

INFORMATION EXCHANGE ON SELF - ADVOCACY AND USER PARTICIPATION

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F E B R U A R Y, 1 9 9 2

Achieving change

Stories of how people are working to get
changes in services.

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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 are keeping 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 work of the information exchange complements and does not overlap the work of the People First Office. The information exchange will concentrate on service development issues. It will 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. However we hope that many service users will also read it, and we will be continually striving to find ways of producing it which will make it readily accessible, whoever is using it.

EDITORIAL

Welcome to the second issue of the information exchange. Thanks to all those who responded to the request for stories about achieving change - an interesting collection of individual and group experiences from both service users and staff members. Particular thanks to those writers courageous enough to admit they have not achieved their aim yet! Please keep us in touch with how things progress.

SIGNS AND SYMBOLS

You will recall that in the first issue we included examples of using symbols and other pictorial methods to make written material user-friendly. Since then we have received some very interesting material from Connect, a Bristol-based organisation whose brief is to provide accessible information and resources for people with learning difficulties. Included in this issue are some examples of their work, principally the consultation document about setting up the Phoenix NHS Trust. Lesley Le-Pine of Connect, says: 'we are approached by many different agencies to translate the text as well as add pictures and symbols. Most texts are full of jargon and complicated concepts and long words which are hard for people to understand. We re-write them using plain and simple English (I hope!)'. For more information about their work contact Connect at P.O. Box 30, Avon House North, St. James Barton, Bristol BS99 7NB. Tel: (0272) 290 777 Ext. 536.

Incidentally, Connect is funded by the four health authorities which are forming the Phoenix Trust. Do readers know of any similar initiatives?

NEXT ISSUE

1. Enabling people with learning difficulties to use complaints procedures effectively.
2. Involving people with learning difficulties on an ongoing basis, in the planning and development of services.

In preparing to invite responses to the above topics, it has been interesting to consider a paradox which seems to underly them. If we are really committed to integrating people into ordinary communities, there is a sense in which we ought to be looking for 'non-service' solutions to people's problems. Then why are we encouraging people to be involved in the 'traditional' systems? The answer is of course, that services do have an important part to play. What we are still struggling with is to find ways of

ensuring that services don't dominate people's lives. Hopefully, involving people effectively in the way services are planned and delivered will result in less service-centred, more ordinary lives for people who need support.

Complaints Procedures

One way of enabling service users to have their voice heard is through complaints procedures. These seem to come up increasingly in conversations and requests for information. The following letter from Mike Leat, advocacy worker in Surrey, is typical of the enquiries we receive.

"As a service we are aiming to adapt our policies and procedures into a more user-friendly format so that users of the service can participate in writing and updating policies that affect them. The first procedure we are looking to tackle is a complaint procedure. We are keen that users of the service are aware of their right to make complaints and understand the correct channels to use when exercising that right.

Has anyone out there tackled this issue, if so any help and guidance would be very much appreciated."

So, for the next issue we will be very pleased to receive:

- examples of user-friendly complaints procedures
- details of how service users have been helped to understand and use the procedure
- problems and successes
- stories of ways of helping people make a complaint other than conventional methods.

Involving service users on an ongoing basis in the planning and development of services

We have deliberately added the words 'on-going' here as we feel there is no need to include examples of one-off events arranged to obtain users' views - e.g. one-day workshops, consultation days. These are a valuable starting point but they have been done on numerous occasions now and are well recorded. What we would like are examples of moving on from this starting point. In your area -

Is there an ongoing consultation process?

Are people involved in official planning groups,
social services committees, community teams, etc?

Do service users regularly meet with senior
managers?

What other opportunities are there for service
users to influence the sort of support they
receive.

See questionnaire for further details.
Responses by Thursday 16th April, 1992 please.

Andrea Whittaker
February, 1992

CREATING EFFECTIVE WORKING LINKS BETWEEN RESIDENTS AND MANAGERS

Mike Leat, Advocacy Worker, Residents Committee,
Greenlaws Day Centre, 65 Cranley Road,
Guildford, GU1 2JW, Tel: 0483-36435

What were you aiming to do?

Create an environment where residents feel free to express their opinions about the services they receive. Also to encourage managers and staff to assist this process and support it appropriately.

How did you do it?

In July 1991 we had an open residents' meeting facilitated by a People First representative and a community care worker from a local voluntary group. No staff were present at the meeting. Discussion centred around five issues - work, leisure, home, staff and independence. The facilitators drew up a written report highlighting comments received from the meeting.

The planning group of residents decided to meet regularly to discuss these comments and future concerns. The idea of having a residents' committee was discussed. The planning group then decided that three representatives from each community home (five homes) should attend the meetings once a month. The first meeting took place in October 1991 and covered many issues that arose from the open meeting.

