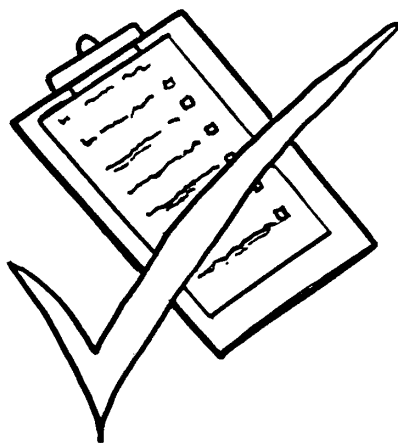


LOOKING AT OUR SERVICES

Service evaluation by people with learning difficulties

A book for people with learning difficulties and their
supporters who want to get involved in evaluating
services



Edited by Andrea Whittaker

King's Fund ■

KING'S FUND LIBRARY

11-13 Cavendish Square
London W1M 0AN

Class mark

Q BJA

Extensions

Whi

Date of Receipt

28/5/97

Price

Donation

LOOKING AT OUR SERVICES

Service evaluation by people with learning difficulties

**A book for people with learning difficulties and their
supporters who want to get involved in evaluating
services**

Edited by Andrea Whittaker

King's Fund

**Published by
King's Fund
11-13 Cavendish Square
London W1M 0AN**

© King's Fund 1997. All rights reserved

ISBN 1 85717 155 1

A CIP catalogue record for this book is available from the British Library.

This report has been produced to promote dissemination of good practice and quality improvement in health and social care.

You are welcome to photocopy it or extra copies may be bought at a cost of £5.00 each (include p&p) through the King's Fund Bookshop. Tel: 0171 307 2591.

CONTENTS

	Page No.
Using this book	5
Introduction	7
Outside but not inside... yet! Evaluating services in Sutton and Haringey Alice Etherington	11
Evaluating Adult Education Brenda Cook, Jennifer Lauruol, Andrew Shepherd	19
Dundee Neighbourhood Survey Christine Fisher Graeme Millar Craig Mulla	29
Looking at food and diet standards Pat Helm Karen Jeffereys Gillian Rhodes	33
Evaluation of information produced by Southwark Inform Andrew Bright	43
Involving people with complex needs	45
Helpful hints	47
Questions for further discussion	51
People to contact	55
Further reading	57

USING THIS BOOK

The left hand side of each page has words and pictures.

The right hand side has only words.

If you would like a summary - a quick read - of what the book says, read down the left hand side.

If you would like more details, read down the right hand side as well.

Terminology - words used in this book

Evaluation	=	Looking at how services are working and giving your opinions about what is good and what is not so good. Often an evaluation is done quite quickly - say, in a few days, or a week.
Monitoring	=	Keeping a regular check on how services are working say, every three or every six months.
User-led	=	Service users are in the 'driving seat'. It is their ideas that matter and they are making the decisions, with help if they need it.
Observation	=	Watching what people are doing and writing notes or using a dictaphone to record what you see.
Criteria	=	Rules for how to do the work.

Illustrations

The pictures and symbols we have used are taken from *A Guide to Using Symbols*, Phoenix NHS Trust; Rebus Glossary; Picture Communication Symbols, Mayer-Johnson; publications of People First London Boroughs.

The Dundee Neighbourhood Survey chapter, also includes pictures used by people involved when telling their story.

Front cover illustration: Dundee Neighbourhood Survey.

INTRODUCTION

Aims of the book

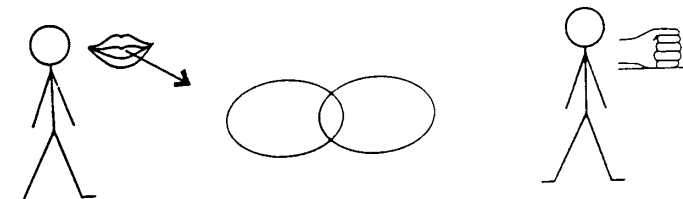
This book aims to help more people with learning difficulties do evaluations.

It is for people with learning difficulties and supporters/staff to use together.



It tells how some people have done evaluations - people from Bristol, Dundee, London and Portsmouth.

The main aim of this book is to help more people with learning difficulties get involved in evaluating their own services. It is written for people with learning difficulties and for supporters and staff who work closely with them. Although we have been able to include some pictures, there are also a lot of words! So we hope people will use the book together, helping each other to read and understand the parts which some people might find difficult.



The book is based on a meeting held at the King's Fund Centre on 19 January 1995 when people from Bristol, Dundee, Portsmouth and People First in London came together to share their experiences of evaluation. Unfortunately, representatives invited from Northampton and Liverpool were unable to attend on the day. The idea for the meeting came as a result of two evaluations of community-based residential services done by People First London Boroughs - in Hillingdon in 1990 and in Haringey and Sutton in 1993. It seemed important to tell other people what People First learned from that work, find out who had done similar work and encourage more people with learning difficulties to get involved in evaluation as another way of improving services.

Since then, various meetings have been held within and outside the King's Fund on the subject and the book includes thoughts and experience arising from those discussions.

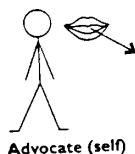
The book talks about:

- how the evaluations were done
- what worked well
- what could have been better.

It gives a list of Helpful Hints.

It asks some questions about how we should do evaluations in the future.

People with learning difficulties now speak up for themselves in many different ways.



The book does not say much about the actual services evaluated because readers can get these by reading the reports. It concentrates on:

- how the evaluations were done
- what worked well
- what didn't work so well
- what would have helped to do the work better?
- what happened afterwards

It also suggests some questions for further discussion. Some readers will be very familiar with these questions and may already have come up with answers. But people new to this work may find the points helpful in prompting further ideas.

Background

The ability of people with learning difficulties to influence how services are developed and delivered is no longer questioned. They speak out about their lives and about services in a variety of ways:

- on a personal level - e.g. through individual personal plans;
- at a local level through self advocacy groups and
- nationally through organisations like People First.

People FIRST
"a voice for people with learning difficulties"



Government documents on community care say users and service professionals should work together.



Government documents on community care emphasise the importance of working in partnership with people who use the services. User involvement is seen as an essential component of planning and delivering good quality services. It follows then, that people who use services should be involved in monitoring and evaluating their services.

For some years, professionals have been asking people with learning difficulties what they think about services.

For some years now, researchers have recognised the importance of asking people with learning difficulties what they think about services. Some have gone further and involved people in the evaluation process as members of teams or helping to collect information.

Now, people with learning difficulties are doing the asking - carrying out their own evaluations of services.

However, there are still relatively few examples of evaluations in which users themselves take the lead and control the outcomes. This book brings together some examples which either were user-led or which demonstrate an equality of partnership between researchers and users which is higher than average. At the end of the book, we list some other user groups who have been involved in this type of work.

Why should users lead an evaluation?

People with learning difficulties know what it's like to be on the receiving end of services.

