



Community  
Care  
Group

# INFORMATION EXCHANGE ON SELF-ADVOCACY AND USER PARTICIPATION

Services to people with learning difficulties



No.6

November, 1993

INVOLVING PEOPLE WHO  
HAVE MULTIPLE DISABILITIES

HOOB:QYA (Kin)

This information exchange relies on its readers for its existence! Any comments or suggestions about how it should operate will be very welcome. Individual contributions -not necessarily related to the chosen topic(s) of a particular issue - will also be welcome.

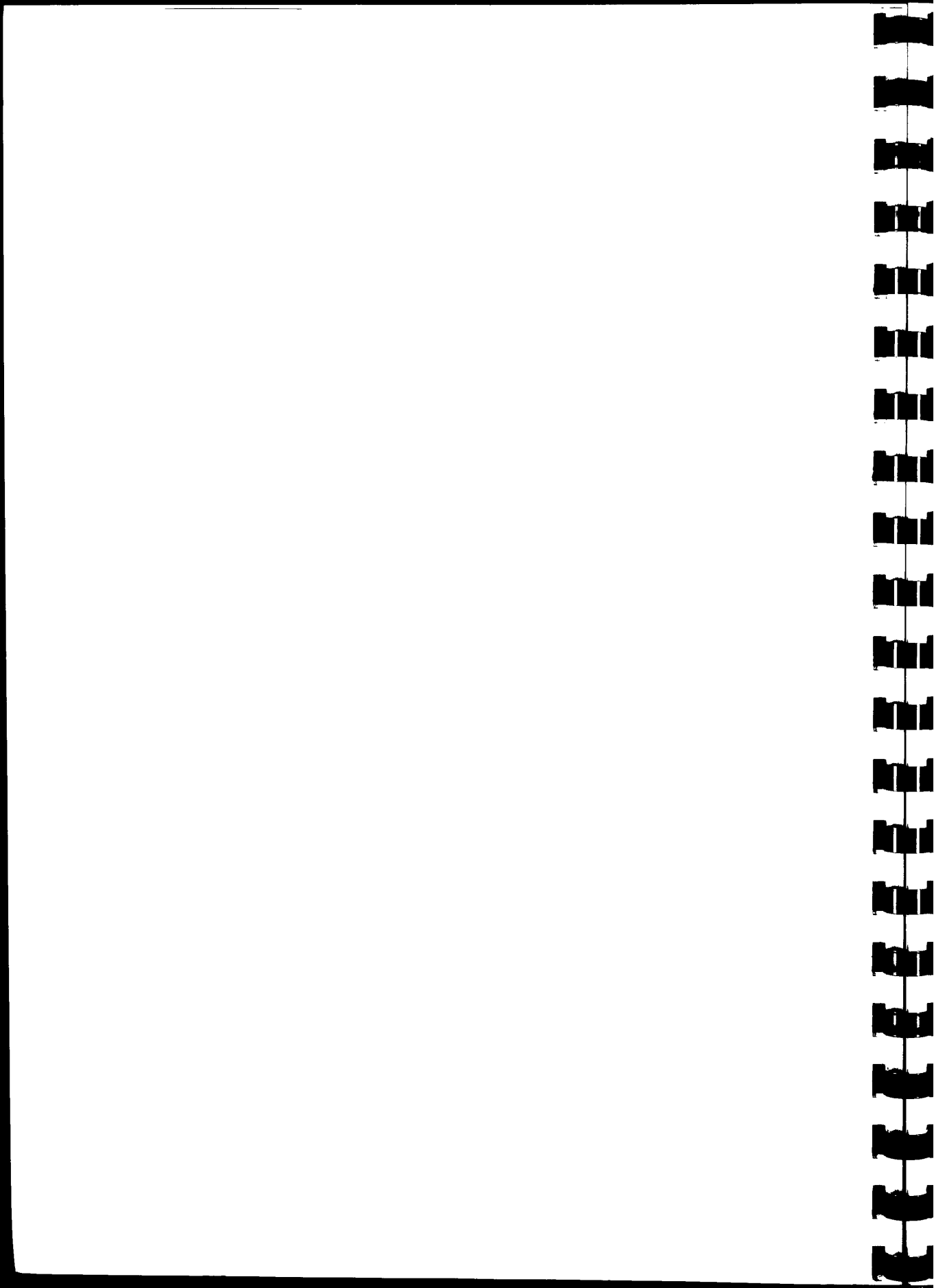
In developing the information exchange, we keep in close touch with People First's London office, bearing in mind their role in providing a link with groups around the country and producing a national newsletter. We want to make sure that the information exchange complements and does not overlap the work of the People First office. The information exchange concentrates on service development issues. It does not, for example, cover the type of self-advocacy group news which is contained in People First's national newsletter.

The information exchange is produced particularly for supporters and advisors of self-advocacy groups and people with responsibility for developing effective ways of working in partnership with users in planning and delivering services.

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## EDITORIAL

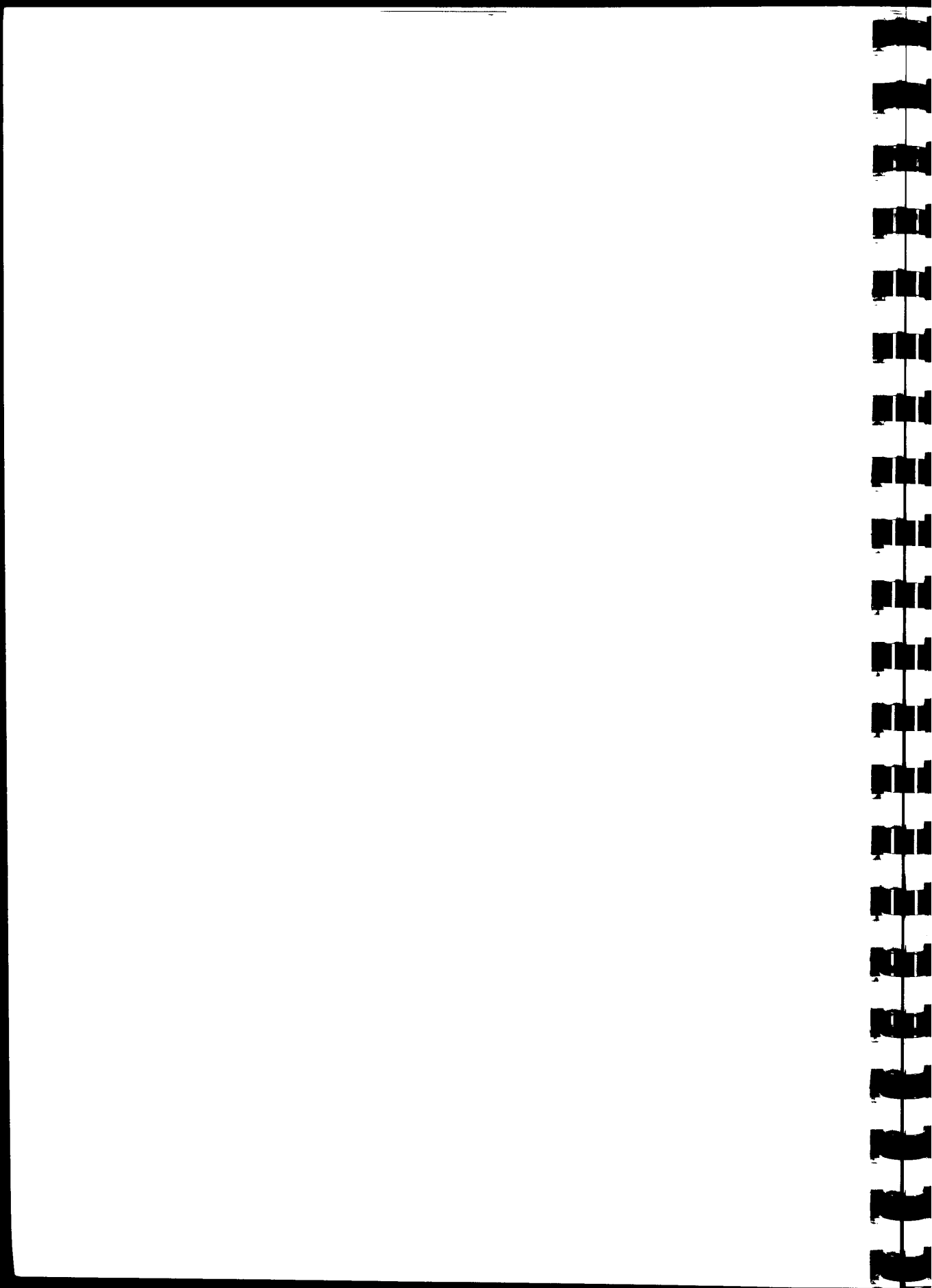
This issue focuses on involving people with multiple disabilities. It's a particularly interesting and wide-ranging set of experiences - from working with people in a special needs unit to including school leavers. If only we could say they were a representative sample of what is generally happening! We can't of course, but what we can be certain of is that they aren't the only good examples - probably each one could be matched somewhere around the country - and perhaps these stories will inspire others to have a go at breaking new ground.