The group decided they wanted to work on the issues of 'meeting the managers' of the service and 'looking after our own money'. As advisors we offered possible ways of tackling these e.g. phoning managers, writing letters, sending Minutes. The group decided to write to the service managers.

The manager of the learning disability service attended the next meeting to introduce herself and to explain who the managers were. A diagram was produced showing the management structure and the names and contact numbers of all the managers.

Meanwhile, it became clear that the structure of the meetings as originally decided was not working. More than three people from each house wanted to attend and this meant that many people who came to the October meeting couldn't attend the next one. As advisors we pointed out this problem and offered the group suggestions for dealing with it. The group decided to re-structure the meetings so that every three months (March, June, September and December) there was a meeting open to all residents and the meetings in between would be smaller and attended by the chairman, secretary and others who wished to make a monthly commitment. The group decided to ballot every resident to find out if they wanted to attend meetings, and if so

whether they wanted to attend monthly or quarterly. So far, this arrangement is working well.

The December meeting was an open meeting and the issue of 'looking after your own money' was the focus. Many residents wished to have more control over their money, and the manager of the residential service agreed to come and talk about it. The committee chairperson and advisor drew up a poster advertising the meeting. The meeting was very well attended. There was a very open and frank discussion between the manager and residents and agreement was made to press ahead with enabling people to be in control of their own benefit books, and to transfer hospital bank accounts to ordinary building society accounts. All parties agreed that this change should not be rushed as new skills needed to be developed by all concerned. To begin with two people from each house will learn the necessary skills and the plan is for those people to assist in helping other people gain the skills.

What were the difficulties?

- (1) Advising a group without controlling it.
- (2) Conflict of interest as advocacy worker is employed by the health authority.
- (3) Encouraging staff and managers to allow things to develop at residents' pace and not their pace.

What were the successes?

- (1) Managers and residents discussing issues together.
- (2) Managers now consulting residents' committee - e.g. on policy for having visitors at the houses.
- (3) Increased awareness of importance of 'customers' views.
- (4) New skills being learnt by everyone.
- (5) Real changes occurring prompted by residents.

Do you feel you achieved your aim? - Partly

What did you learn from the experience?

I personally aimed to create an environment where residents felt able to express views freely, and where service providers felt able to take those views on board and adapt accordingly. It is still early days. Self-advocacy is still quite new and in its honeymoon phase. The real test will come when a conflict arises between service users and service providers. I would hope then my role of supporting the group would be replaced by an independent person. We do have an independent person currently helping to support the group.

LEARNING TO TRAVEL INDEPENDENTLY

Giovanni Vella, Hill House SEC,
117 Church Lane, Tooting, London SW17 9PT
- Tel: 081-871-7180

What were you aiming to do?

To travel to Hill House with a friend.

How did you do it?

Our key worker did the journey with us for two days and then we did it by ourselves.

What were the difficulties?

My difficulty was getting out of bed early!
Finding the right platform and train.

What were the successes?

We did it.

Do you feel you achieved your aim? - Yes

What did you learn from the experience?

1. Travel training.
2. Meeting up with a mate.
3. How to use the underground.
4. How to cope with problems that arose e.g. when the station was closed due to a bomb and we had to walk to work.

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PERSUADING SOCIAL SERVICES TO STOP MAKING CUTS

Hilary Drage, Banbury Self-Advocacy Group.
Contact: John Rose, Orchard Health Centre,
Cope Road, Banbury Oxon. Tel: 0295-257727

What were you aiming to do?

Social Services have stopped our £4.00 allowance for attending day centres in Oxfordshire. We want them to start paying us again.

How did you do it?

We discussed it at our advocacy meeting. We all agreed that it wasn't fair that our money should be stopped. We talked with the staff who help us with the advocacy group. They listened to us and asked us what help we needed. They said they could not get our money back.

The staff said we would have to contact other people above them, including the Director of Social Services. We rang his office and wrote a letter inviting him to a meeting. We prepared for the meetings by having lots of extra advocacy group meetings and talking about what we wanted to say:

1. We want our money back.
2. Keep Redlands Centre open.
3. Don't cut staff.
4. Keep everything going.

What were the difficulties?

He didn't turn up for our first meeting because he was busy. We have invited him to another meeting in the New Year.

What were the successes?

None, but we will let you know how we get on, if you are interested.

Do you feel you achieved your aim?

What did you learn from the experience?

Not yet, but we are still trying. Getting this letter in your newsletter might help us to get our money back or some of it.

Ed. Certainly we would like to hear what happens. Please keep in touch.

IMPROVING THE FOOD AT OUR DAY CENTRE

Keith Dalgleish. Brian Didsbury Users
Committee, 2 Brian Didsbury Close, East Ham,
London E6. Tel: 081-552-8948.

What were you aiming to do?

We were trying to make the dinners better - to arrive on time, hot and with more meat and more hot puddings instead of yogurt or cheese and biscuits.

How did you do it?