People who use the services have a unique contribution to make because of their own personal life experience. No-one else has this particular insight. They see services from a different angle which is vital for managers and planners to understand. Managers get a more complete and often more true-to-life picture of their services.

They can talk easily and honestly with other people with learning difficulties.



People who use services often have an advantage over professionals when interviewing. They may get more honest and straightforward responses because they can identify with the other person's experiences. It can help avoid the problem of the person being interviewed feeling obliged to give the answer the interviewer wants.

Doing an evaluation gives people confidence. They also learn new skills.



Users being involved also empowers them. They gain confidence and a greater sense of self-worth. They gain skills which are useful to them in their own lives. They become more effective partners, not only in this aspect of the work but in other areas of involvement.

Sometimes things change quicker because people with learning difficulties are involved.

Having users involved sometimes makes change quicker. They can push change. Coming face-to-face with someone who is experiencing the services you are operating can be a powerful motivator for getting on with change and improvement.

It also demonstrates that the service is operating from a user-led value system: as long as the work is being done within a culture where users views are listened to and acted on, and is not just tokenistic - for the sake of 'looking good' or as part of a cost-cutting exercise.

OUTSIDE BUT NOT INSIDE... YET!

Evaluating services in Sutton and Haringey
by Alice Etherington

Alice Etherington and Brian Stocker from People First talked to people living in hospital and living the community, in Haringey and Sutton.

This chapter describes how People First evaluated services in Sutton and Haringey. We looked at the lives of people living in various places in the community and also talked to people still living in hospital. This evaluation was building on work which People First did in Hillingdon in 1990. Then, Hillingdon asked People First to come and evaluate two houses. This time, People First decided they wanted to do more evaluation and wrote a proposal which was sent to the Joseph Rowntree Foundation. This job was much bigger than the first one and meant that there was a lot more work to do and people had to learn new skills.

We interviewed 34 people with learning difficulties and 28 staff and carers.

We interviewed 34 people with learning difficulties living in hospital, in group homes and hostels, and living with a host family. We also talked to 28 staff and other carers, including host family carers and members of the person's own family.



The aims of the work are set out on the following page.

HOW WE DID THE WORK

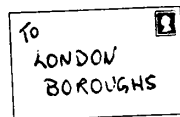
Asking People First members

First, we talked to members of two People First groups and people living in a group home. We asked them what it was like leaving hospital. This helped us decide on the right questions to ask in the evaluation.

We wanted to make sure that the work was based on the experience of People First members who had lived in hospital. We talked to people in two People First groups and people in a group home about how they were helped to leave hospital. These meetings were important and useful. They helped us decide on the questions for the questionnaire. They also helped us to learn more about how we should do the work. For example, how to 'interview' people who don't use words to communicate.

Choosing the Boroughs to work in

We sent a letter to a number of London Boroughs, inviting them to take part.



We chose two
boroughs - Haringey
and Sutton



We had several meetings in each borough to plan the work.



We sent a letter to various London Boroughs asking if they wanted to take part. This letter set out:

The aims of the work
What they could expect from People First
The help we would need from the borough.

How you can help us

We need:

- To make sure residents and staff will welcome us
- To talk to people in hospital and community places
- To talk to residents on their own
- To talk to staff on their own
- Help from staff about arranging to meet people
- Agreement to make results public

How we can help you

Respect confidentiality - no real names used
Least possible upset to staff rotas and residents' timetables

We decided to choose two Boroughs that were different in a number of ways:

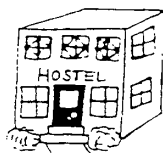
- One Inner London - one Outer London
- One rich borough - one poorer borough
- Different regional health authorities
- People from different cultures in each borough.

Setting up the work in Haringey and Sutton

We had a number of meetings in the boroughs to plan the work. The purpose of the meetings was:

- to get agreement from all the key people (stakeholders);
- to discuss in detail how we would do the work;
- to make sure we would get the help from the Borough that we needed to do the work.

Both Haringey and Sutton were keen for us to do the evaluation and everyone was very welcoming and helpful.



QUESTIONNAIRE

1. ☒ ☐
2. ☐ ☒
3. ☐ ☒
4. ☒ ☐
5. ☒ ☐

13

Collecting information about the services

We talked to
(interviewed) people
on their own.

We spent time with
people, seeing where
they lived, what they
did and learning
about their families
and friends.

We did this by:

- interviewing people on their own
- spending time with people and seeing what went on in their lives.

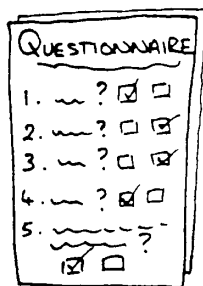
Deciding on the questions

We had seven
different
questionnaires!

We had seven different questionnaires. We were able to use a lot of the questions used in the 1990 Hillingdon evaluation, but we changed some questions, cut some out, and added some new ones. We made up two new questionnaires.

The questionnaires were:

- Leaving hospital (new questionnaire)
- Living with other people
- Leisure/weekends/evenings
- Questions to staff
- Questions to senior managers
- Questions to host families (new questionnaire)



Even so, this number of different questionnaires did not cover all the different ways it was necessary to ask questions. For example, some questions had to be changed slightly, depending on whether we were interviewing a person in hospital or someone in the community:

e.g.

'Did you visit the house before you moved in?'
(person living in the community)

'Have you visited the house you are going to live in?'
(person living in hospital)

We had to learn how to change the wording of a question very quickly if necessary during an interview.

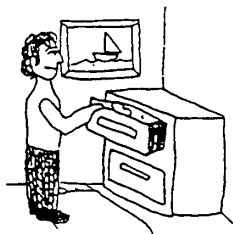
We also had to learn how to explain questions to people if they did not understand.

For example:

'Can you choose what to wear?'

became

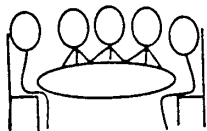
*'When you get up in the morning,
can you choose what clothes to put on?'*



Group interviews

We tried once to interview people in groups. But it didn't work very well.

We did two group interviews in a large group home. Although people seemed to enjoy these groups, we did not feel that the discussion helped us get the answers to our questions. For example, some people were not used to speaking up in a group and just repeated what someone else had said. Some people said one thing and then quickly changed their minds and said the opposite. It was difficult to find out what people were really thinking.



Using pictures

We used pictures when talking to people. This worked well.

We spent a lot of time choosing pictures to use when talking to people. These were put on the questionnaires to help us remember the questions, and we also made up a book of large copies of the pictures. Using pictures worked well.

The sad/happy faces

We used cards with sad and happy faces on them.



These were helpful sometimes, particularly with people who felt shy about using words to answer the questions.



Photographs

We tried to use photographs but this did not work very well.