Also included are five contributions which hark back to topics of earlier issues - four of them providing further excellent examples of using pictures and symbols to make written material easier to understand. We are very pleased to receive additional contributions at any time on any of the topics featured in the Information Exchange. Every example is helpful in increasing our knowledge and sharing the learning.

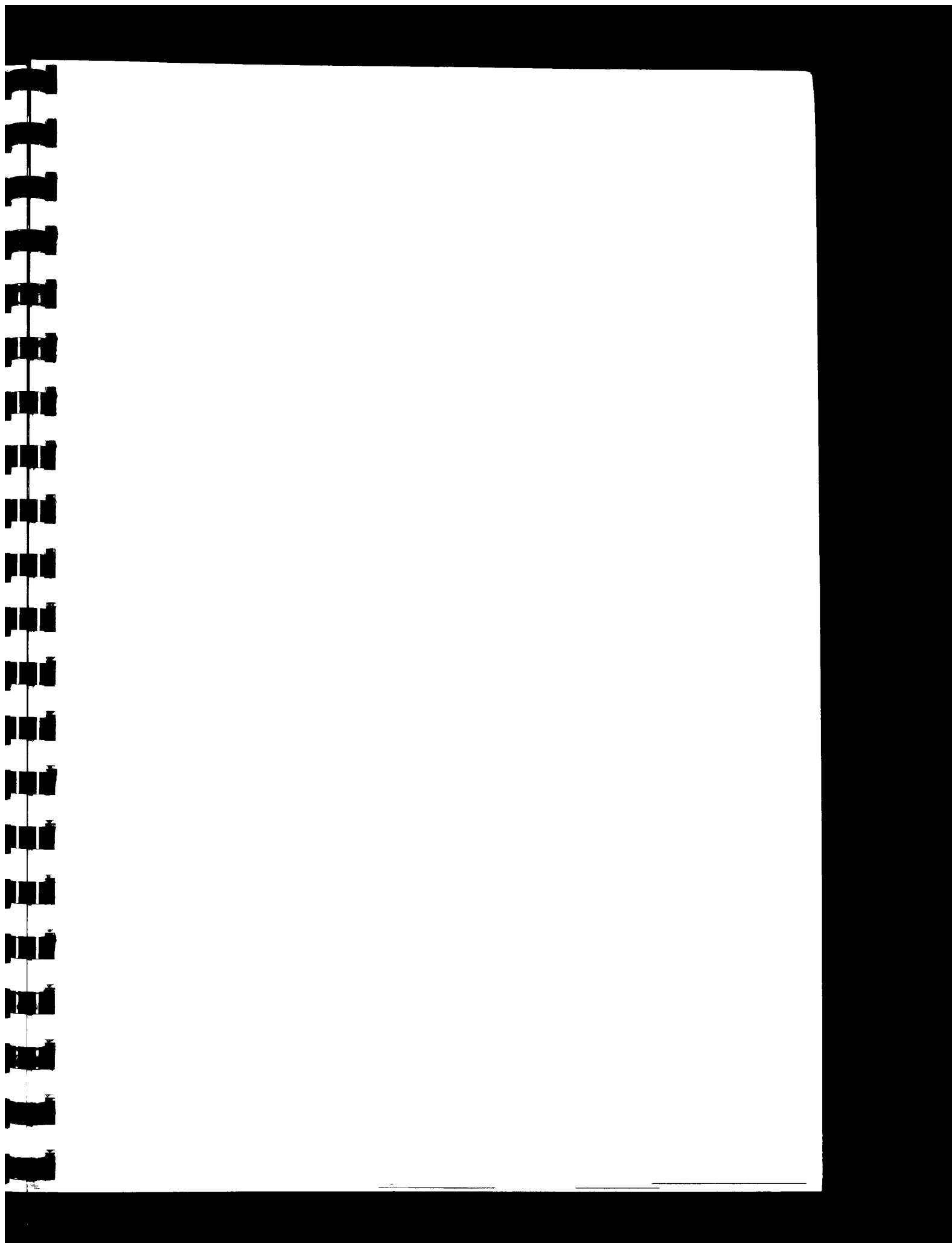
### Your views please

Thanks to the willingness of readers to contribute, we have now produced six issues of the Exchange. As we approach the end of its second year, it seems a good moment to pause and take stock. So this time, instead of a topic questionnaire to complete, there is a short questionnaire about the Exchange itself. Please send in your comments and suggestions in order to help shape its future. It would be helpful to have your response by 31st January 1994. We will aim to feed back the results by February 1994.

Andrea Whittaker  
November, 1993



INVOLVING PEOPLE WHO  
HAVE MULTIPLE DISABILITIES





## INVOLVING PEOPLE IN RECRUITING STAFF

West Berkshire Housing Consortium  
Contact: Jill Woods  
155A Whitley Wood Road, Reading, Berkshire RG2 8JH.  
Tel: 0734 875840

Five people with multiple physical disabilities and severe learning disabilities were moving into purpose built residential accommodation. The manager (Jill Woods) and the deputy were already in post, but we wanted to involve residents in the selection of the rest of the staff team.