We had a meeting where we practised talking to the Contracts Monitor, Chris Norman, and wrote our complaints and suggestions on two large sheets of paper. We invited him to the next meeting.

Chris told us about the contract the council had with the caterers. We could not get more meat unless the council paid the caterers more money. The Council was looking at this. We must ask if we can have more hot puddings.

The food was sometimes cold because we had old containers and meals on wheels had to be delivered on the way. We should write to social services asking for new containers. The meals should not be late. He was trying to find out why. The cooks had to cook from the start now and not just re-heat food. He didn't know if the cooks were taking a longer time or if the drivers were.

We wrote all this on seven large sheets of paper and put them up for all the users and the staff to see. Chris said he would come back to us in four weeks' time. Later, he sent us the contract to read.

Helen from Social Services and Stephen from Direct Services came to see us. Stephen said we should order our dinners before ten o'clock if we want them on time. He said that from January we could have a week's menu in advance and that would help us to book early. He said we could have two or three hot puddings a week.

Helen said that social services were looking at paying more for more meat when there was a new contract. We might have to pay more too. She said there were new containers and there would be new heaters in January. The food would come hot. She said the new contract should be better for us.

Do you feel you achieved your aim? What did you learn from the experience?

We think we got somewhere. We learned it is good to ask questions.

GETTING MANAGERS TO LISTEN

Percy Dangerfield, People First of
Cheltenham, 4 Bishops Court, Devon Avenue,
Cheltenham, Glos

What were you aiming to do?

To get managers of services to listen to our view about how services should be run.

How did you do it?

We discussed in the self-advocacy group what we thought of services.

We wrote and sent a letter to the Director of Social Services and the Chairman of the Social Services Committee.

No reply - so wrote again!

Meeting arranged between People First Group, managers and councillors. Another meeting took place of People First to make sure all People First members knew what they wanted to say.

Then came the meeting! The views of People First members were listened to.

What were the difficulties?

1. No reply to first letter as Director of Social Services was off sick.
2. Managers and councillors wanted to meet in the daytime. People First wanted to meet in the evening. (We met in the evening.)

What were the successes?

1. They listened to us.
2. They stopped charging for day centres.
3. They agreed to have another meeting in six months' time.

Do you feel you achieved your aim? - Partly

What did you learn from your experience?

Not to give in.

How to speak up and help others.

* * * *

**CREATING MORE OPPORTUNITIES FOR PEOPLE TO TAKE PART IN
SPORT**

John Sheridan, Leavesden Special Olympic
Sports Association, c/o Leavesden Sports
Association, Leavesden Hospital, College Road,
Leavesden, Herts, W05 ONU. Tel: 0923-674090
Ext 157

What were you aiming to do?

Develop hospital residents through sport and enable them to participate in special olympics.

How did you do it?

Discussed within self-advocacy meeting.

Formed sports association. Contacted sports bodies and groups. Joined national special olympic organisation.

Held trials - contacted all areas. Undertook CSLA courses (Sports leadership). Established training nights. Fund raised (£16,000).

Joined local groups. Entered regional, national and international events. Wrote reports.

Had people selected to represent England at European Special Olympics and Four Nations tournament.

What were the difficulties?

The bigotry of Special Olympics groups and their failure to offer opportunities for all levels of handicap (especially hospital residents). The fact so much was voluntary and finding time and money.

What were the successes?

Gold medals at all levels (and many other medals). Six residents in England team at European games, 1 resident in England team at Four National tournament. Breaking three national athletic records at mini olympics. Holding world record for 100m. Winning Linford Christie trophy. People with severe learning difficulties being successful at Alconbury games.

Do you feel you achieved your aim?

What did you learn from the experience?

Yes very much so. People now see hospital residents in a different light - although the Special Olympic groups still tend to manipulate their athletes and not provide them with adult status. There is also not enough integration with ordinary sports meetings.

GETTING A RECREATION CENTRE IN THE HOSPITAL

David Lewis, Leavesden Hospital, c/o Nurse
Education Centre, Leavesden Hospital, College
Road, Abbots Langley, Herts WD5 ODR.
Tel: 0923-674090. Ext 151

What were you aiming to do?

Trying to get the hospital to provide a 'place of our own',
a resource/recreation centre.

How did you do it?

Approached hospital manager informally and asked for her
support.

Identified the need and how the area would be used.

Met with planning officer and support services manager to
discuss availability of space/accommodation and changes
required.

Agreed proposal, sat back to wait for action.

No action occurred - continue to push.

What were the difficulties?

Contraction (closure) of hospital meant limited space.
Difficulties due to resettlement with continued presence of
members.

What were the successes?

Filmed at meeting by BBC - shown on TV November 17th. Used
by Open University, K666 package (participation.) Entries in
Anthology 'Know me as I am'.

National conference held here in 1987.

Do you feel you achieved your aim?

What did you learn from the experience?

We are still striving for our aim.