We tried to use photographs people already had about their lives. But not many people had photographs which were helpful in answering our questions. We found it very difficult to get any photographs of the hospitals where people had lived. One set of photographs which would have helped did not arrive in the post in time! Having realised this difficulty about photographs, we tried to take our own but there was not enough time left to get permission to do this and have the photographs ready for the interviews.

Choosing people to interview

We chose people to interview:

- of different ages
- short and longer time living out of hospital
- living in different places - e.g group home, hostel, foster family.

We got lists of people who had moved out of hospital into the community as a result of the new community care arrangements. We found out their age, how long they had been out of hospital, where they had lived.

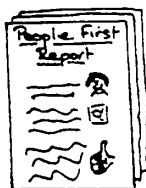
We chose people to get an age range, short and longer time out of hospital, people from minority ethnic groups, men and women, range of places where they were living (hostels, group homes, host families).

Putting the results together

We made up a chart with columns and put ticks in the columns. Then we could see how many times people said YES or NO to a question. We looked at all the comments people made to help us decide:

We wrote a report.

- what they liked and what they didn't like about their lives
- what we thought was good and not so good about services.



There were lots of different sections and topics. We worked on one section or topic at a time. We put comments about each section on tape.

Writing the report

First we thought of the main parts of the report and wrote them on a flipchart. Then we talked about each of those main parts and what should be written in it. This made it easier to go on and write each part in detail.

You can read a lot more details about how we did the work in our report.

WHAT HAPPENED AFTERWARDS

In Haringey, managers said they would include our comments when planning new services.

In Haringey, we had a large feed-back meeting, with staff, parents, users and managers. The managers said they would take account of our comments when planning new services.

In Sutton, People First began helping to set up a People First group. This has continued.

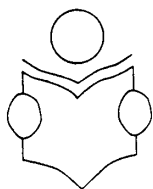
In Sutton, we also had a feed-back meeting with managers and users and People First has continued to work in Sutton, helping to set up a People First group.

You can read more about this work in: **Outside but not Inside... yet! Leaving hospital and living in the community: an evaluation by people with learning difficulties. People First. London 1995. People First, Instrument House, 207-215 King's Cross Road, London, WC1X 9DB. Tel: 0171 713 6400.**

EVALUATING ADULT EDUCATION

by Brenda Cook, Jennifer Lauruol and Andrew Shepherd

Brenda Cook and Andrew Shepherd looked at education services in Bristol and Leicester. They evaluated courses for adults run by the WEA (Workers Educational Association)



At the Norah Fry Research Centre in Bristol, people with learning difficulties have been involved in several evaluations. Here we describe an evaluation of WEA (Workers Educational Association) classes for adults with special needs in which Brenda Cook and Andrew Shepherd were recruited as co-evaluators. Both are active self-advocates and users of services in the Bristol area. The overall study covered all the English WEA districts, but we looked at projects in two districts. The work took place between September, 1993 and March, 1994.

AIMS

The main aims of the work were:

They wanted to find out:

To find out:

- how the WEA helps people with special needs;
- how it helps people take part in courses with other students;
- how this helps people make links in their community.

- how the WEA helped people with special needs in two districts, the Personhood and Citizenship Project (Western District) and the One-0-One Project in Leicestershire (East Midlands District);
- how these districts helped students with special needs to take part in courses alongside the other students;
- how going on these WEA courses helped students become a part of their wider communities;

To make sure the evaluation was done in a way that was easy for students with special needs to take part in.

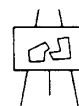
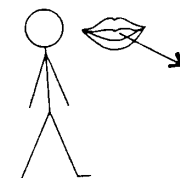
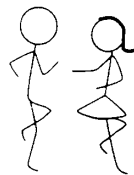
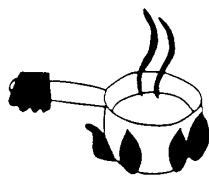
THE PERSONHOOD AND CITIZENSHIP PROJECT

This project was for people who had lived most of their lives in hospital but were now living in the community. It helped them become more independent and make new friends.

This project worked with people who had lived most of their lives in hospital but had now moved out into the community. It aimed to help people learn and do a range of interesting things during the day instead of spending all their time at a day centre. It also aimed to increase people's independence and opportunities for making friends and taking part in their local community.

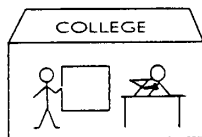
Andrew Shepherd evaluated a number of the courses. He was able to make important comments about the cooking course because he is a trained catering assistant.

Andrew Shepherd was most involved with evaluating this project. He went to a number of courses including cookery, dance, sculpture, music and self-advocacy. He was particularly interested in the cookery course because he is a trained catering assistant. He showed his book of recipes to the cookery tutor, because he felt some of the recipes could be helpful in the future and also he thought that some of the pictures in his recipes were clearer than those in the WEA course.



THE ONE-O-ONE PROJECT, LEICESTER

This project has courses for people with a variety of special needs. It also helps Asian people, particularly women and elderly people.

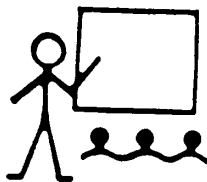
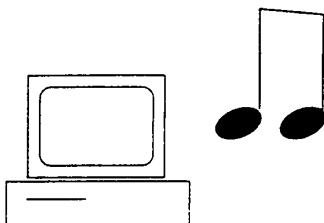


We made two visits.
The second visit lasted for three days.

We went to classes on:
literacy/numeracy
computers
music

We read their leaflets.

We talked to the students and tutors (teachers).



The One-O-One Project works with a wide variety of adult learners from a multi-cultural, inner-city environment. It has developed special courses for groups of people who share certain special educational needs. These have included people with learning difficulties, physical disabilities and mental health problems. It also helps Asian students, particularly women and elderly people. The team made two visits to this project. On the first visit, we interviewed the tutor/organiser, talked to some of the tutors and visited a literacy/numeracy class and a computer class.

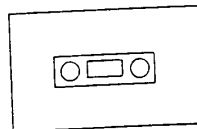
The second visit was for three days. We evaluated:

- the building and surrounding area
- access for people with physical disabilities
- safety features for people with sensory impairments and/or learning difficulties.

We visited two computer courses and a music class and spent time talking to the students there.

We examined the leaflets and course information available for students to see if it would help people who cannot read or who have a sensory impairment.

We talked together about what we saw and recorded our opinions on audio tape. Jennifer also added her written notes.



We had a one-day training session at Norah Fry Research Centre.

We read leaflets about the courses.

We met Mandy Neville and the other tutors.

We visited some of the courses held on Bristol.

We made a three-day visit to the courses held in Leicester.

We took part in some of the classes there.

We taped our thoughts and opinions about the courses.

HOW WE DID THE WORK

- We had a one-day training session at the Norah Fry Research Centre, led by Ken Simons. We put together a list of questions and also decided how we would do the work.
- We read the course catalogues, leaflets and other printed materials from the two projects.
- We met Mandy Neville, Western District Special Needs Tutor/Organiser and her team of tutors.
- We visited a number of Personhood and Citizenship Project courses in Bristol, and attended an Advisory Group Meeting of students, tutors and residential care staff.
- We made a three-day visit to Leicester to meet the students and tutors and see the classes.
- We participated in several courses at the One-O-One Project.
- We taped our thoughts and impressions about the courses after visiting the two projects.