**What were you aiming to do?**

Enable residents to interview and select staff.

**What has been done towards achieving your aims?**

We employed a Community Arts Worker to run a workshop alongside formal staff interviews.

We planned a two-day workshop. We realised that we didn't have enough time to prepare residents to interview candidates but would assess candidates on their interaction with the group.

Planned two days of informal activities based around moving to their new home - planning their rooms etc.

We held the workshop and interviews over two days. Each candidate had a 30 minute formal interview and then joined the group for 30 minutes.

Candidates were selected on feedback from the formal interview and on how they reacted to the idea of residents being involved in staff selection and their interaction with the group.

**What have been the difficulties?**

The time constraint - we had very little time to get to know individuals - April 1st deadline.

Equal Opportunities - making sure each candidate had the same opportunity. For example, the workshop had different kinds of activities going on for the residents. Candidates were being involved at various times during the day so were taking part under differing circumstances - making comparisons difficult.

Ensuring the people with learning disabilities were able to contribute and not just token.

**What have been the successes?**

It started us as we mean to go on - involving the people we work with in decisions.

**What did you learn from this experience?**

Shorter days - the two days (20 interviews) was very hard work.

A longer time to prepare so that each person understands the process of interviewing.

Make the group participation more formal - with direct feedback from clients wherever possible.

Working creatively to get answers from each client - observation - providing alternative forms of communication etc.

Any other comments?

I'm very glad we did it. Although it wasn't exactly as I would have liked, overall it was a very positive experience and we learned lots of lessons for the future.

\* \* \*

## INVOLVING PEOPLE IN A USERS COMMITTEE

Brian Didsbury Users Committee  
Contact : Harold Roberts  
Brian Didsbury Centre, 2 Didsbury Close, East Ham,  
London E6. Tel: 081-552 8948.

We have a users committee with twelve members. Three have multiple disabilities - one is blind and two have hearing difficulties and wear hearing aids. The Committee does a lot of talking and listening and some reading and writing.

### What are you aiming to do?

To help everyone contribute equally - to make it easier for people who are blind or hard of hearing to join in.

### What has been done so far?

We sit in a circle or oval so we can see each other's faces to lip read and see expressions.

We talk slowly and clearly.

We take turns to talk and have a rule about not talking altogether or interrupting each other.

Sometimes we use sign language. We use charts and pictures.

We describe how things look to our blind member (eg. the curtains are torn and faded).

### What have been the difficulties?

We have to repeat things a lot.

Some of the correspondence we get is hard to sign.

Attending large meetings can be a bit of a problem.

### What have been the successes?

Our chairperson is deaf but can do the job.

### What did you learn from this experience?

It is very important to notice differences and deal with them - not ignore them.

We have to think hard!

\* \* \*

## SETTING UP A SCHOOL LEAVERS GROUP

Lambeth Accord - School Leavers Project  
Contact : Jackie Downer/Jane Lewis  
Lambeth Accord, 336 Brixton Road, London SW9 7AA.  
Tel: 071-274 2299

The project was set up to promote self-advocacy and maximise life choices amongst young people with learning difficulties who are about to leave school. Many school leavers in Lambeth have no day care provision. Others go to college but once their courses finish they are offered no other opportunities for development. The project has mainly focussed on students from schools for students with severe learning difficulties. Several of these students have severe difficulties in communication. Several have little or no mobility and some have limited sight.

### What are you aiming to do?

Prepare the young people and their carers for making the most out of limited opportunities. We are working to enable them to express choices about what they would like to do with their lives and to push for resources to enable them to realise their wishes.

### What has been done so far?

The self-advocacy development workers visited the schools to meet the students and the teachers. Plan for a school leavers' conference were discussed and a planning group of school leavers organised.

This group met weekly for five weeks. The students were encouraged to express likes and dislikes, make choices and express emotions.

A "Leaving School - Making Choices" conference was held, with workshops on leaving school, what I'm good at, gardening, film, art and drama.

A school leavers group met once every 3-4 weeks. The group focussed on issues of basic assertiveness and choice making.

An ongoing school leavers group is planned leading to a presentation to the council by the young people regarding what they would like in their future.

### What have been the difficulties?

Finding ways in which all the young people, regardless of their different abilities, can express themselves in a group in an equal way.

### What have been the successes?

The young people have gradually started to feel more comfortable with each other. They have become more confident in expressing their likes and dislikes and their emotions through verbal means, facial expressions, movement and art.

What did you learn from this experience?

It is very important to tune into each individual's unique way of communicating and to encourage them to express themselves as fully as possible in whichever way best suits their ability. A move away from purely verbal means of communication is essential when working with a group of people with diverse and multiple disabilities. The evaluation of work in a variety of forms such as verbal, written, art, movement, video, facial expression is also important.

\* \* \*

## **WORKING WITH PEOPLE IN A SPECIAL NEEDS UNIT**

People First Mid Glamorgan.  
Contact: Katrina Kurowski,  
Ty Canol, Clun Avenue, Pontyclun, Mid Glamorgan  
CF7 9YB. Tel: 0443 228 681

Mid Glamorgan People First was asked to explore working with people in a 'Special Needs Unit', to enable the people there to develop skills in expressing themselves.

### **What were you aiming to do?**

Give people the opportunity to express themselves, using various mediums as triggers.

### **What has been done so far?**

Held a 'Getting to know you' session, whereby the member from People First and Adviser spent time learning how people in the Special Needs Unit communicate.

We used a video on 'Communication' to trigger a session on expressing emotions (anger, sadness, happiness etc).

We learnt how frustrated people are that they can't walk, talk, get around on their own, using previous session's 'emotions'.

We used photographs of friends/families to look at people's network of relationships - touched on difficult relationships with parents, and bereavement.

Using slides shown on a screen, learnt what people would like to do and where they would rather live. All wanted to live in ordinary housing, and going to the pub/horseriding were favourite activities.

### **What have been the difficulties?**

'Hit and run' sessions - people opened up so easily but had so much to express, the sessions were always difficult to bring to an end.

### **What have been the successes?**

People showed clearly how they communicate, and what they want.

### **What did you learn from this experience?**

Mid Glamorgan People First have learnt a lot from the people in the 'Special Needs Unit'; most importantly that the people there want the same as other people: nice houses, friends/relationships, an active social life etc. Also that they have the same problems with their parents that most people have - never allowed to grow up, used as a scapegoat for serious problems in other members of the family, unable to confront parents on an equal basis.

\* \* \*

## GETTING THINGS CHANGED WHERE WE LIVE

TALK' Group  
Contact: Jude Jordan  
Southside Partnership, Scout Hall, Scout Lane,  
London SW4 OLA Tel: 071-498 2533

We are people with learning disabilities.

We live in seven houses that are managed by Southside Partnership. Many of us have physical disabilities as well. About fifteen of us take part in the Talk Group).

What are you aiming to do?