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GETTING EXTRA STAFF

Newbold Centre Committee.
Contact: Jon Eccles, Newbold Centre,
Leicester Street, Leamington Spa,
Warks. Tel: 0926-334973

What were you aiming to do?

Get supply staff in to cover events which are missed due to staff sickness. Because of lack of staff, people are missing out particularly on away-from-centre activities like swimming, bowling etc.

How did you do it?

Delegation from Newbold Centre visited the SEC in Warwick to organise a common front.

Centre Committee organised a petition to take to head of Social Services for people with learning difficulties in Warwickshire. They are still collecting signatures.

Next step will be to go and see senior people in Social Services.

If that fails we will take action under the Official Representation procedure. If that fails we will think about what other action we can take like writing to papers, picketing offices, etc.

What were the difficulties?

Due to charge-capping there have been swingeing cuts,, leading to loss of staff, meals and attendance allowance already.

What were the successes?

Client-led action. Establishing links between us and Warwick SEC. Increased people's awareness of power structures and funding issues outside SEC.

Do you feel you achieved your aim? - Not yet

What did you learn from the experience?

Client-led activities take longer but are more worthwhile in the end. As a result of this and other activities the Centre is shortly to elect a chairperson with learning difficulties for the committee - a hugely important step towards control.

READERS' LETTERS

Stranded in Surrey!

Is there anybody out there in the Surrey area who would like to meet with supporters/advisors of self-advocacy groups to share experiences, information and frustrations.

I am very keen that we start networking locally and would like to hear from anyone in the Surrey area currently involved in or planning to support any form of advocacy work.

Please contact: Mike Leat, Advocacy worker, Greenlaws Day Centre, 65 Cranley Road, Guildford, Surrey GU1 2JW (Tel: 0483-36435).

Wanted by Southside Partnership

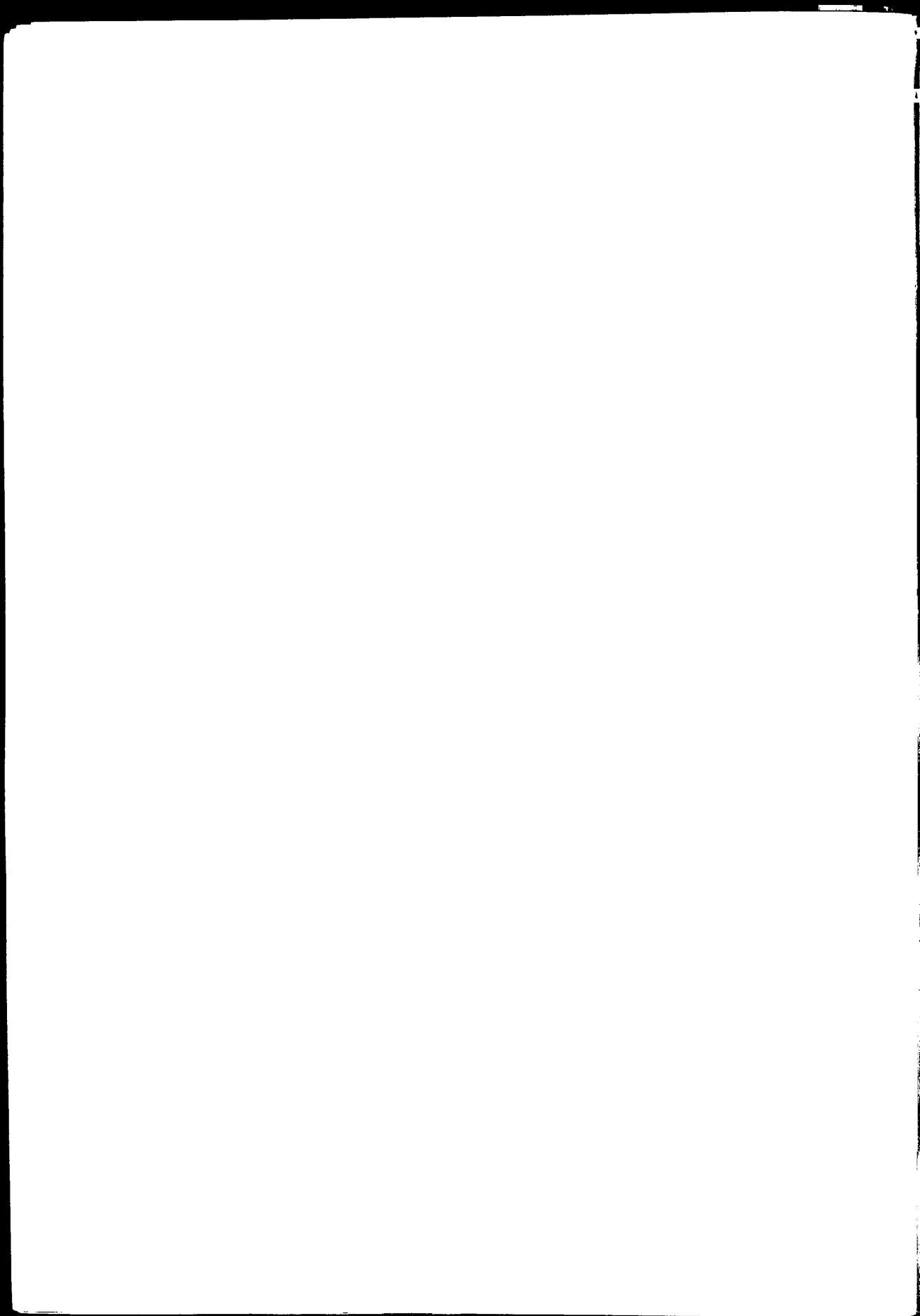
Co-advisor for a self-advocacy group for tenants with learning difficulties. "We talk about what we like to do....about day to day issues....all different things.