The one-day training session

At this training session we talked about:

During this training session we discussed issues and made up questions for the evaluation. Topics we discussed included:

Communication

Communication:

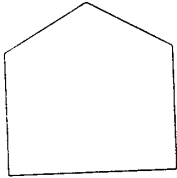
- How do tutors and staff speak with students?
- Is non-verbal communication available - e.g. signers for deaf people; visual and pictorial information?

Choices

Choices:

- What sort of courses can people choose?
- Do they play a part in deciding about future courses?
- Are they helped to try new things?

Venue (the building)



Venue:

- Is the place where courses are held accessible, easy to travel to, safe and welcoming?
- Do students with special needs mix with non-disabled students and with the wider community?

Staff



Staff:

- Are there enough tutors and staff to support students properly?
- What are staff attitudes like towards students?

Course content (what people are learning in the classes)

Course content:

- Is it interesting, challenging?
- Does it take note of students' interests and level of skills?
- Can people go on to other courses if they want to?

OUR RULES

- Introduce ourselves
- Explain what we are doing
- Be polite and pleasant
- Respect other people's nationality
- Keep people's trust. We don't pass on what people say to us (Confidentiality) unless people are very unhappy and want us to pass something on.
- Ask people's permission to ask them questions.

1. Don't worry
3. Listen

2. Relax
4. Watch

QUESTIONS USED IN THE EVALUATION OF THE LOCAL SCHEMES

The following questions were used as a framework for the evaluation of the local schemes:

IN A GOOD CLASS:

This is what we thought
a good class should be
like →

People are treated properly

- with respect
- listened to
- not rushed
- are included (they are not left out)

People should enjoy it

- should feel safe
- should feel free to express yourself

People should have choice

- asked what they would like to do
- have a chance to try things
- enough help to do things
- information to choose

These are the questions
we asked to help us
decide how good the
classes were.



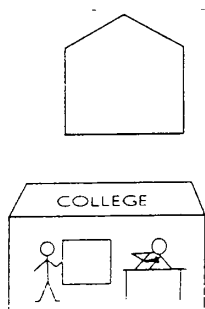
The way people are treated

- are people treated with respect?
- are people rushed?
- can people trust the staff?
- do people get enough help?
- are people called names?
- are people left out? (*is there signing, symbols or Makaton?*)
- are staff pushy?
- are they too strict?

Choices

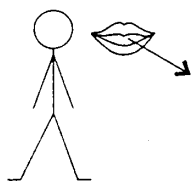
- have people had to stop doing things because staff have gone?

- is there information about what is on?
- are people helped to be more independent?
- are people allowed to try things? (*is anybody allowed to have a go?*)
- a chance to do real things in the real world (*not to be stuck in all day*)
- different courses/activities to try (taster sessions)
- do people have a say in deciding what courses/activities there are?
- the chance to get a qualification?
- can you choose your key worker?
- can you change your key worker if you don't get on?



The place where things happen (Venue)

- what is the place like?
- is the building accessible to people in wheelchairs?
- is there a chance to mix with other people, or is it just for people with learning difficulties?
- are people safe? (*is there a problem with bad traffic*)
- do they feel safe there?
- are things stolen?
- is there a safe place to put things? (*a locker?*)
- are people able to work in small groups?



Self-Advocacy

- do people have a say in how things work?
- are people's views heard?
- do staff ask what people want?
- do staff listen?
- when people make a choice, do staff follow it up?
- do you have a woman or a man to talk things through with? (*a chance to talk in private*)
- do people know about self-advocacy?
- is there a chance to join self-advocacy groups?
- do people get to here about their rights? (*e.g. to complain, vote, etc*)
- do you have a chance to choose the staff?

Atmosphere

- do you feel comfortable there?
- do you feel safe?
- is there a lot of arguing/fighting/shouting?

COURSE EVALUATIONS

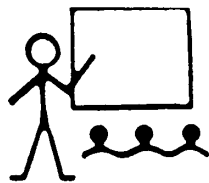
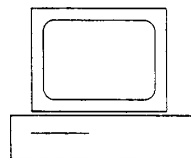
Brenda and Andrew made many positive comments about the computer classes.

Brenda and Andrew attended two sessions of the computer course for people with learning difficulties. They had many positive comments to make:

- the tutors were helpful, patient, respectful and encouraging
- the other students were friendly, relaxed and welcoming
- what we did in the class was interesting and challenging, and the tutors tried to make sure each person could take part.

Brenda wrote a poem during the computer class.

Brenda, who is a poet, used her time in the computer class to write a poem and find a suitable colour illustration for it in the software package.



I did a poem about the dance and I've got a picture of a rainbow and some flowers in it to brighten it up... [The tutors] gave you all their time, and sometimes there is quite a few of us at one time... they came when you wanted them, ...once I was shown how to do it, it worked lovely.

It made me feel really good that I was able to do it without any help. By the afternoon I mastered it and I found I could go on to the next line without being shown how to use the different keys.

She thought the computers were more up-to-date than those at her day centre.

She noted that the Hinckley Road computers and software were more up-to-date than the older equipment available to her at the day centre she attends in Bristol.

That's the only copy [I have] from here, but I don't know about [printing out another copy] in Bristol, though. On our computers... they don't have anything so fancy as that.

Andrew Shepherd said about the tutors:

Andrew thought the tutors were very helpful.

They were so... respectful persons that they treated us like their friends [They] showed me other activities to do and it was very interesting.

He suggested the computer course should include office skills.

He suggested that the computer course be widened to include learning other office skills. His idea was:

...[for people] with learning difficulties, special skills like word processors, using the phone, filing and making photocopies.

Brenda said:

The building was very old: not for people in wheelchairs. The person organising the classes had managed to get one room built at the back of the building which was accessible to people in wheelchairs and to get a small lift for a part of the building. But people in wheelchairs couldn't get to the place where the leaflets were kept so it was difficult to get information in the first place. Spaces were too narrow for wheelchairs to get through. The organiser is enthusiastic but her boss doesn't care about people with disabilities. This lady works full-time but is only being paid part-time.

WHAT HAPPENED AFTERWARDS

We produced a report and a tape. We said some things the bosses didn't like. Nothing changed as a result.

We produced a report and a tape. We said some things that the bosses didn't like. The report was not allowed to be shown to staff. They did not even let us know that they had received the report. Nothing changed as a result.

But Andrew and Brenda enjoyed the work. They have also been involved in other evaluations in Dorset.