Talk about different things. Support each other. Have a chat. Talk about changes we'd like to see. We do Minutes of our meetings. Then we do a Newsletter (summary) and send it to the managers.

What have been the successes?

We produced a leaflet to tell all tenants how to make a complaint. We made the leaflet so that you didn't have to be able to read. We have sent the leaflet to the managers and hope it will be printed soon.

We got the time of our meeting changed to make it more convenient. The managers asked us if we could change the meeting time. We discussed it and gave them three different times to choose from.

One person moved house because he didn't like his house. We helped him to write a letter to the managers asking to move.

What have been the difficulties?

Staff shortages in the houses mean people can't always get to the meetings.

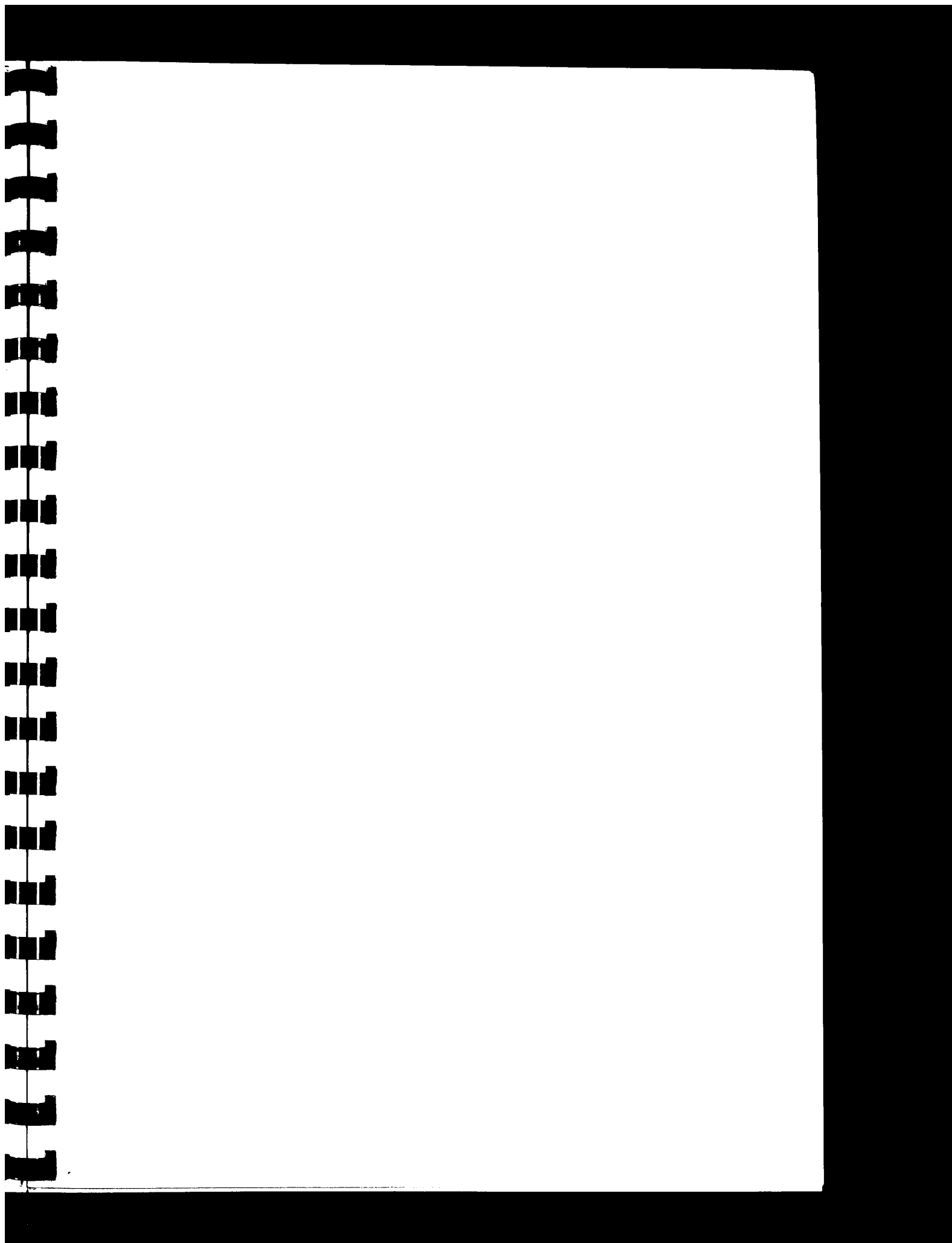
What did you learn from this experience?

Things don't always happen straight away and don't always turn out how you want them to.

Any other comments?

"I enjoy it"; "It's alright"; "I like coming"; "We've learnt things about other people, we understand each other better. We accept people for what they are."

\* \* \*





INVOLVING USERS ON  
MANAGEMENT COMMITTEES



## **INVOLVING USERS ON A COUNTY PLANNING GROUP**

South Glamorgan Self-Advocacy Forum  
Contact: Sonia Liggett  
D.A.R.T., The Friary Centre, The Friary, Cardiff CF1 4AA  
Tel: 0222-644696

### **What type of management committee?**

County planning group - multi-agency group which advises on service planning and developments in south Glamorgan that are funded by the All Wales Mental Handicap Strategy.

### **How many people are on the committee and who are they?**

20-25 people usually attend. Members include service users, parents, representatives from the voluntary sector and senior service personnel.

### **How many users are on the committee?**

Three at present (4 seats).

### **How long have users been involved?**

One year.

### **How are they supported?**

Practical support - mostly by the self-advocacy co-ordinator (assisting with transport arrangements, preparation between meetings, support during meetings). Some service staff support with reading of minutes and documents.

As representatives - regularly monthly meetings of the Self-Advocacy Forum and meetings with their local groups give an opportunity to discuss issues raised at the County Planning Group. (But see below).

### **What changes have come about because of users' involvement?**

There is raised awareness of the fact that service users have valuable contributions to make and should be listened to.  
Service users are developing an understanding of how county planning and systems work. Members are getting to know other members - who they are and what they do.

### **What have been the successes?**

Acknowledgement that the term 'mental handicap' offends many people and the agreement that it will not be used by the group.  
A two-day consultation meeting with service users on individual planning was requested and took place.  
A 'user-friendly' version of the County Plan for Services to People with Learning Difficulties is in preparation. Service users on the group frequently comment on the need for more accessible information.

#### Difficulties and comments

The Consultation and Representation Role: Documents distributed for consultation are usually weighty and complicated and lack summaries of main points and implications. Reading and understanding such documents is time-consuming and difficult. Time for consultation is often very limited and therefore most issues get little meaningful discussion. (This problem is common to all representatives and attempts are being made to allow more time). Also, members of the Self-Advocacy Forum and other self-advocacy groups are reluctant to spend too much time talking about large planning issues which can seem rather remote. Time has to be carefully balanced so that local issues that concern people can be discussed and then raised at county level when the groups decide that it is appropriate.

Language: more effort is needed to make presentations clearer. This would benefit all members, not just service users.