The group meets once a fortnight on Thursday afternoons, 2-4 p.m., in Clapham, with two advisors.

Pay: £20 per hour

For application form and further details please ring Jude on 071-498-2533 (mornings only and not Wednesdays).

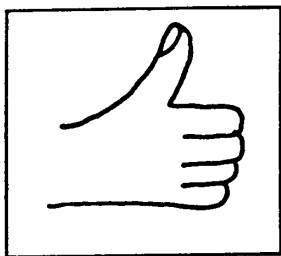
Closing date: 13 February 1992.





**This booklet tells you about the PHOENIX TRUST and how it
could work for people with learning difficulties.**

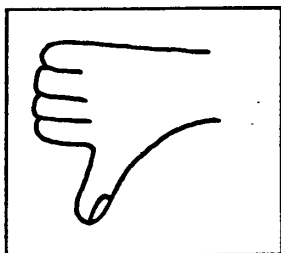
**This is your chance to 'Speak Up' about what
you think of the trust.**



The Phoenix trust will use the words:

PEOPLE with learning difficulties

NOT

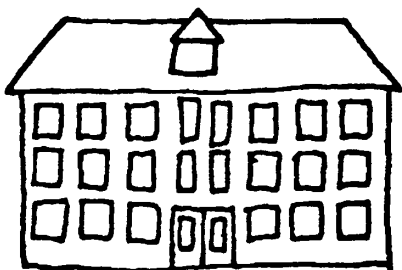


mentally handicapped

or

people with a mental handicap

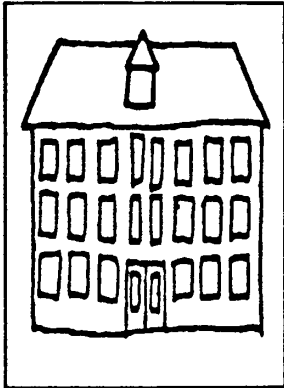
The Phoenix Trust is being set up to help people with learning difficulties who live in hospital, to move into houses in the community and help them live there. It will also provide health care for people growing up with their family.



There are still 800 people living in hospitals in Avon. They could live in their own home with the right help. Some people are worried about moving from hospital. Staff will help people to talk about this change.

In Avon there are quite a few hospitals where people with learning difficulties live:

These are:



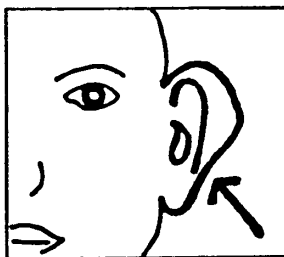
Brentry Hospital and Hortham Hospital -
looked after by **Southmead Health Authority**

Stoke Park Hospital and Hanham Hall
Hospital - looked after by Frenchay Health
Authority.

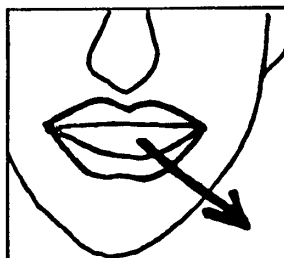
Farleigh Hospital - looked after by Bristol
and Weston Health Authority

If the **Phoenix Trust** was set up it would look after all the hospitals. This would make it much easier. It would be the **Phoenix Trusts** job to close the hospitals and help people to live in their own homes.

The good things in this change will be:



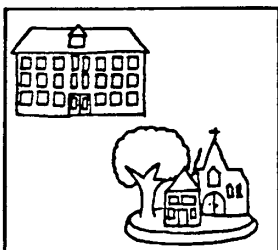
Better ways of listening to what people say
they need;



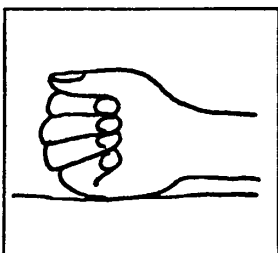
Helping people speak up about the
services they get;



Giving people more choice in where they want to live and who runs that house;

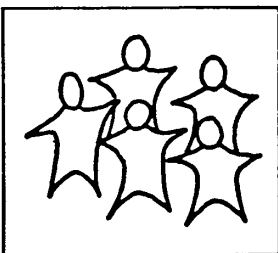


Making it easier for people to move from hospital to the community;

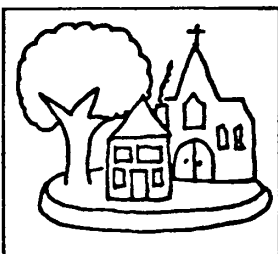


Helping the staff do their jobs well so people get the help they need.

