICE PLANNING AND DEVELOPMENT

The main focus of this presentation was how Colwyn Bay People First members were participating in the planning process for services with people with learning difficulties in Clwyd. But David and Paul began by showing the following illustration of Colwyn Bay People First to describe how it works and what it does.

COLWYN BAY PEOPLE FIRST

- * MEETS WEEKLY, IN THE EVENING
- * HAS 14 MEMBERS
- * ALTERNATES MEETINGS BETWEEN INFORMAL FLEXIBLE ONES AND COMMITTEE MEETINGS
- * RECEIVES FUNDING FROM THE COLWYN LOCAL PLANNING AND COORDINATING GROUP
- * HAS ITS OWN INDEPENDENT, PAID, SUPPORT WORKER
- * HAS MEMBERS WHO ARE DIRECTLY INVOLVED IN PLANNING AND DEVELOPING SERVICES
- * USES: DISCUSSION, ROLE PLAY, ASSERTIVENESS-TRAINING, PROBLEM SOLVING AND THE SHARING OF PERSONAL EXPERIENCE IN ITS DEVELOPMENT

They went on to describe the ways the group has become linked to other services, people and places because of its varied activities.



How these links work

College

The College has a service user group, whose purpose is to make sure the course content and management meets the needs of those attending. The College tutor has noticed a marked increase in group work skills by people who are both members of this service user group and members of the People First group.

Politics

Colwyn Bay People First is involved in two types of politics. Firstly, the group tries to educate its members about their human rights and responsibilities. It also supports members who may be affected by things like changes in the Social Security benefits regulations or the closure of local social service hostels. Sometimes the group invites relevant people along to their meetings to discuss such changes. On other occasions, the advisor or another group member might contact the appropriate professional directly, at the request of an individual member.

Secondly, the group occasionally finds that they have to challenge decisions made by the health, education or social services departments. A recent example was when the group wrote to the Joint Secretariat asking why there were no people with learning difficulties on its committee. The Secretariat said they needed time to discuss this and asked the group to find out the views of other self-advocates. Colwyn Bay People First consulted all the self-advocacy groups in Clwyd and sent their findings to the Joint Secretariat. The result was unanimous agreement about the request for a place on the Secretariat, and a further request to have the words changed on all documentation from 'services to people with a mental handicap' to 'services to people with learning difficulties'.

This prompted a series of open meetings and eventually the Joint Secretariat approved the original request. A member of Colwyn Bay People First now sits on the Joint Secretariat.

Citizen Advocacy

David Roberts is a founder member of the Management Committee of a citizen advocacy scheme in the neighbouring county of Gwynedd. The scheme is attempting to recruit advocates for people who have more profound learning difficulties, including communication problems. David has been involved in the advertising, recruitment and selection of the co-ordinators of the scheme.

Other self-advocacy groups

Colwyn Bay People First have close links with self-advocacy groups within Clwyd, other parts of Wales and throughout the United Kingdom. From 1986 onwards, members have participated in, and later run, self-advocacy workshops and conferences.

In order to achieve this, it was essential that the group drew on the vast experience which other self-advocacy groups had acquired. It was important that the Colwyn Bay group developed within the overall spirit of the self-advocacy movement. Many important and enduring friendships have been made with self-advocates and their advisors from all over the country, and it is often these friendships which help spur on the group.

Training

Leadership training within the group is particularly important, to prevent the advisor being seen as the leader. This means that the advisor will spend a lot of time developing qualities of leadership in a small number of people. However, it is important that all members have opportunities to learn and improve their self-advocacy skills. On-the-job training such as practice at chairing meetings, speaking in public or preparing talks, is often the most useful and relevant.

Clwyd has placed great importance on joint training initiatives for staff and service users. Members of the group have also spoken on training courses for nurses, social workers and teachers.

Day centres

Just over half the members of the group attend one of the two local day centres. Each centre has its own service user committee concentrating on issues to do with the centre – for example work experience or further education. For many people with a learning difficulty, these service user groups provide the first opportunity to learn to work in a group – to speak up, to take turns, to listen, to be a chairperson or secretary. Members of Colwyn People First are often called upon to chair these meetings and always try to act as a link between the self-advocacy group and the service user group. It is important that relevant information is passed between groups, so that people are sensitive to the real issues that people are facing.

*People First London
and Thames*

The work of the People First London and Thames group has been instrumental in the way in which self-advocacy has developed throughout the UK. Within the membership of this group are some of the most experienced and skilled self-advocates anywhere. Colwyn Bay People First has been privileged to draw upon the individual and collective experience of self-advocates from People First London and Thames and believes that among its members are some of the best 'role models' self-advocates can have.