\* \* \*

CONSULTING USERS ABOUT  
COMMUNITY CARE PLANS



## CONSULTING USERS ABOUT COMMUNITY CARE PLANS

Horizon Community Meeting  
Dore Sadler  
Horizon Resource Centre, Coldhams Lane, Cambridge.  
Tel: 0223-248681

### How were users consulted?

Users were not consulted at planning stage, but a students from the Community Care plan Information Unit is working with a group of people from the self-advocacy group on an information tape and leaflet.

### When did the consultation begin and when did it finish?

Autumn term 1992 to Spring 1993.

### How was written material made accessible for users?

Tape.  
Pictorial version. (see following pages)

### What were the difficulties?

A special group was set up for a pilot testing. There were very few difficulties according to the student. Her comment: "We managed to communicate the idea of community care in a very short time and they are comfortable with it".

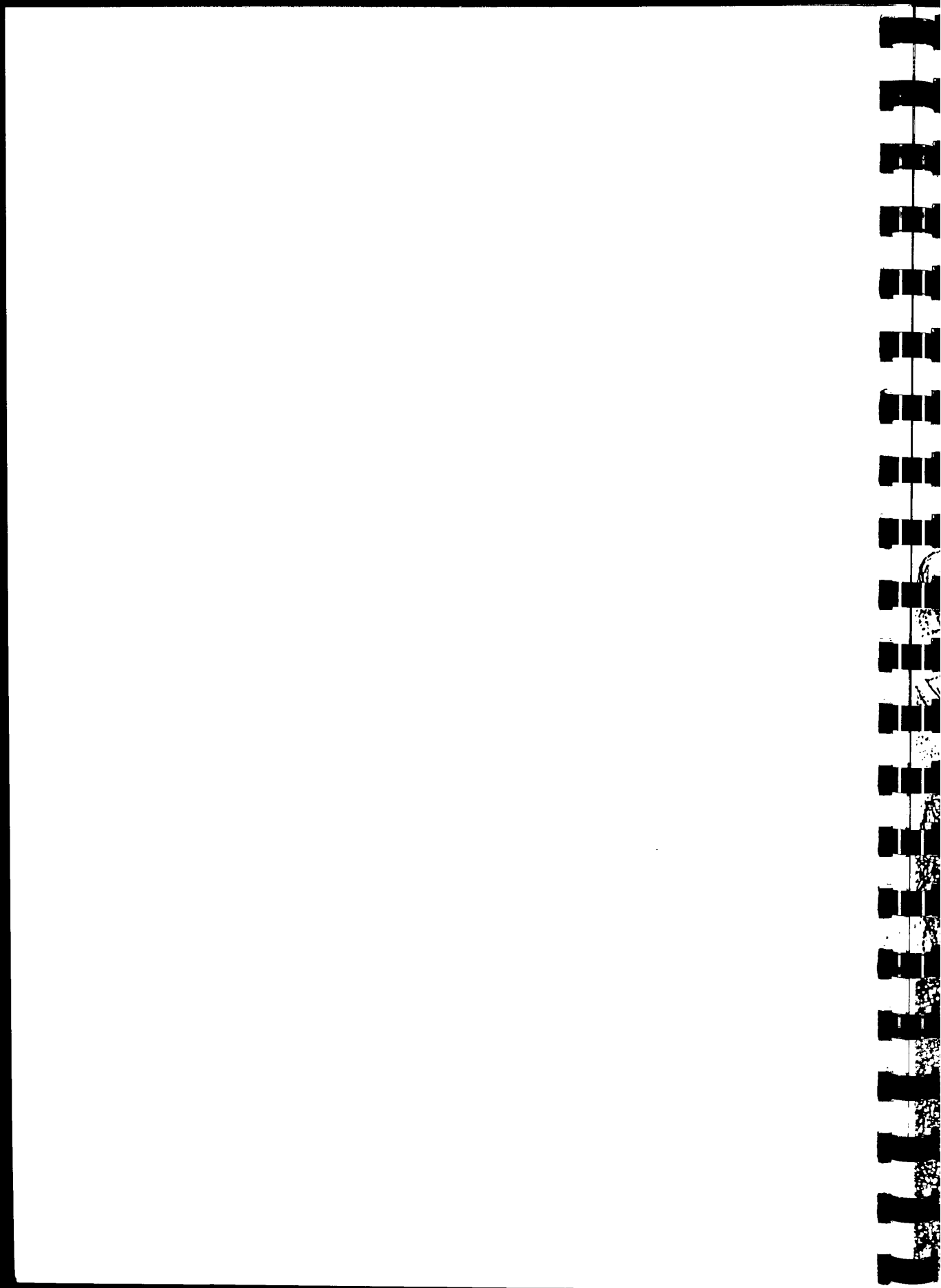
### What were the successes?

We successfully communicated the information we needed to. We understood it and everyone is happy with the results of our meetings - ie. the information pack.

### What arrangements have been made for ongoing consultation?

The users are going to be given more information as it becomes available.