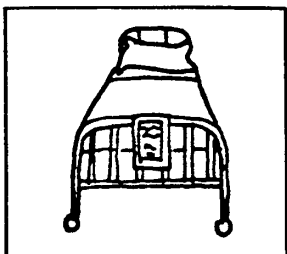
The **Phoenix Trust** will make sure these things happen for people with learning difficulties:



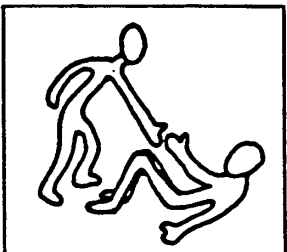
Community Teams to help people. These might be a social worker, an OT, a speech therapist, a doctor or other staff with special training. (These are called CMHTS)



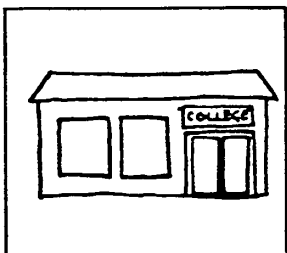
Places to live in the community with staff to help people who live there.



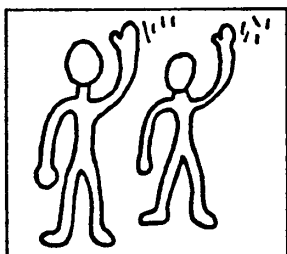
Beds in hospital if people get ill or need special help for a while.



Help and support for people who sometimes get angry or upset that they hurt themselves or other people.



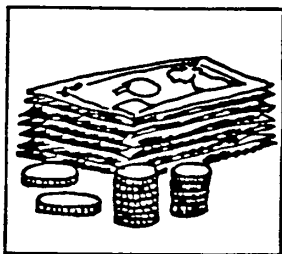
Places for people to go during the day like RACs, college or training courses. (The Phoenix Trust will try hard to help people get jobs)



Find people who will have adults to stay with them, so they can have family sometimes. This is called a family placement scheme.



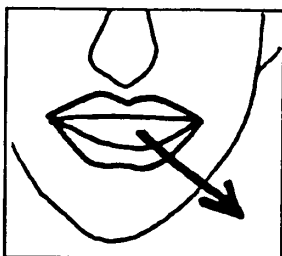
Run an information shop like Connect, with people to help you find out what you want to know.



Money

The Phoenix Trust will look at ways to make sure that money gets spent in the places where people need it, to get the help they want.

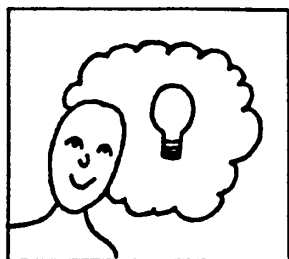
Helping people have a say in how the Phoenix Trust works



It will have meetings that everyone can go along to, and **speak up and say what they think of the Phoenix Trust.**

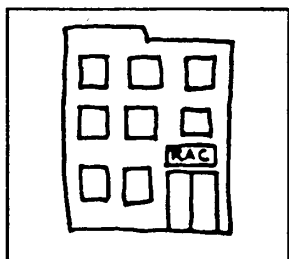
People will be able to speak with bosses in Phoenix Trust and tell them what they think about the services they get. It will help people come along to meetings to think up new ideas and plan services.

Visions and Aims

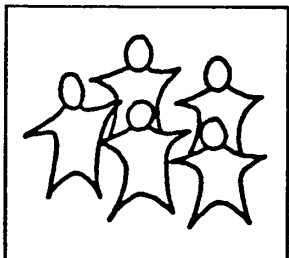


The Phoenix Trust wants to run lots of different sorts of services. It will treat people with learning difficulties as **people** first. Helping you to learn new skills, feel proud of yourself, speak out for your rights.

The Phoenix Trust will work with other people too:



Like groupworkers in RACs and Social Workers;

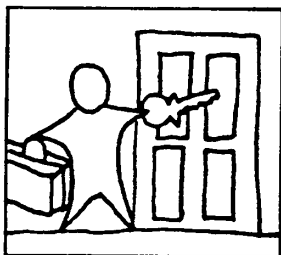


In Voluntary Agencies like MENCAP, Wholebaked Cafe, City Farms and WEA.