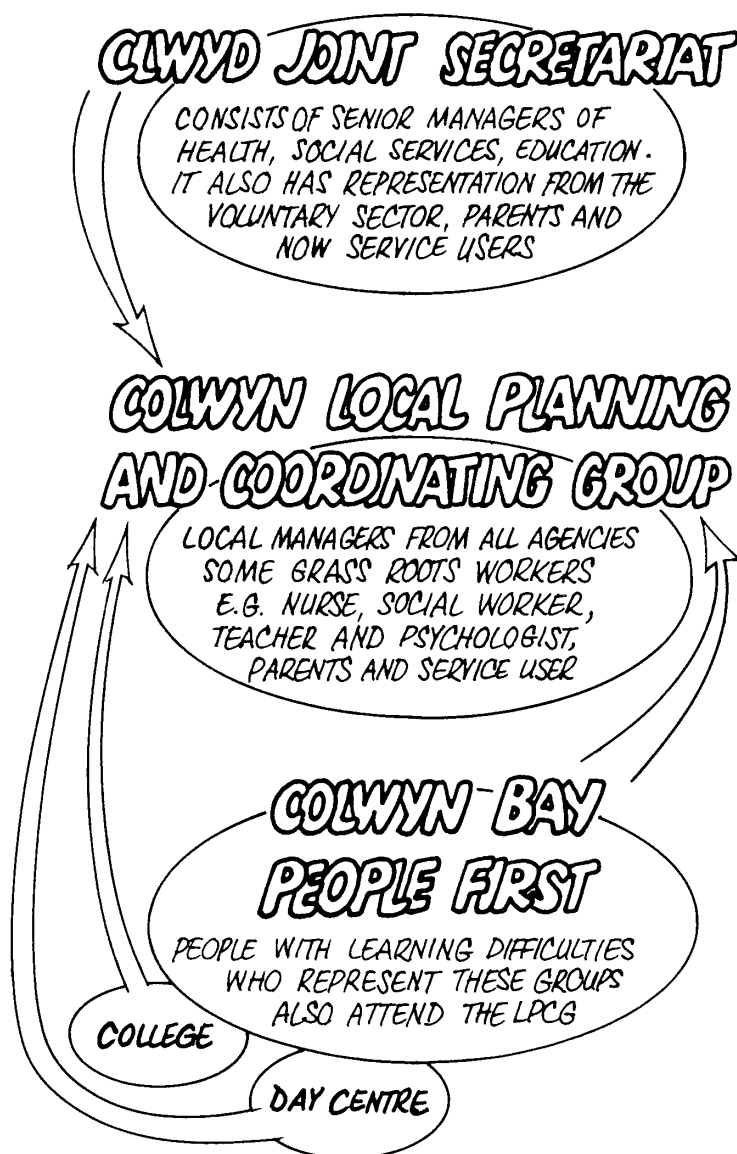
Background to participating in the planning process

The story of the group's involvement in the planning process really begins with the All Wales Strategy, a Welsh Office plan aimed at providing locally-based services for people with learning difficulties that are close to where they live and can help individual service users get what they want and need. Under the terms of the Strategy, regions have to show how they are going to involve service users in their local districts before they can get funding. Clwyd was one of the first regions to respond to this challenge: they didn't spend too much time agonising about how to do it, but made the decision and got going!

Clwyd has six local districts, each with a Local Planning and Coordinating Group (LPCG) responsible for planning and developing local services for all people with learning difficulties in the area. As well as aiming to have service users on each of their planning groups, Clwyd set out to establish service user committees within

its existing services, such as day centres, colleges and hostels. The purpose of these committees is to consult those who use the service about proposed changes. It is a two-way process: managers bring issues to the committees and individual service users can raise issues that they are concerned about.

The following illustrates what this system looks like.



*Local planning and
co-ordinating groups*

The LPCGs are required to include people with learning difficulties, but the number of people and who they should represent is down to local negotiation. In some areas it took a number of years before the service user representatives on the LPCG equalled the number of parent representatives. In areas like Colwyn, where the contribution of service users is acknowledged and valued, an increase in the number of service users was encouraged and supported.

Each consumer-representative group in Clwyd may apply for a grant from their LPCG. This money is to cover costs of meetings and training sessions, training literature and videos, and attendance at courses. Some groups hired external advisors to help tackle the paperwork – whether it was reading documents or dealing with the secretarial side.

David Roberts was chosen in 1985 to represent his local day centre. Now two members of Colwyn Bay People First and one of their advisors attend the Colwyn LPCG.