\* \* \*

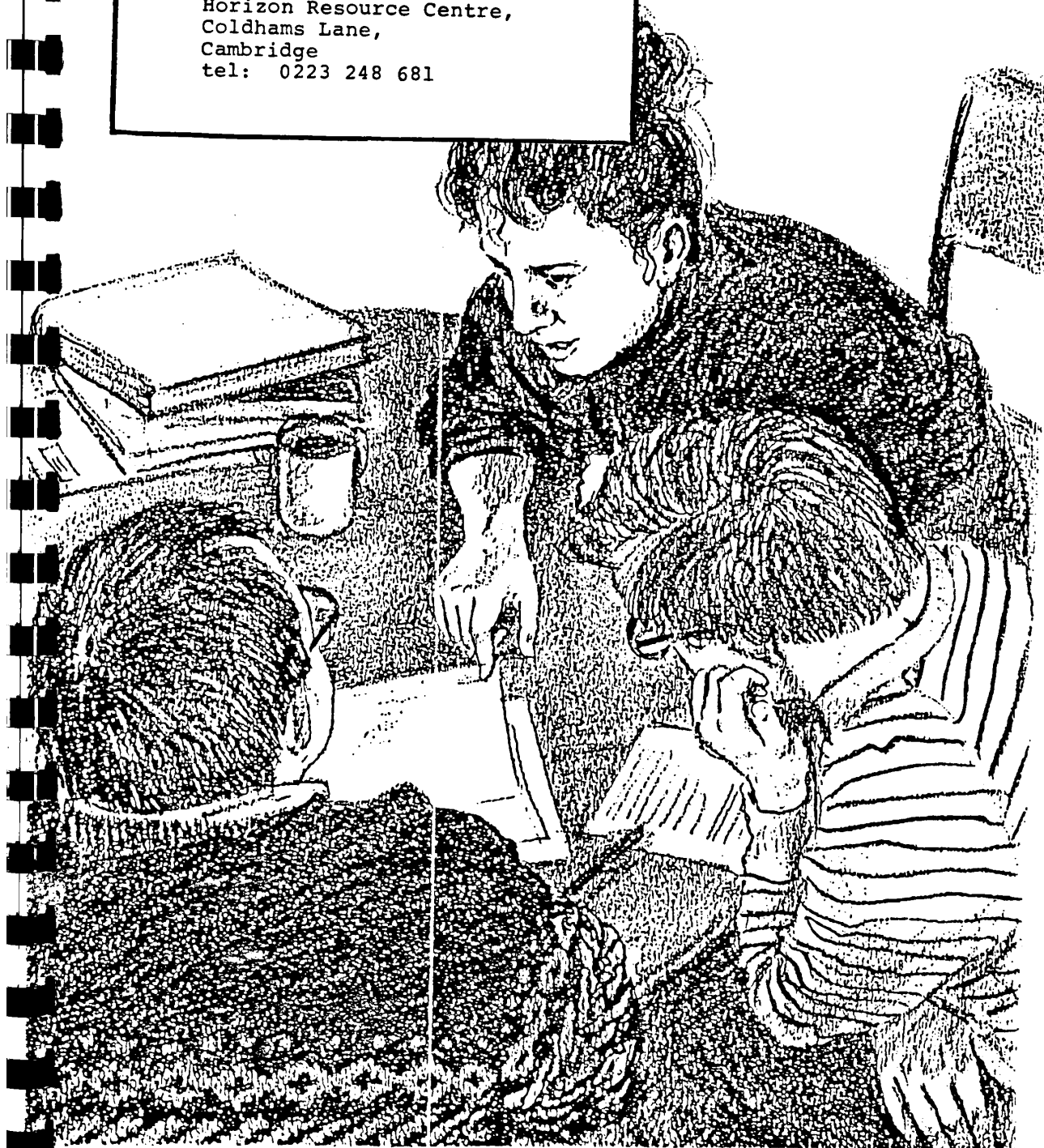


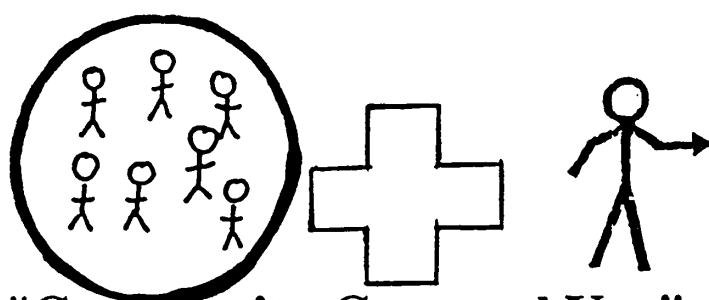


# "Community Care and You"

**Contact:**

Horizon Community Meeting  
Dore Sadler  
Horizon Resource Centre,  
Coldhams Lane,  
Cambridge  
tel: 0223 248 681





"Community Care and You"

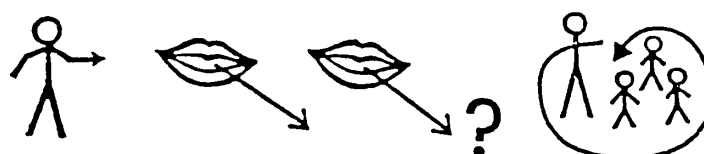
? is it?

What is it?

For + needs  
It is for you, and your needs



We want to help you meet "Your Individual Needs" we do this by "reviews"



But we want you to tell us what you " need"



You will be helped to do this by



ADVOCACY



This means you speaking **FOR YOURSELF**



- OR Asking someone to speak for you



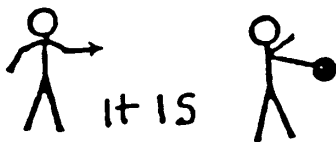
with **ADVOCACY** what you need will be



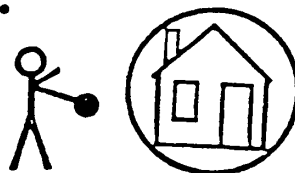
M	T	W	T	F	S	S
AM			?		?	
PM	?	?				

made for

found, and a programme will be made for



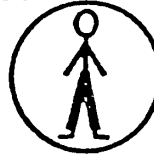
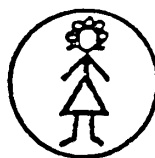
you. It is yours to keep.



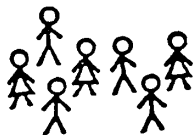
The next thing is about your home.



live



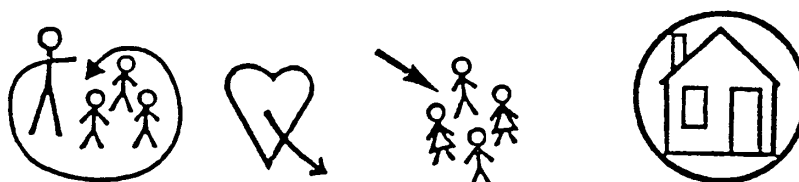
You might live with your Mum and Dad,



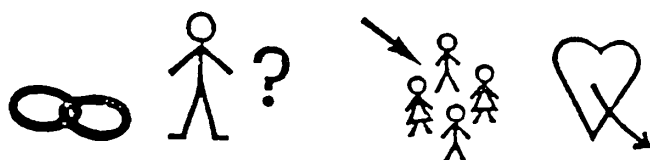
or in a hostel with other people.



Lots of people still live in hospitals



But we want them to have their own home



with people that they choose.

We see good things now and  
we want to make them better.

MAKING WRITTEN MATERIAL  
EASIER TO UNDERSTAND



We hope you think this  
is a good idea



and

that you will want to tell us **what you like** and  
**what you don't like** about what we do here at  
Ferguson Close



*I want to go  
swimming more*

*I like dancing*



*I don't like being  
told when to go to bed*



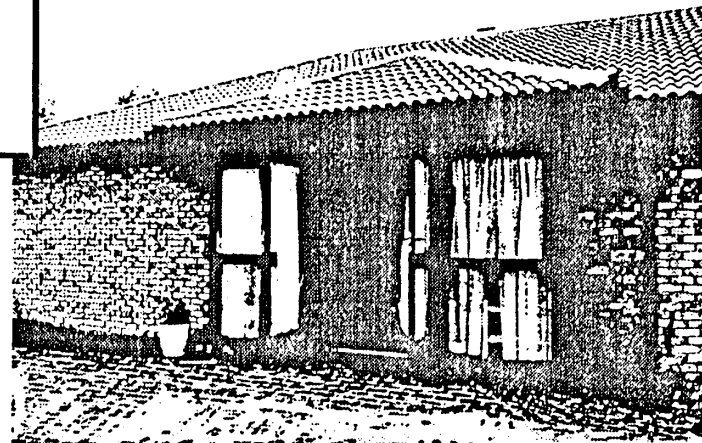
*I like being  
asked what I think*

Someone called Angela Cole is helping us find out  
these things. If you would like to meet her we will  
ask her to visit

Contact:

Angela Cole,  
Anglia Polytechnic University  
Victoria Road South  
Chelmsford, Essex CM1 1LL  
tel: 0245 493 131


FERGUSON CLOSE  
SAFFRON WALDON



**Your** home and **your** Day Centre

These are some of the things that happen at  
Ferguson Close ....