Nevertheless, Andrew and Brenda enjoyed doing the work. They have also been involved in other evaluation work inspecting day centres at Bridport and Poole in Dorset. Brenda is starting another piece of work looking at local residential homes. It is about the rules of these organisations and whether staff are keeping to the rules. Brenda is helping to decide on the questions to ask people - e.g. about getting up in the morning, having your own money, whether people like their home?

You can read more about this work in the report:
Lauruol et al. Learning Together: An evaluation of WEA provision for adults with special needs across the English WEA districts. Norah Fry Research Centre, 1994. Norah Fry Research Centre, University of Bristol, 3 Priory Road, Bristol BS8 1TX. Tel: 01179 238137.

DUNDEE NEIGHBOURHOOD SURVEY

by Christine Fisher, Graeme Millar and Craig Mullan

INTRODUCTION

Kemback Street Adult Resource Centre is a day centre for 80 adults with learning difficulties in Dundee.

People at the Centre were worried that the neighbourhood around the Centre still thought of people with learning difficulties as children, rather than as adults. They wanted to change that.

Kemback Street Adult Resource Centre provides day services to around 80 men and women with learning difficulties in Dundee. The Centre's aim is to promote social independence and normal patterns of living. It aims to treat people with learning difficulties with the respect and dignity which they deserve as adults, and it was concerned that the public continues to see them as objects of pity, child-like and dependent. This survey hoped to begin a dialogue with the local community around Kemback Centre and through involving people who use the centre at all stages in the project to challenge many of the prejudices against people with learning difficulties.

AIMS

The aims of the survey were to:

- find out what local people knew about the centre and how they felt about it;
- open the centre to the public;
- find out how much people from the centre were a part of the local community.

We also wanted to:

have fun
learn new skills

The aims of the survey were to:

- collect information on the general public's attitudes towards people with learning disabilities;
- open the Centre to the wider public;
- evaluate how much people from the Centre were a part of the local community;
- educate the local community about people with learning difficulties;
- learn how much local people knew about the Centre.

We also wanted to:

- have fun;
- learn new skills, especially how to do surveys;

have staff and clients working together help people's self-confidence.

- improve the service provided by the Centre;
- have staff and clients work together on this project as real partners;
- help people's self-confidence;
- adapt and apply research methods to local community surveys.

HOW WE DID THE WORK

We set up a steering group called The Neighbours Group - 4 people who use the centre, 5 staff. This group met for about 18 months to prepare for the survey.

We decided:

- where to do the survey
- to use volunteers.



We did a lot of work on the questions before finally deciding which ones would be in the questionnaire.

The volunteers met the Neighbours Group.

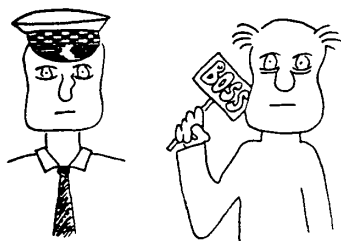
- We set up a steering group for the project consisting of four people who use the Centre and five staff members. We gave the group a name we could all remember and feel part of - The Neighbours Group. This group met regularly for about 18 months to discuss and plan the survey. This meant that everyone was able to learn and practise new skills. The group meetings became an important part of the participative process.
- We decided where we would do the survey and also the local shops we would visit.
- We decided to use volunteers to support people who were going around the neighbourhood with the questionnaires. This meant that we did not have to rely on staff or other people who knew us well. It helped us to be more independent about doing the survey.
- We did four or five draft questionnaires until we were happy that we had got the questions right. We asked people did they know about the Centre, who went there and what was done at the Centre. We asked them if they knew anyone who went to the Centre. We also asked what community care meant to them. We asked the shops whether there were any opportunities for people from the Centre to work there.
- We introduced the volunteers to the Neighbours Group.

Everyone took part in a training course. We learnt about assertiveness skills and did role plays.

- All members of the Group took part in a training course at the College. We learnt about assertiveness skills and we did role play to get used to knocking on doors. Two members of the Group also attended a one-day course on how to do local surveys organised by the Educating Communities Network.

We told the Police and senior managers.

- We told the local Police.

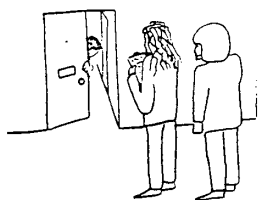


- We told higher-up bosses in the Region.

We did a small survey to practise our skills.

- We did a pilot survey to practise our skills and try and make sure the main survey would go well.

Then we did the main survey.



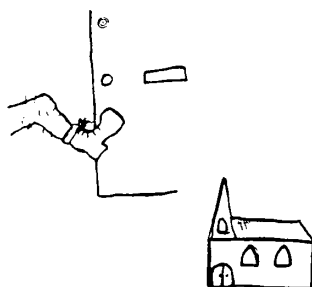
- We did the main survey. Two of the group went around the shops on Albert Street, the main shopping area close to the Centre. We handed the questionnaire to as many people as were working in the shops or however many people were willing to fill them in. So in some shops we left a number of copies of the questionnaire. The shops included a large supermarket, several Banks, bakeries, hairdressers, second-hand furniture shops, charity shops, bookmakers, chemists, butchers, cafes, take-away foodshops and pet shops. Questionnaires were collected a few days later or were returned in the envelopes left.

We produced a report.

- We analysed the results on the computer. 70 out of 140 people from the local shops returned the questionnaire. 110 out of the 250 neighbours returned theirs. More women (64%) than men replied; a finding similar to other surveys.



Glad to meet you



WHAT HAPPENED AS A RESULT OF THE SURVEY

Good things for ourselves:

- We gained in confidence.
- It let us get to know more people.
- We learnt more about meeting and getting to know new people.
- We learnt how to run meetings.

Good things for the Centre

- A foot in the door of our community.
- Use of church hall
- Put us on the local map

We changed the community's attitude to us

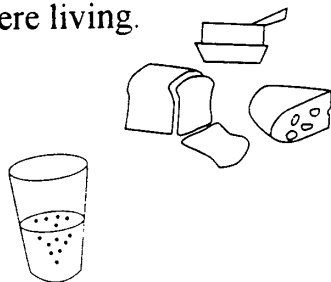
You can read more about this work in the report: **The Neighbours Project, Reactions of neighbours and shopkeepers to a Resource Centre in Dundee.** Copies available free of charge from: Education Communities Network, St. Aiden's, Gattonside, Melrose, Scotland TD6 9NN.

LOOKING AT FOOD AND DIET STANDARDS

by Pat Helm, Karen Jeffereys and Gillian Rhodes

INTRODUCTION

This evaluation aimed to find out about food and drink, and how people's meals were organised. Pat and Gillian, the two evaluators, visited seven houses where people with learning difficulties were living.



This project was done as part of Karen's social work training. Karen is Chief Dietician for Portsmouth & S E Hampshire Health Authority. She wanted to see what food people ate and how their meals were organised now they had moved from hospital to live in the community.

She also wanted to employ people with learning difficulties to do the research with her.