One of their responsibilities is to give an account of how the money given to them by the LPCG is used. In the early days, the group had to request small amounts of money two or three times a year. Now, having demonstrated how effectively they are using the money, it is given annually (recurring revenue). This means they can plan their activities in advance, and need not spend so much time and effort fund-raising which can be very time-consuming and can have negative connotations of giving money out of pity.

Specific moves by Colwyn LPCG included making a video of one of their meetings to show potential service user members, and helping service users learn committee skills. David's group took on the job of teaching its members these skills. They had to learn not only basic knowledge about how meetings are run, but also information about power structures and the 'games' people play. They had to learn about local politics and how to get on with local managers and senior managers and how to challenge them effectively when necessary.

Supporting users' involvement

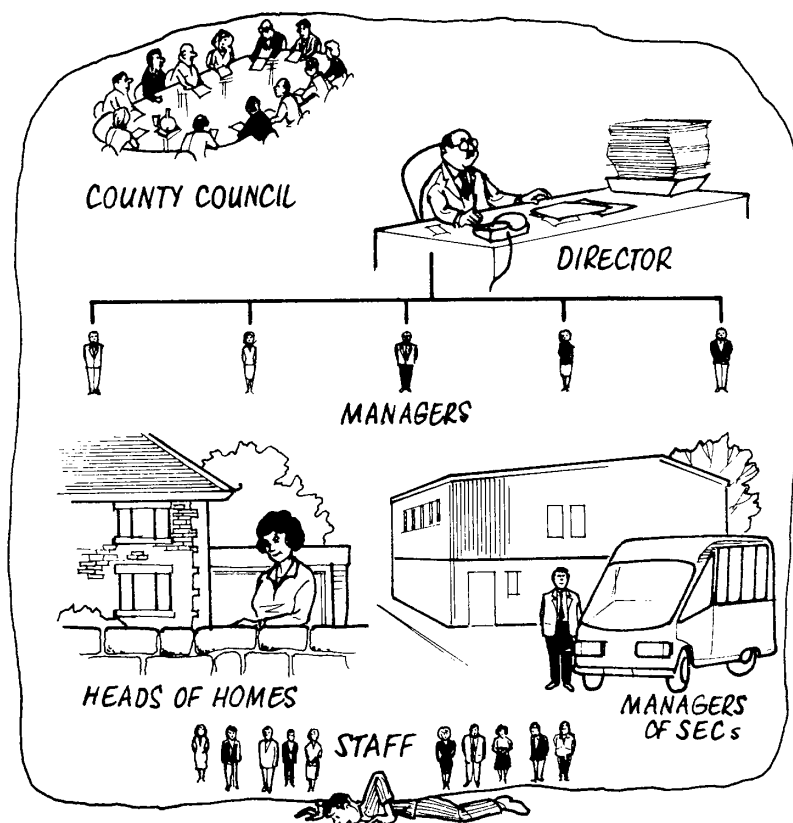
Clwyd's experience demonstrates the following important points about enabling participation:

1. Have a written policy which says that service users must be consulted and involved, and that services have to set out clearly how they are going to do this.
2. Seek written and verbal reports on progress and share the results with other people.
3. Provide financial back-up. Ideally, each self advocacy or consumer representative group should be independently financed, having total control over its budget, planning and implementing its use. From this budget the group could then employ a support worker who would be independent of all service providers.
4. Arrange meetings at times which are suitable to service users. Daytime meetings can be difficult for people who have jobs, attend centres or college. In Clwyd, some people found they would lose pay if they went to a meeting in the daytime. This problem can be overcome by arranging at least some meetings in the evening.
5. Transport. Most service users do not drive and in some cases cannot independently travel on public transport. It is essential to work out ways of ensuring that service users can attend meetings.
6. Provide training opportunities – particularly those which enable staff and service users to learn together. Training needs include:
 - self-advocacy skills – confidence, assertiveness, committee work skills, knowledge of own rights, listening skills
 - knowing how to represent effectively the views and opinions of other service users in your area
 - understanding the structure of meetings and the roles of the members (committee work skills)
 - understanding local and regional policies and how they affect existing services and the development of new services.

Charlotte Douglass –
Principal Training
Officer, Oxfordshire
Social Services

SUPPORTING SELF-ADVOCACY 'FROM THE TOP'

Social services departments are here to stay, at least for some time, and we have to live with them. The illustration below shows the main 'layers' in the structure of the Social Services – and how it must feel sometimes to be a service user trying to get what you want in your life!