In 1992 we want to see   
**what you think** about Ferguson Close

what's good



what's not so good



We want to make it an **even better** place for you  
to live in or for you to visit





We hope you think this  
is a good idea



and

that you will want to tell us **what you like** and  
**what you don't like** about what we do here at  
Great West Hatch



I want to go out to  
restaurants more

I like  
watching cricket



I don't like being  
told when to go to bed



I like being  
asked what I think

I don't like  
noisy people



Someone called Angela Cole is helping us find out  
these things. If you would like to meet her we will  
ask her to visit


# GREAT WEST HATCH CHIGWELL



Your home

These are some of the things  
that happen at Great West Hatch ..



In 1992 we want to see   
**what you think** about Great West Hatch

what's good

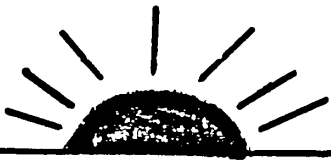


what's not so good



We want to make it an **even better** place  
for you to live in

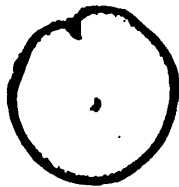


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ANGRY ?

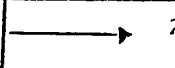
Contact:

Horizon Community Meeting  
Dore Sadler  
Horizon Resource Centre  
Coldhams Lane, Cambridge.  
tel: 0223 248 681



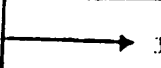
Angry/Pleased

SIGNATURE

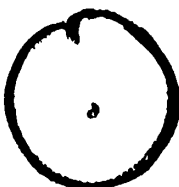
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2

SIGNATURE

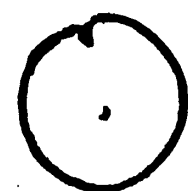
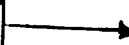
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3



Angry/Pleased

SIGNATURE

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Angry /Pleased

DATE

NATURE OF COMPLAINT (DETAILS)

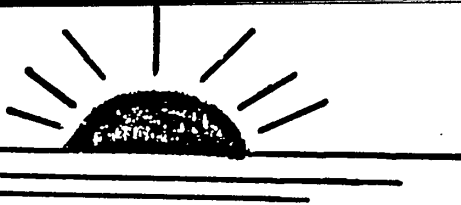
PEOPLE INVOLVED (WITNESSES)

ACTION

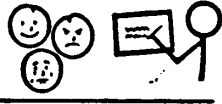
DATE RESOLVED

COMMENTS

SIGNATURES



RIGHT TO REPLY



NOTES FOR STAFF WHEN ASSISTING WITH COMPLAINTS PROCEDURE

**STAGE ONE**

- 1 Place a photograph of the complainant in the top left-hand box of the complaint form.
- 2 Ask the complainant to write about the complaint (if applicable) in detail, in the larger top right-hand box.
- 3 Place a photograph of the complainant's keyworker in the box under that of the complainant.
- 4 Use the reverse side of the complaint form to complement the existing information given by the complainant.
- 5 If the complaint is of an interpersonal nature ask the person who is the focus of the complaint to complete the Right to reply form.  
  
N.B. The keyworker must at this stage acknowledge the complaint to the complainant in writing (or appropriate means of communication) within five working days. The acknowledgement must be made in a formal way, and evidence of the acknowledgement and the completed Right to Reply form handed in to the office at Horizon.
- 6 Then, if after a meeting with all the relevant parties, the complaint is now resolved, illustrate a pleased face and ask the complainant to sign the box next to the tick.
- 7 If the complaint is not resolved, illustrate an angry face then place a photograph of the Horizon Centre Manager in the box under that of the keyworker.
- 8 If, after a further meeting with all relevant parties, the complaint is now resolved, illustrate a pleased face and ask the complainant to sign the box next to the tick.
- 9 If the complaint is not resolved, illustrate an angry face, then place a photograph of the Area Manager - Romsey, in the box under that of the Horizon Centre Manager.

- 10 If, after a further meeting with all relevant parties, the complaint is now resolved, illustrate a pleased face and ask the complainant to sign the box next to the tick.
- 11 If the complaint is not resolved, illustrate an angry face and move on to STAGE TWO. Any outcome of STAGE ONE must be notified to the complainant in writing (or appropriate means of communication) by a designated staff member within fourteen days, and evidence of the communication handed in to the office at Horizon.

STAGES TWO & THREE (IF APPLICABLE)

Please refer to the Complaints and Representations Procedure (1992) published by Cambridgeshire County Council.

These paragraphs are taken from Canbo. Canb  
Council complaints and representations procedure  
Jan 92)

THE COMPLAINTS AND REPRESENTATIONS  
PROCEDURE (JANUARY 1992)

STATES THAT -

- " Normal good practice should sort out, to the user's satisfaction, the queries and grumbles which are part of a Social Services Department's daily workload. Stage 1 of the procedure alerts the relevant worker, Supervisor or Manager to the fact that there is a more fundamental problem as perceived by the user, carer or his/her representative. "

(P.17, PARA.2.1)

IT ALSO STATES THAT IF A COMPLAINT IS MADE THAT -

	Action by	Timescale for Completion
" The nature of the comment/complaint is recorded, and the outcome noted using the Complaint & Representation Index Form SOC948. This is completed by the person investigating the complaint. These are filed in the Area Team Office or establishment where the comment or complaint is made. A copy of the Complaint and Representation Index Form SOC948 for all complaints recorded in establishments e.g. residential establishments, day centres etc. is sent to the Area Team and filed on the Area Team's Complaints Register. The Area Manager is responsible for ensuring that the Complaints Register is maintained. The staff member responsible for working with the client should check whether or not they are satisfied with the outcome. "	Person investigating the complaint	14 days from receipt of complaint
	Area Manager	
	Worker allocated to client	

(P.18, PARA.2.4)



Sutton Social Services welcomes complaints or suggestions on the services it provides. If you want to complain it is your right.

Name .....

Address .....

Telephone No .....

Please make your complaint or suggestion below:

.....  
.....  
.....  
.....  
.....  
.....  
.....  
.....

(continue on a separate sheet if you wish)

Have you discussed this with the person you normally deal with in Sutton Social Services?