We had a letter from Karen explaining what the job was about. This letter had been sent to all statutory, voluntary and private services for people with learning disabilities in and around Portsmouth. There was a job description and an application form.

Pat and Gillian got the job after going for an interview. Six other people applied for the job.



Eight people applied for the job and all were interviewed. As a group we were told about the research and more about what the research assistants would do. We also had an observation test and individual interview.

The interview was at St James Hospital with Karen and Mike Drake, the manager of the houses for people with learning disabilities. Out of the eight people, we got the job on the team with Karen. Our job was to go into seven houses in Portsmouth to observe their meals from before breakfast until after the last meal of the day.

JOB DESCRIPTION

This job is to work within a team to look at the nutrition standards in community houses for people with learning difficulties. The job is for a research assistant. He or she will be accountable to the dietician. The team will be the dietician and two research assistants.

MAIN TASKS

1. Producing a check-list with the dietician and another research assistant.
2. Spending two days with another research assistant in each house to observe mealtimes.
3. Discussing your observations after each house and writing reports with the team.

REQUIREMENTS FOR THE POST

Applicants should have lived or be living in residential accommodation for at least two years.

Applicants should not be living in accommodation owned or managed by the health authority nor staffed by people employed by the health authority.

The ability to work with another person for six hours at a time.

The desire to watch a situation and then discuss what has been seen.

A commitment to see the whole project to its end.

To want to support other team members if things get tough.

TRAINING - will be given to enable the assistant to be critical. However, applicants should feel that they want to make their opinions known.

FINANCE: all travel expenses and training will be paid for. Sponsorship from a variety of agencies and food companies is being chased to pay a reasonable fee to each research assistant.

TIMING - the training should start as soon as possible in November.

HOW WE DID THE WORK

We got together as a team - Pat, Gillian and Karen. We met on many days to prepare for the work.

- We got together as a team. We met on many days and:
 - made a checklist
 - thought about how to introduce ourselves in the houses
 - decided what we wanted to know. One thing was how to use Karen's computer. We used it for basic typing.

We went to each house for two days.

- We went to each house for two days. That was 14 days observation.

We filled in checklists (questionnaires) about the food, drink and snacks people had.

- We wrote down the food that was prepared, the drinks people had and anything else that went on to do with food and drink. That included snacks between meals.
- After each meal we both wrote what we saw down on the checklist that we made up. There were a lot of checklists to write. (See sample pages).
- We also had a good diary of everything they ate. Some meals were missed, like breakfast, so we could not record that particular meal.



The staff were asked to fill in questionnaires too. Karen put all the information together for the report.

- After the observations, Karen sent questionnaires to the staff in the houses to complete. These gave a lot of information about people's nutrition. Karen then pulled all this together to put in the report.
- We decided ourselves when we wanted to have breaks. Some houses offered us a meal. Also we needed it because it was tiring and boring at times. We also needed to have a break from each other.

CHECKLIST - SAMPLE PAGES

6. Is the kitchen safe?

YES

NO (describe why it is not safe)

.....

.....

7. Are spilt drinks mopped off the floor immediately in case of accidents?

YES

NO

NA

IF NO, HOW MANY TIMES A DAY (tick each time it is not mopped up immediately).

CHOICE

8. Are people offered drinks which they like?

YES

NO

NA

NOT SURE (explain why you are not sure)

.....

.....

9. Is there enough choice in food?

YES

NO

NA

10. Was there a choice at the mealtime?

YES

NO

NA

11. How many choices were there?

NO Choice

Vegetarian & non vegetarian

2 choices

3 or more choices.

26. What do the clients think of the staff member during mealtimes?

LIKE THE STAFF
DISLIKE THE STAFF
NOT SURE
NA

27. How does the client feel during the mealtime?

HURTFUL	ANGRY	MAD
SAD	FRUSTRATED	TERRIFIED
IN PAIN	DISSAPROVED	COMFORTABLE
HAPPY	ENJOYED IT	

NOT SURE

INDIVIDUALITY

28. Do people take other people's drinks and food?

YES NO NA

HOW MANY TIMES DID IT HAPPEN (tick each time it happens)

29. Do people use their own special mugs?

YES NO NA

30. Are there special mugs used by other people?

YES NO NA

NUTRITION/FOOD

31. Is there enough nutrition for people?
Did they achieve 4 2 2 4?

YES NO NA

What training did we have?

We spent two days in different houses, practising how to

observe people and how to fill in the checklists.

The main training was to spend a day in each of two houses which were not part of the survey. We practised how to observe without making the people we were observing feel uncomfortable. This was important because some people don't like being watched while they eat and drink. We also tried out the checklists.

We also had training about:

- working contracts
- team-building
- office work
- using a computer
- nutrition - what you should eat to keep healthy.

Checklists (Questionnaires)

The checklists had questions based on Pat and Gillian's personal experiences and from talks with other people with learning difficulties.

We made up checklists to be used during the observation periods. These were based on:

issues important to Pat and Gillian, drawn from their own experience of day services and residential accommodation;

informal discussions they had with other people with learning difficulties.

Observations - how we worked in the houses

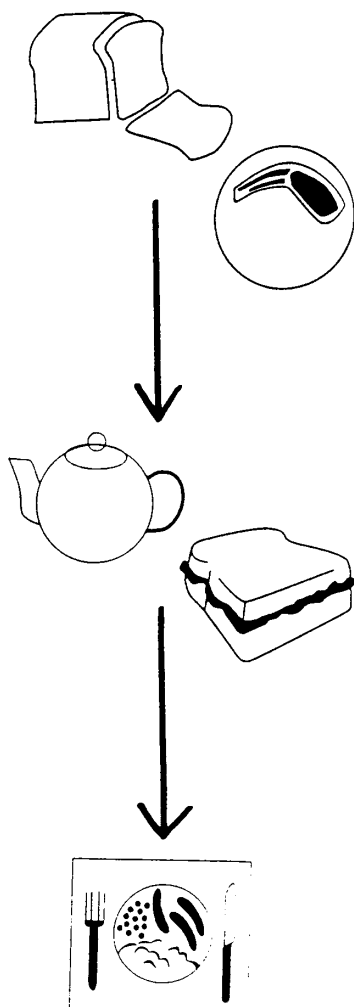
We spent two days in each house, at times when people were at home.

Dates were set with the person in charge or deputy in each house to carry out observations on two consecutive days. These days were chosen according to the activities of the people who lived there. For example days when people were not attending day services. In one house this required working at a weekend.

We were in the house from before breakfast till after the evening meal.

Letters were sent to each house explaining what would be happening during the observation periods and asking them not to change any of their usual way of doing things.

We decided ourselves when to have breaks during the day.



We wrote a report.

We talked to all the staff and some of the people who lived in the houses.

Pat and Gillian, the two research assistants, were introduced to the people living in the house and the staff on duty on the morning of the first observation day. They aimed to commence work before breakfast and stayed in the house until after the evening meal. They decided themselves when to have breaks, according to house routines, so that the meals were observed by two people.