It looks overwhelming, but change can be achieved. Directors of Social Services have a crucial role to play in order to create an atmosphere that fosters self-advocacy – an atmosphere in which

people believe that things are possible, and they do in fact make things possible. For example, in Hillingdon, Ian White (then Director of Social Services) when asked to support a People First Conference, agreed to fund it and to speak at it.

The first and most important step is to have good communication. Departments need to plan, work and operate on the basis that *everyone* can communicate whether or not they can speak and whatever their disability. Staff members and self-advocates need to learn to listen to each other properly.

The second step is to recognise that *everyone* has power, whether they have a learning difficulty or are staff or managers. The question is: are people aware of this, do they understand the sort of power they have and how are they choosing to use it? Organisations are slow, cumbersome and difficult to change, but there are lots of things people can do if they choose to use their power in positive ways and set out to make things happen.

The third important step is to ensure that everyone is aware of their responsibility – what it is that they are expected to do, what they are personally responsible for, and to make sure that if they are going to help someone to take a risk, they must recognise exactly what that risk is, and take steps to ensure safety without impeding development. It is not good enough to say self-advocacy means that people with learning difficulties can make all their own decisions. There is a responsibility to protect where necessary, to teach where necessary. Self-advocates need to learn to be responsible for their own behaviour and how they treat others.

All of us are responsible for:

- saying what we mean, honestly and clearly
- knowing and using our power
- being responsible for others without misusing our power.

All of this can be summarised as follows:

FIVE WAYS TO HELP STAFF TO HELP SELF ADVOCACY

PEOPLE

- * ARE BUSY SO YOU HAVE TO FIND WAYS OF GETTING THEIR ATTENTION/TIME.
- * CAN LISTEN IF APPROACHED IN THE RIGHT WAY
- * NEED TO EAT - MEET THEM AT MEALTIMES, FOR EXAMPLE INVITE TO LUNCH
- * ARE AFRAID OF CHANGE
- * CAN BE TRAINED - TO CHANGE THEIR PRACTICE / ATTITUDES

POWER

- * KNOW AND USE YOUR OWN
- * GET TO KNOW WHO MAKES DECISIONS
- * DON'T EXPECT 'THEM' TO DO ALL THE THINKING
- * AND RESPONSIBILITY - YOU NEED TO BE PREPARED TO TAKE RESPONSIBILITY AS WELL AS POWER

PLACES

- * BUILDINGS SLOW DOWN CHANGE BUT
- * WE NEED ROOMS TO MEET IN - SO THEY CAN BE USEFUL

POUNDS

- * SOCIAL SERVICES HAVE GOT LOTS
- * THEY COULD LET YOU HAVE SOME
- * THEY CAN CHANGE HOW THEY USE IT

POLITICS

- * DON'T FORGET YOUR M.P., COUNCILLOR, ETC.
- * YOU HAVE A VOTE

Keep it simple!

HOW WE DO IT: PARTICIPANTS' EXPERIENCES

This section of the report is a record of the participants' discussions. They covered a broad range of topics relevant to self-advocacy. Not all of the topics were discussed in great detail, but some interesting ideas and practical tips emerged. Even where a topic is only briefly mentioned here, it may be useful as a way of encouraging discussions, or as a starting point for finding out more, or to prompt ideas for further action.

Good things about self-advocacy groups

Participants had a lot to say about being involved in a self-advocacy group. The following summarises the main points.

Solving problems

Users of services living in the community can meet, discuss and solve problems of individual members.

Helps to support and help each other especially when there are big problems.

Making friends

Getting together with friends to discuss things that are important to us, and in the community.

Meeting nice friends: 'It's helping me a lot, to get out and mix'.

Increasing self-confidence

Sharing experiences gives reassurance and confidence.

Learn to take control of your own situation.

People being leaders.

Helps to understand people better.

Broadening experience

Meeting other groups.

Getting out and about speaking to different people.

Independence of group leads to new-found freedom to take up opportunities.

A chance to learn new skills, gain information, share common interests.

Having the meetings away from service establishments (for example, in the local arts centre, recreation centre or church hall).

Involvement in committees leads to further committees and groups.

Working together

Helps people to work as a team.

Giving others a chance – everyone should have a chance – everyone has their own opinion.

Giving *everyone* the choice.

Making people think.

What groups have achieved

Change does not come about quickly and easily. Even seemingly simple changes may have involved a lot of time and effort. Since most groups have started in a day centre, the first objectives have been about day-to-day changes at their centre – like improving food choice or quality. Now many have progressed to more outward-looking objectives like writing letters to the local newspaper or negotiating a pay rise.