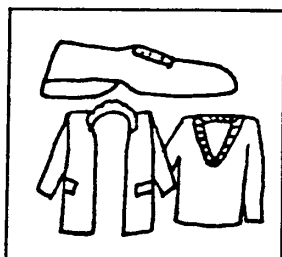
What things happened before the Phoenix Trust

Over the years a lot has changed for people with learning difficulties who live in hospital. Staff have learnt what hurts people and what helps people to live a good life.

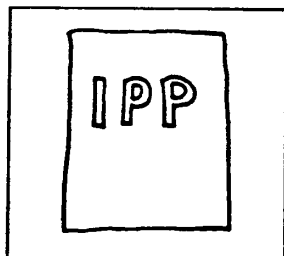
Some of the changes have been really good, like:



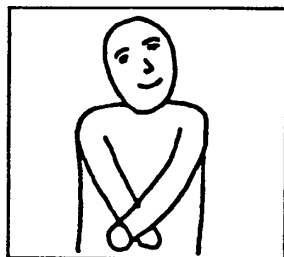
helping people move from hospital to their own house;



making sure people have nice clothes to wear;

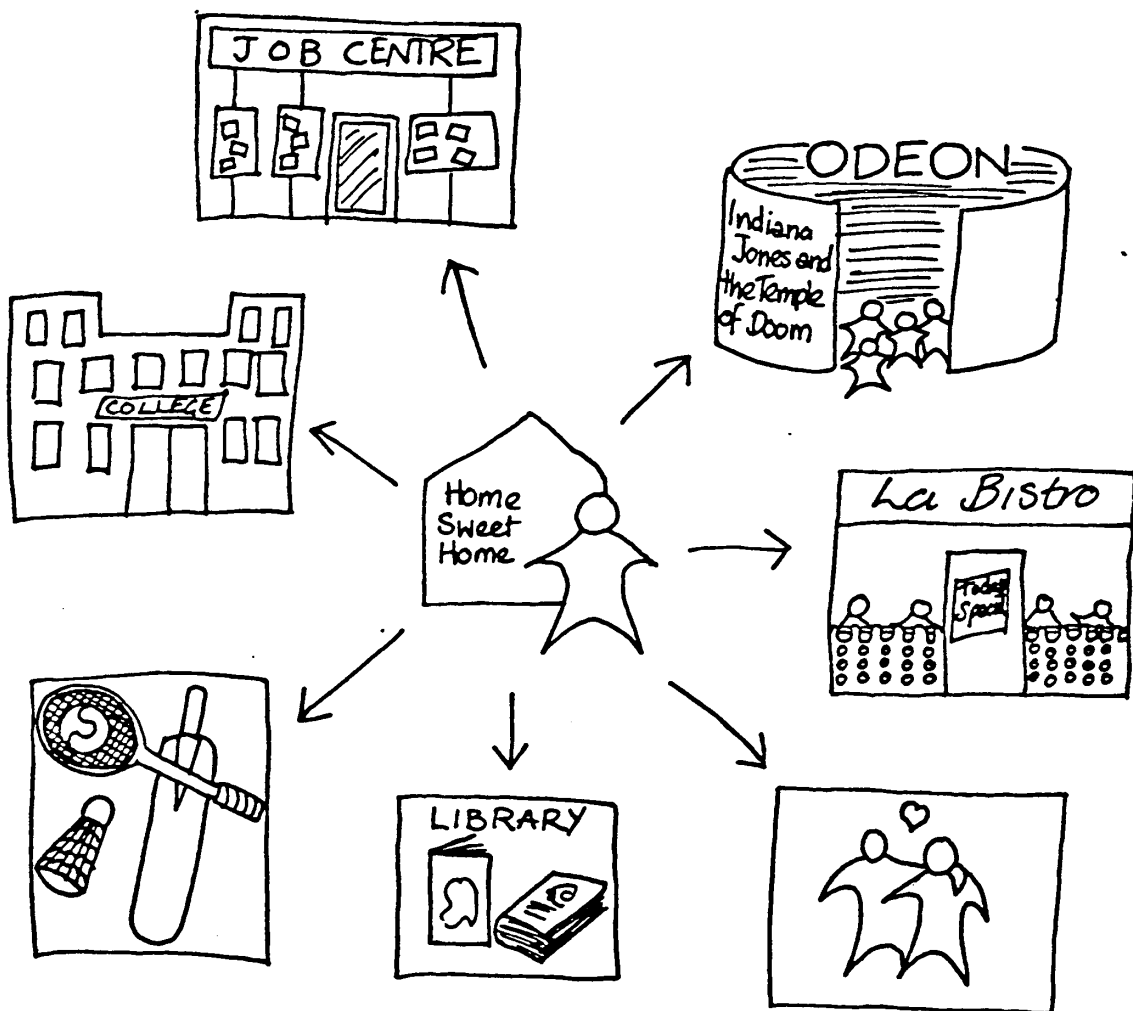


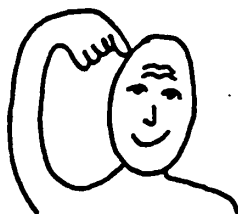
helping people to make their own plans for what they want in their lives;



helping people feel proud of what they can do;

The Phoenix Trust wants to keep on doing the good things which have helped people live better lives. The Phoenix Trust will work hard to help people use ordinary places and do ordinary activities like everybody else in the community; like have a job, a good place to live, go to the pub, use sports centres, go to the cinema, have friends and lots more things to do.