Pat and Gillian were asked to be as discreet as possible without seeming to be rude or ignoring the people who live in the house.

Observations were recorded in four ways:

- Detailed activities around food and drink on a time structured sheet in their own words.
- Food diary summarising the food offered over the day.
- Checklist 1 was completed after each meal summarising the points.
- Checklist 2 was completed at the end of the two days.

At the end of each day Karen, the researcher, met Pat and Gillian. They went away from the house and talked about what had happened during the day. At the end of the second day staff on duty were encouraged to feed back to the team how they felt about the two days' observations.

WHAT HAPPENED AS A RESULT?

We wrote a report on what we had seen in the houses and what we thought. We went back to all seven houses and spoke to all staff in their meetings. We told them what we thought was good and bad.

We gave them a copy of our report so that they could look back and do something about it. Nearly all the staff thought it was a good idea. In most of the houses people could not speak for themselves. In the one house where people speak for themselves they were present at the feedback meeting.

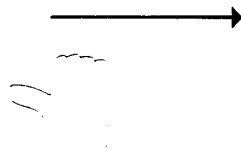
Karen also gave two talks, one to the dieticians in Portsmouth and the other at a very large dieticians' meeting in Oxford. None of the managers in Portsmouth ever asked us to give a talk about what we did.

Learning to work together

A problem was that Gillian and Pat did not always get on with each other. But they still made sure the work got done.

All through the survey there was something that could have been a real problem. This was between Gillian and Pat. We knew each other from the same day services and we did not get on at all. It made it very difficult. However, we finished the survey successfully keeping our disagreements out of the houses and we felt that we achieved our goal even though we didn't get on.

These things worked well.



What worked well

The interview - meeting new people

Staff respected us

Observation was good

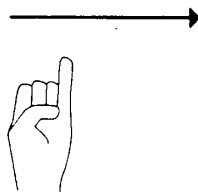
Leisure breaks were good

Feedback to staff - staff preferred us to do it

Feelings to each other - dealing with conflict before it got out of hand

Staff were pleased with what we did.

These things did not work so well.



What didn't work well

Too much writing

Feedback to training house because only had ½ day and no questionnaires

Using one of the houses as a training house

People got upset at us observing

Long days, boring and tiring

Breaks - did not know the area, no money to do things, stayed in - 'boring!'

Poor pay.

What would have helped?

More training - computer and in how to observe

More time to be together before observations

Shorter hours

Concentrating on one particular area rather than several different ones

Interviewing people who speak for themselves - not observations

Top managers should know about project.

You can read more about this work in the report: **An Investigation into the current nutritional standards in seven small community houses, for children and adults with learning disabilities, in Portsmouth and South East Hants Health Authority. August 1993. Karen Jeffreys, Chief Dietitian, Portsmouth Community Team, PO Box 107, Southsea, Hants PO4 8NG. Tel: 01705 734175.**

EVALUATION OF INFORMATION PRODUCED BY SOUTHWARK INFORM

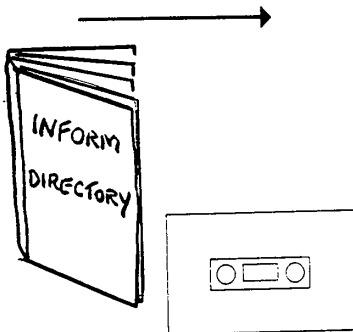
by Andrew Bright

People First did an evaluation of information produced by Southwark Inform.

People First of London Boroughs was asked to carry out an evaluation of information produced by Southwark Inform. Andrew Bright did the evaluation supported by Declan Treanor.

Southwark Inform was a project funded by the Department of Health as part of their National Disability Information Project. In its two years it produced a number of information products for people with learning difficulties. These were:

The things they looked at were:



- an information directory in book format
- audio tape - to accompany the information directory
- video - Check it Out! - on leisure services in Southwark
- posters on health, happiness and housing
- 'What's the Point in Writing' - a report on how to give information to people with learning difficulties.

AIMS

The aim of this evaluation was to find out from people with learning difficulties whether they understood the information and if it was useful to them.

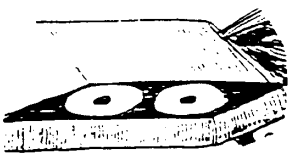
HOW WE DID THE WORK

To carry out the work we had to:

We talked to:

- people with learning difficulties
- two user groups
- staff

- gather information on Southwark Inform;
- analyse the information;
- try out the information with five people with learning difficulties who were not part of the project or from the same borough;
- interview the project co-ordinator;
- interview two user groups in Southwark about the information;



- interview a member of the management of Southwark Inform;
- gather all the data and write the report for RICA.

RESULTS

Posters with photographs were what people understood best.

We found that the posters were what people with learning difficulties understood best. This was because they used photographs on them. People did not understand the symbols that were used in the information.

The video also worked well.

The video was also a good way of getting information over to people with learning difficulties. We thought it would be most useful in group discussions and not watching it all at the one time.

We felt that people with learning difficulties should have been involved more with the work.

We felt that people with learning difficulties should have been involved from the beginning, both in the day-to-day running of the project and in testing out the materials. This could have resulted in more people understanding more of the information.

You can read more details about the results of our work in our report. **Declan Treanor and Andrew Bright. User-led evaluation of information products produced by Southwark Inform. Southwark Inform 1994.**

INVOLVING PEOPLE WITH COMPLEX NEEDS

It is very important that people who don't speak are helped to say what they think about services.

There are few conversations about services for people with learning difficulties which do not eventually include the question "*but what about people with complex needs?*" So to, on the subject of monitoring and evaluation. Parents and people working in services are rightly concerned about including the views of those who are often unable to express their wishes, preferences and needs in the ways we are used to and find easy to understand. Also people with complex needs now make up a greater percentage of people in traditional services, so more attention is focusing on them.

We now know lots of ways of helping people say what they want and need.

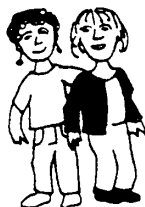
Traditionally people with complex needs have been left out of the picture when it comes to trying to find out people's opinions and needs. However, now we have learned much more about different ways of communicating with people.

We know that each person has his or her own unique way of getting their point of view across, and over time, we can learn to understand what they are saying. We can get to know their preferences and needs. The many stories now available of the changed lives of people who have challenged services over long periods proves this.

It can take a lot of time.

Getting to know someone with complex needs very well often takes a great deal of time - much more than time than is usually available in the type of evaluation described in this book. So for short, one-off evaluations you need to rely a lot on people who know the person well.

They can get a friend or advocate to help.

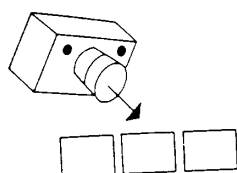


They should have a life-story book.