The following examples show the wide range of aims and levels of development of the groups represented at the conferences.

- A group in the South West of England were able to use the Authority's graphics department. This group also now has their own venue.
- A Council in the North of England wanted to close a hostel. Service users spoke up, and now there is an independent complaints committee.
- Centre users complained about their dinner being cold – now meals come piping hot!

- In London, wages were restored when service users protested.
- Another group wrote a letter to their MP.
- Service users at another centre now show new staff around.
- Others wrote letters to their local newspaper asking for the 'language' to be changed.
- A hospital-based group wrote to a doctor who had 'labelled' a group member with a physical condition.
- At another centre they now do not allow the use of the term 'mental handicap'.

Starting a group

Where to meet

The best place to meet is somewhere in the community where other local groups meet – like a community centre, arts centre, church hall, meeting room in a pub. It should be close to public transport so that it is easy for people to get to and be accessible to people in wheelchairs.

Transport is a big problem for some groups particularly those in country areas. This can limit the choice of places to meet and the times the meetings can be held. Nevertheless, although most groups started off by having their meetings in a day centre or other place owned by services, more and more are now meeting out in the community.

Getting people to come

Get things started by talking to people about the group, what it aims to do, how it might help them. Ask them for *their* ideas; do they have a problem they would like the group to help with? It might be something like gaining confidence to speak up for themselves or it might be a practical problem like finding a flat to move into. Make sure they understand the group is for them and is there to help them.

This 'talking stage' might take some time before you find out who is keen to belong to the group but you have to stick at it!

Be sure people know where and when the group meets and how to get there.

Produce a leaflet and distribute it in places where you know people with learning difficulties or their families and friends will see it.

Put posters on notice boards.

Get an article in the local newspaper.

Some groups have found that personal contact is the best way – even visiting people in their own homes to invite them to a meeting.

Learning to be a chairperson

The meeting should be chaired by a member of the group – not an advisor or member of staff. At the beginning, the chairperson might need a lot of help from the advisor, but gradually the advisor should be able to sit back and let the chairperson run the meeting.

Invite a trainer in to help you, as in the example of Westminster People First described earlier in this report.

To start with, you could let anyone in the group who wants to, have a go at being chairperson – even for part of a meeting. Then everyone gets a chance to see if they would like to learn more about being a chairperson.

Learning to be a secretary

You need a secretary to keep a record of what is decided at the meeting. This should be done by a member of the group, even though you might need a lot of help from your advisor at the beginning.

The job could be shared by two or three people so that it is not so much work for one person.

Think about using a tape recorder as well as the more usual way of writing notes.

You can use written training materials like the LASA⁶ training pack to learn more about how to be a chairperson, secretary or treasurer.

Keeping people interested

Sometimes a group will start off well and full of enthusiasm, but after a while people lose interest and stop coming to meetings. Then it often happens that very few people are left to run the group.

Arrange the agenda so that people have enough time to share experiences and express their feelings.

Don't try and cover too many topics at the one meeting.

Let the members vote on the most convenient time and day for holding the meetings – this makes everyone feel they have a part to play and helps to keep them interested in coming.

Helping people to speak up in a big group

It can be a very frightening experience to speak up in a big group. Even a group of about eight to ten people can feel big to someone who is nervous. Some participants felt that there were people who wanted to attend self-advocacy groups but were unhappy about having to speak out.

It can be difficult if someone is not given enough time to say what they want to say. It can feel as if people are getting impatient with them, so they don't try.

If someone has a physical disability which makes speech difficult, it can be twice as hard (see section on helping people with severe disabilities).

What helps?

Make the group smaller. For example, if there are eight people divide into two groups of four.

Have coffee at the beginning of your meeting instead of, or as well as, at the end. This will help people relax and get to know each other before the meeting starts.

Have a warm-up activity at the beginning of the meeting – like throwing a ball to one another and saying the person's name as you throw it, or talking to the person next to you for two minutes and then introducing that person to the rest of the group.

Everyone in the group needs to understand how important it is to help the nervous people to speak up. This will help build trust and confidence.

The advisor's role

Almost every group will need help from an advisor.

The advisor:

- should help only where necessary and decrease that help as members of the group gain more skills
- can give practical help and information
- can help to clarify the needs and purpose of the group
- should be independent of services.

Fund-raising

Fund-raising was frequently mentioned as a problem for groups.

There are many different ways of raising money. These include:

- sponsored activities – sponsored swims, sponsored walks, sponsored silences!
- getting local businesses to sponsor you
- grants from the DHSS
- grants from grant-making Trusts (like Rowntree, Sainsburys, Mental Health Foundation)
- social events – jumble sales, discos, and so on.