What do you think?



If you want to find out more about the Phoenix Trust ask for David Selway who is the boss. David will come and talk to groups and answer their questions.

Write to him:

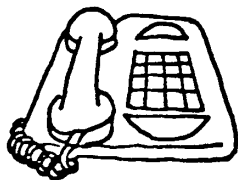
David Selway
Brentry Hospital
Charlton Lane
Westbury on Trym
Bristol
BS10 6JH



Or Telephone: 500500
(Ask for David Selway)

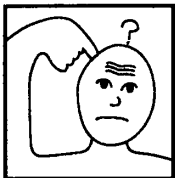
If there is anything you want to say about the Trust:

Muriel Summerell
Assistant Review Manager
Services Planning
South West NHS
King Square
Bristol



Telephone: 423271 (ext. 4512)

Avon Policy on Consultation with disabled people.



Consultation means talking to people and asking them what they think about the services they get - things like going to R.A.Cs, living in a hostel, getting meals on wheels.

*sample pages only
of
7-page document*

Some people from Avon Student Council and Avon People First met with Viv Lindow who asked people what they would like to say about services and how they would like Avon to listen to them. These ideas were written down in a report. (If you would like a copy phone Junior Edwards on 244474 - you can have it on tape or with words and symbols)

In October Avons Councillors talked about this report and liked some of the ideas. They want everyone in the County of Avon to use these ways of consulting disabled people and people with learning difficulties to find out what they think. This will start in April 1992 if there is enough money.

The Councillors want to know if people with learning difficulties think they should be doing these things.

**Please fill in the form and send it back by Friday
December 13 or as soon as you can**

What the councillors are asking you

Your name

Are you speaking for yourself YES ☐ NO ☐

or for a group of people ? YES ☐ NO ☐

If you are speaking for a group of people what is the name of your group?

The words written in the biggest letters are the ideas agreed by the councillors. Please decide what you think about the ideas, then answer the questions by ticking the boxes.



1. Avon County Council should have good ways of asking disabled people what they think of services. These ways of asking should be rules that all Avon staff have to do.



Do you think Avon should have these rules?

YES ☐ NO ☐

Is there anything that you think the council should put in these rules which would help people with learning difficulties?



2. Once a year the council will write a book which will tell disabled people if the council's work is helping disabled people or not helping disabled people.



Do you think the council should give you a report every year?

YES ☐

NO ☐

Is there anything you would like the council to tell you in this report?



3. There are lots of groups of disabled people in Avon. The council should keep a list of all the groups. Anyone should be able to get a copy of this list.

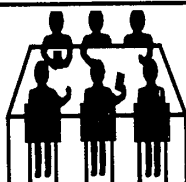


Do you think a list of groups would be helpful?

YES ☐

NO ☐

Do you want to say anything else about the list?



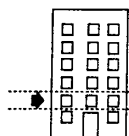
4. One way of making your voice heard is to go to meetings where you can talk to people from the council. These meetings are called Local Forums. The council wants to have meetings near where you live. Any disabled person could go and talk to people from the council.



Do you think there should be meetings for disabled people to speak up near where you live?

YES ☐

NO ☐



The council wants to have the meetings in these places.
Please tick which place is near where you live

Bristol North ☐

Bristol South ☐

Bristol Centre ☐

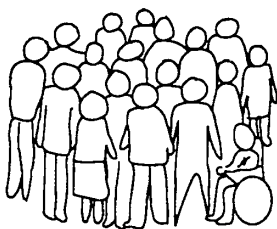


Bath/Wansdyke ☐

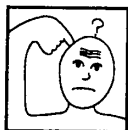
Weston-Super-Mare/Woodspring ☐

Kingswood/Northavon ☐

Do you want to say anything else about local meetings?



5. Twice each year the council would hold a big meeting of disabled people called a County Wide Forum. Disabled people from all over Avon could go to this meeting. Each local forum would send someone to the big meeting. The person would talk about everyone's ideas and things the council does. Also people from other groups who have members all over Avon could go to the meetings.



Do you think the council should have meetings where disabled people from all over Avon speak up about the council and the things it does.

YES ☐ NO ☐

If you are part of a group with members all over Avon, would you like to send someone to the big meetings?

YES ☐ NO ☐

Do you want to say anything else about the County-wide meeting ?

King's Fund



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