Please circle YES / NO

Return to: Complaints Officer, FREEPOST,  
Sutton Social Services  
St Nicholas Way, Sutton, SM1 1EA

IT'S YOUR RIGHT



Sutton

Comments,

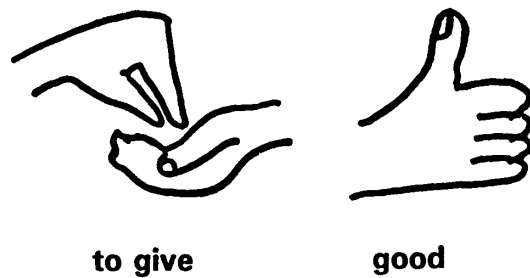
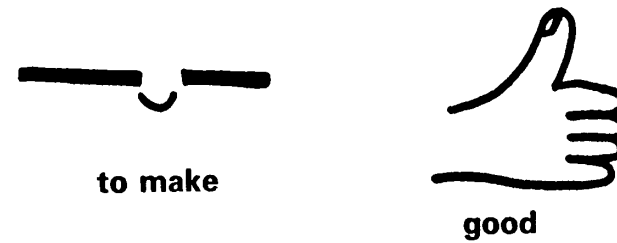
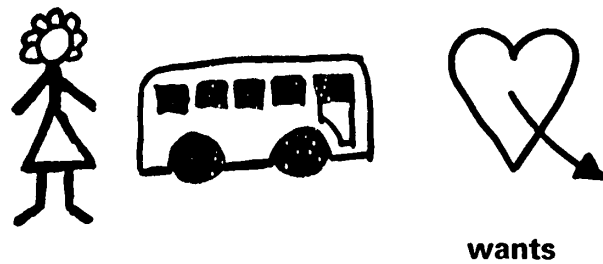
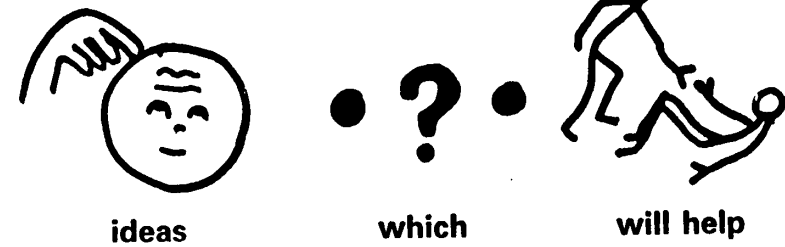
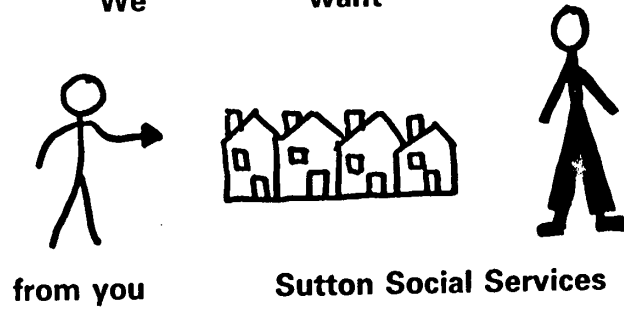
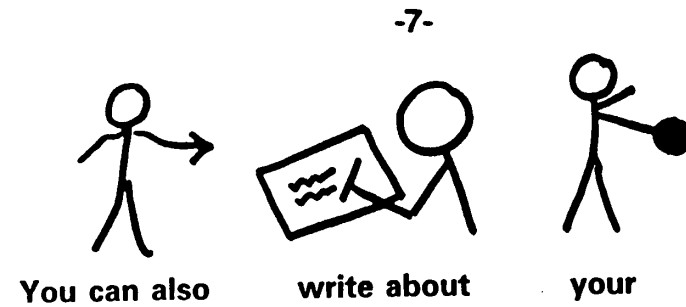
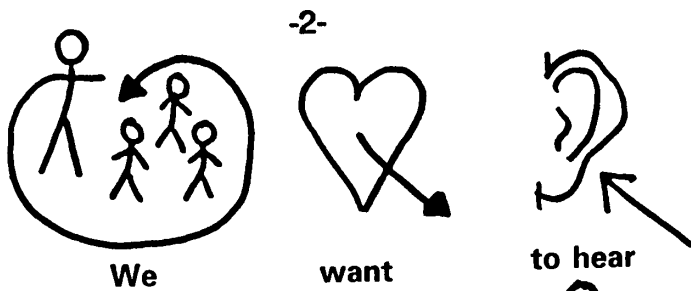


Complaints?



Contact:

Barbara Nurse  
Service Manager (Learning Diffic.)  
Housing & Social Services)  
London Borough of Sutton  
Civic Offices  
St. Nicholas Way  
SUTTON, Surrey SM1 1EA  
tel: 081 770 5000



services.

-6-



not happy

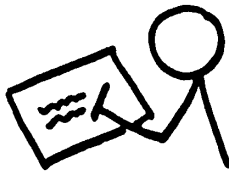


Telephone

081 770 4946



or you



can write to the



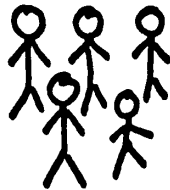
Complaints



Officer



find



someone

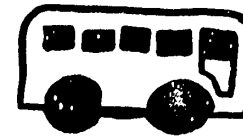


to help



you

-3-



Services.



If you



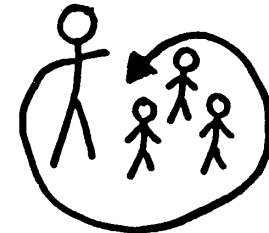
want to



make



a complaint



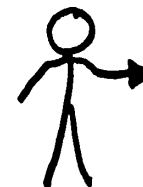
we



want



to know



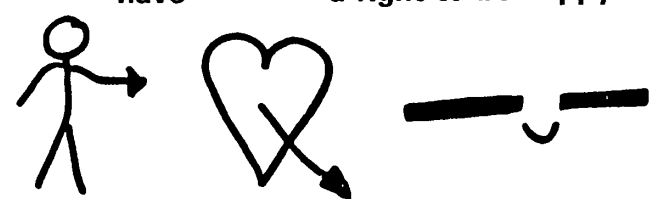
you

41-

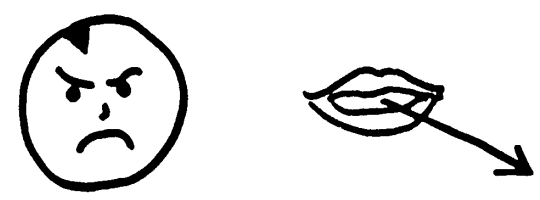
-4-



have a right to be happy.



If you want to make

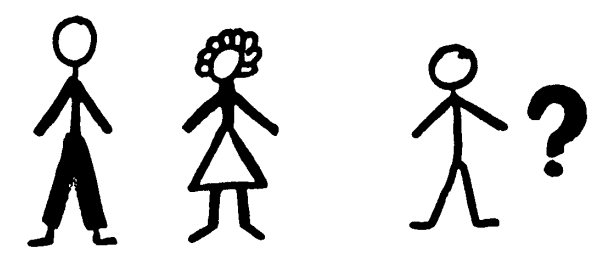


a complaint ask



first to speak to

-5-



the person who



works with you.



If you've complained and

King's Fund



54001000392509

# PAST ISSUES

- |      |   |               |
|------|---|---------------|
| No.1 | Involving service users in appointing staff.<br><br>Using pictorial methods to enable people to communicate more effectively. | November 1991 |
| No.2 | Stories of how people are working to get changes in services.   | February 1992 |
| No.3 | Involving users in the planning and development of services.<br><br>Complaints procedures - using them effectively.           | June 1992     |
| No.4 | Conflict of interest.   | November 1992 |
| No.5 | Involving users on management committees.<br><br>Consulting users about community care plans.                                 | May 1993      |