Raising money takes time and can often be a lot of hard work.

These are some points to think about:

- Preparing an application for a grant from a Trust is not much fun – but you might receive a lot of money from it.

- Running a sponsored swim or disco might not raise so much money but is fun to do.
- People were also concerned about raising money being seen as being given 'charity' – people giving money out of pity. They did not want this.
- You need to decide which way of raising money will be the right one for what you need.

There are a lot more ideas about fund raising in the LASA pack.⁶

Meeting in a group home

People from a group which meets in a group home said it was sometimes difficult to run the house like an ordinary home because of rules and regulations. For example, they had to have menus to fit in with rules about Registration. They had to have fire extinguishers installed with signs near them which made the house look like an institution. These sort of rules can make it difficult for staff who want to help people run the house themselves.

Meeting in a hospital

People from a group living in a hospital talked about how they wanted to change things:

- *I want to be able to choose when I go to bed.*
- *I'd like to choose what's on the menu.*
- *I would like to choose and buy my own clothes.*
- *I don't want to share a room – I want to have my own privacy and space.*
- *I want to go out when I like – to the local shops.*
- *I want to move out of hospital.*

Listening

The issue of listening came up in all the groups and was obviously a very important issue for everyone. This is not surprising since good listening is a crucial first step towards understanding another person's problems and working together to get things changed.

It was good to note that at these two conferences some people were able to make positive comments on this subject. This very welcome sign of progress is summed up in the following statements:

- People are being taken seriously – are now being listened to.
- Members are now able to challenge inappropriate rules and regulations.
- People can speak for themselves without repercussions.
- Being listened to can help people get things.

Nevertheless, many people were still experiencing problems and discussion focused on three main areas:

- the problem of not being listened to
- learning to listen properly
- helping people in groups to listen to each other.

People not listening

Self advocates talked about how it feels when people don't listen to them. Some people get angry and end up shouting at people. Some people felt that the only way to get people to listen was to scream and shout at them:

- *If you get angry, people will listen to you afterwards.*
- *If someone starts on you, it makes you fight back.*

Other people just withdraw into themselves. They feel they can't do anything about it anyway:

- *It makes me feel sad.*
- *You keep it to yourself.*

- *Being not listened to because you're handicapped hurts.*

Participants at the conferences talked about what makes it difficult for staff to listen.

Not having enough time to spend with people. 'Sometimes staff are busy and won't look at you when you talk to them. They shuffle paper and just want to get on with it.' Often the problem is not that the staff member is not listening, but that they are not understanding. It takes time to get to know somebody well and to understand what they are trying to say.

Staff not knowing how to listen. You have to listen to what people are saying – not what you think they are saying or what you would like them to say.

What helps?

Go and talk to someone else higher up. You can insist on making an appointment to see them.

Ask them to listen. 'Please come. I want you to understand what I'm saying.'

Get the right people together.

Find people (friends, relations) who are willing to listen and are there when you need them.

Make sure each person in the group gets a turn to speak. Choose at least one topic for discussion or item on an agenda when the leader or chairperson invites each member of the group in turn to make a comment.

Make sure the discussion is interesting and understandable to everybody.

Avoid interruptions or distractions – for example, people getting up in the middle of the meeting to go and get a drink. Have a proper break so everyone can get a drink. Hold the meeting in a place where you know there will not be people walking in and out of the room.

Teach listening skills. There are books with exercises and games which help people to learn to listen. When helping people to speak together in a group, or to run a meeting, it helps to separate out time for teaching skills from the time needed to get through the business of the meeting.

Helping people with severe physical and communication disabilities

Many participants were very concerned to make sure that people who cannot speak or who have other disabilities which make it difficult for them to help themselves should be involved. A lot of this discussion focused on how to help people with severe disabilities as individuals, rather than as members of a self-advocacy group, but the suggestions are just as helpful to group members considering ways of involving their less able friends.

One group decided to try and put themselves in the place of a person with severe disabilities, and imagine what it must feel like. They felt the person would say:

- *Treat me like an individual.*
- *Treat me like an adult – not a child.*
- *Allow enough time to get to know me properly – try and put yourself in my shoes – try to understand how I feel.*
- *Vary my opportunities and activities.*
- *Let me make choices – find out for myself what I like – I may spit it out!*
- *Let me make some mistakes.*
- *Allow me to rebel.*
- *Include me in decisions and reviews.*
- *Involve my parents – encourage them to let me go.*
- *Help me find my advocate. Someone who is independent of services so that they can always be 'on my side'. Think about ways in which my friends from the self-advocacy group might act on my behalf.*
- *Enable me to get equipment which will help make my life better – but don't overdo it! Do I really need that 'special table' to sit at? Or that special unit to live in?*
- *Make sure that staff are properly trained and educated to help me use equipment and get the most out of my life.*

Some people have difficulty in speaking, but given enough time will be able to make themselves understood. Others will be helped by having a friend to help get their message across.

It is not easy to be patient when a person has difficulty in communicating – discussion slows down, meetings take longer. But if we really want to involve everyone then this is when we must use our imagination to think of new ways to help people. For example, discussion topics or agenda items are usually known in advance. The person with severe disabilities might be helped to make a contribution by having someone write down before the meeting what that person wants to say.

It is important to remember that speaking is not the only way to communicate. Symbols and sign language can help a lot of people. Others can play a part in other ways. For example someone may not be able to speak at a meeting, but they might help to set the room up, prepare and serve coffee, hand out agenda or programmes as people arrive, or simply welcome people with a smile.

Helping parents to let go

Most parents want to see their sons and daughters become more independent but they can feel threatened and anxious when their son or daughter starts speaking up for themselves. They often find it very difficult to realise that their child has become an adult with adult feelings and adult responsibilities and rights.

With regard to marriage, divorce, and children, parents at the conferences had different views. However, most favoured freedom of choice for their sons and daughters and acknowledged their need and right to have companionship and love. It was pointed out that, as in other areas of their lives, people with learning difficulties are often denied the right to make mistakes; one wrongly chosen relationship can be interpreted as meaning an inability to make any long-term relationship.

Points to remember are:

- Involve parents right from the start. A parent 'on your side' is a vital asset!

- Recognise their point of view and support them in dealing with their anxieties.
- Give them information about self-advocacy.
- Provide opportunities for parents to draw on the experiences of self-advocacy groups and to communicate with other parents.

Issues for staff/advisors/supporters

Issues which concerned staff and other supporters at the conference can be summarised under two main headings:

1. How to create an environment in which self-advocacy can develop.
2. How to help groups and individuals gain more self-advocacy skills.

There were numerous comments about the need to change attitudes so that staff don't see self-advocacy as threatening. This takes time, but self-advocacy can never flourish if staff are antagonistic or defensive.

Staff need to know that their managers and other people in senior positions believe in self-advocacy enough to:

- support them when they are helping service users take risks
- allow them to work in partnership with service users
- give them appropriate training opportunities
- employ enough staff to make sure that there is time to work with self-advocates in a way which results in changes in people's lives.

'How do you motivate people to grasp the opportunities of self-advocacy?'

Staff were concerned about how to motivate service users and help them develop their own ideas. When people have spent most of their lives having other people make choices and decisions for them, it can take a very long time for those people to learn that they can do it for themselves. It takes time and patience on the part of staff and there can be a danger of staff 'taking over' in their desire to see results.

'When do you stand back – when do you give information and advice?'

Staff were concerned about getting the balance of help right. Every advisor faces this question frequently and there is no easy answer. But if he or she has a sound understanding of, and a commitment to, the basic principles behind self-advocacy and is backed up by a supportive environment there will be a good chance of making the right decisions most of the time.

Training for self-advocates and for staff

Learning more about self-advocacy can be done in a number of different ways.

- Through, *books, videos, training packs*. It is important to make sure this information is distributed to everyone who needs it in your area.
- Through *personal membership of People First*, to get their newsletter and link up with other members around the country.
- Organise joint *training events* for staff and people with learning difficulties. It was felt important to arrange these in different places and at different times to make sure the greatest number of people have the opportunity to take part.
- People with learning difficulties who have learnt to speak up for themselves and who have had experience of being involved in self-advocacy groups are now doing training. Sometimes they work on their own – sometimes in partnership with an advisor/supporter. Sometimes they take part in events organised by someone else, sometimes they organise the event themselves.
- Self-advocates talking to other self-advocacy groups, social workers, community groups and so on.

Gary Bourlet
– President, People
First London and
Thames
Steve Dowson
– Director, VIA (Values
into Action)

IN CONCLUSION

Gary and Steve shared the chairing at both conferences and the following is a summary of their concluding remarks.

Gary Bourlet

We have talked about self-advocacy, now we must try to put words into action. There is a lot of enthusiasm to get started and make things happen.

It takes a long time: you have to have patience, but hopefully you will be able to take these ideas back to your part of the country and put them into practice. Ask yourselves: How are we going to use our power to make things change?

I hope that wherever you have come from this has given you a new insight into self-advocacy and that you will progress to the top.

Steve Dowson

At first self-advocacy seems quite a simple idea. It is easy to talk about people 'speaking for themselves', and it is obviously very important. It can also be fun and exciting, as it was at the international conference in Twickenham and as it has been taking part in these conferences.

It is only when we spend more time thinking about self-advocacy that it becomes clear that this simple idea is surrounded by much confusion and many difficult questions waiting to be answered.

The speakers' presentations gave us useful information about the activities of self-advocacy groups, but they also showed how much we all still have to learn. One of the main difficulties concerns the use of power. Sometimes the supporters and advisors of self-advocacy are too ashamed of their power and skills. There is a kind of power – 'personal power' – which we can have without stopping other people from having their own power. We need to learn more about that kind of power, and how to use it.

We, the supporters of self-advocacy, also need to learn how to hand over power. Sometimes we seem to throw our power away, or use it against ourselves. Instead of handing it over, the power

somehow gets lost. It's easy to tell when that has happened, because the group becomes dull and cannot make any changes to the world.

For me, self-advocacy is about getting things done. It isn't just about talking, though that is important. If people are encouraged to speak up for themselves, but the services don't change to take notice of their views, life could be made worse for them. Sometimes people who speak up for themselves inside services can be regarded by staff as nothing more than 'a pain'. In fact, perhaps there is another definition of self-advocacy: people learning to have challenging behaviours!

I worry that service providers will learn how to allow self-advocacy without making any real changes. We need to recognise that most of our services started when it was assumed that users could not speak for themselves, and they leave little chance for users to make choices. We must expect 'the system' to resist change. If we are not careful, self-advocates will be given all the time they want to speak for themselves, to say what they want, to publish books. And the system may not take a blind bit of notice.

If that is so, it is all the more encouraging that self-advocacy can mark up some real achievements. Important changes have been made because self-advocates demanded them. Conferences in support of self-advocacy show that many people – self-advocates, service workers, parents – recognise how important self-advocacy is and are determined to make it work.

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- Five booklets:
1. 'What is self-advocacy?'
 2. 'Getting going'
 3. 'Running a group'
 4. 'What next?'
 5. 'Basic skills that help'

APPENDIX

Where to get more information about self-advocacy

*Self-advocacy
resource list*

A comprehensive list of books, videos and training materials is available from:

Community Living Development Team, King's Fund Centre, 126 Albert Street, London NW1 7NF. Single copies free on receipt of a 9 x 4 inch stamped addressed envelope.

Useful organisations

London

People First, People First Office, Oxford House, Derbyshire Street, London E2 6HG (071-739 3890)

VIA (Values into Action, formerly CMH), Oxford House, Derbyshire Street, London E2 6HG (071-729 5436)

King's Fund Centre, Community Living Development Team, 126 Albert Street, London, NW1 7NF (071-267 6111)

Skill (National Bureau for Students with Disabilities) 336 Brixton Road, London, SW9 7AA (071-274 0565)

Nottingham

Advocacy in Action, Princes House, 32 Park Row, Nottingham NG1 6GR (0602-500 537)

Newcastle

Skills for People, Haldane House, Tankerville Terrace, Newcastle upon Tyne NE2 3AH (091-281 8737)

Scotland

Lothian Rights Group, c/o Alec Greenhill, 8/4 Moncrieff Terrace, Edinburgh (031-667 7441)

N. Ireland

Belfast Self-Advocacy Group, Bryson House, 28 Bedford Street, BT2 7FE (0232-325 835)

Wales

Wales People First, c/o Aneurin Williams, Sandbrook Day Centre, Queens Road, Merthyr Tydfil, Mid-Glamorgan (0685-721 764)



- How are self-advocacy groups developing?
- What successes have they had?
- What challenges do they face?
- How can we encourage a supportive environment for self-advocacy?

Supporting Self-Advocacy contains contributions by people with learning difficulties and by people working in supportive roles. It provides information and practical ideas as well as stimulating discussion. It will be of help to both self-advocates and staff and can also be used as an aid to training.

Solving problems

Confidence

MAKING DECISIONS

Self-Advocacy

Making friends

Confidence

Taking action

EMPOWERING

Confidence

Speaking up for yourself

Taking action

Confidence

Taking action

Solving problems

Making friends

Self-Advocacy

MAKING DECISIONS

RIGHTS AND RESPONSIBILITIES

Self-Advocacy

Speaking up for yourself

Solving problems

Making friends

Confidence

Self-Advocacy

Making friends

Solving problems

Confidence

Taking action

RIGHTS AND RESPONSIBILITIES

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