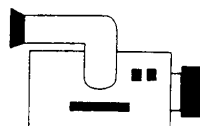


Decide who might be the best person to help someone express their views e.g. an independent advocate? A friend of the person being interviewed? Has the person got a life-story book which could show how their life has changed; what new opportunities they have had? Some people may have video material that would help them tell you more about their life, their likes and dislikes.

Photographs and videos are helpful.



Even better for people with complex needs, will be an on-going system of monitoring their lives and services. This enables people's reactions, responses, wishes and needs to be noted regularly over a much longer period of time.



There will be pros and cons to whatever method is chosen to involve people with complex needs. The important thing is that they are involved and we need to keep on trying and testing out ways of doing this well.

HELPFUL HINTS

Be clear about your aims

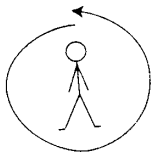


It is important to spend time being very clear about what the aims are -why you are doing the evaluation. There might be one aim or there might be more than one. For example:

- To compare one service with another (e.g. life inside a hospital and life in the community);
- To see how good (or bad) a service is in order to improve it or make changes (e.g. the dietary services in Portsmouth)
- To raise public awareness (see how well people know us) (e.g. the neighbourhood survey in Dundee)
- To see what people think about a new way of doing things (e.g. producing accessible information).

Different evaluations will have different aims. It depends on who the evaluation is for and what you want to find out or learn more about.

Get everyone to agree about the work



It is important to get commitment from everyone who has an interest in the evaluation. This means particularly managers and other senior staff - top people who have the power to get things changed. Everyone has to agree about:

- the way you want to do the evaluation
- who you will talk to
- when you will visit them
- how much time it will take
- telling people how the work is going - will you need to do this during the evaluation or only at the end (e.g. the feedback days held in Haringey and Sutton)?

Get agreement about action afterwards



Making sure some action happens after an evaluation is probably the most difficult part of the work! So it is essential that you get agreement about this before you

start. This will usually be with senior managers or other top people. Make sure the action agreed is written down in a letter or a simple contract - who is going to take action and what that action will be.



User researchers need special skills

It is likely that people with learning difficulties who are going to be involved in evaluating will already have some of the necessary skills (e.g. experience at speaking up for themselves, the ability to get on well with people; are interested in other people and what they think and feel). But you will need extra skills, particularly important when evaluating. You need to learn interviewing skills. You need to work out which method of recording information will suit you best (e.g. writing, using a dictaphone, having someone else write your comments for you).

When looking at services you will be thinking a lot about what has happened in your life. Your own life experiences are very important but it is also important to take into account the experiences of friends or acquaintances which might be different from your own. Having a broader knowledge of what services can be like is useful and can be important in making judgements and decisions.



Teamwork is very important

Everyone involved in an evaluation should be able to work well together, whether it is a small team like the People First example or in Portsmouth, or a larger group as in Dundee. Teamwork was good in most of the examples in this book. In Portsmouth, there were some problems because two of the team did not get on well with each other. But the important thing was that they talked through the problems they were having and went on to finish the work.



The supporter needs support too!

All team members need support, including the supporter. If there is a lot of work involved as in the People First evaluation, you need to consider whether more than one

supporter is needed to share all the supporting jobs. Using volunteers to support users worked well in Dundee. They could give more time to supporting people and the interviewers could work more independently without being influenced by staff. But it is important to make sure that the users stay in control.

Supporters need training, for example, to make sure their ideas, comments or reactions don't influence the user researchers. There is also a question around the boundaries of the supporter's role. For example, one supporter felt obliged to support some of the professionals who were being interviewed. This took time away from supporting the user researchers and made it difficult to stay in the role of impartial researcher. Professionals and other people asking supporters to do this work need to understand that it is very time-consuming and may well take longer than other evaluations.

In Dundee the volunteers who supported people to do the survey, were trained not to influence what was going on. Also they did a pilot test to see whether the public's reaction to people with learning difficulties being the interviewers was genuine. They asked some of the volunteers to do some interviews. There was no noticeable difference in how the public reacted.



Learning how to do evaluations

It is a good idea to get help from professional researchers on how to do this kind of work. But it is most important that they don't 'take over'! To help stop this happening, agree a set of ground rules right at the beginning about how you will work together.

In Dundee, the assistant principal officer of research was involved in the training and also gave general research advice, for example about the questions. People First had help from Charities Evaluation Services with training, designing the questionnaire and using pictures.

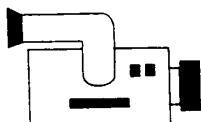
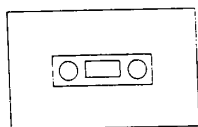
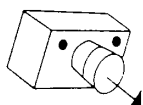
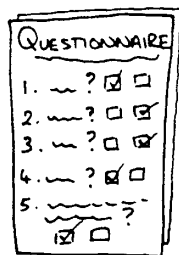


How to collect information

You have to decide how you will find out what you need to know about a place or a service in order to give your opinion about what is good and what is not so good.

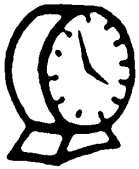
There are a number of different ways of doing this:

- Using a questionnaire
- Interviewing (talking to) people on their own (individually)
- Talking to people in groups (group discussion)
- Using pictures and photographs to help people understand what you are asking or to help them answer questions
- Observation - spending time with a person, or a group of people e.g. a day or a half-day and seeing where they go, what they do and what happens to them. Then recording this in some way - writing notes, or putting it on tape (dictaphone), taking photographs. It is important to do this straight after you have spent the time with people while everything that happened is still fresh in your mind.
- Using photographs, tapes or video to help you remember what you've seen. If you want to do this, you need to get people's permission to do it before you start the work.
- Asking people to keep a diary. Provided they don't have to do it for too long. Provided you make it clear what you want them to record.
- Clock faces - people colour in the clock face according to what they do during the day.



QUESTIONS FOR FURTHER DISCUSSION

? *Time vs Cost*



User-led evaluation can be more time-consuming and more expensive. It will almost always be necessary to have someone to support the people doing the evaluation - someone skilled at guiding and assisting with the process without in any way influencing the opinions or judgement of the evaluators. It is important that the work proceeds at a pace which is acceptable for the people involved, recognising different levels of skill and energy. Extra time may be needed to record information - e.g. someone who can help with reading or writing - learning and using some other means of recording observations (e.g. a dictaphone). Interviewing people - particularly those with complex and severe disabilities may take more time. Producing a report takes more time.

? *What are acceptable evaluation strategies to make the time input realistic?*

For example, in the People First evaluation, could there have been less questions? This would have cut the interviewing time - but would the knowledge gained have been the same or would the quality of the information gained have suffered?

? *Appointing/choosing the team*

When you want to employ evaluators, as in Portsmouth, how do you make sure that everyone who might want to apply gets the information? It might happen that the only people who apply are those who managers or other professionals think would be appropriate? Should job agencies be used? This could be less of a problem where there is a strong self-advocacy group or network.

? *What is the appropriate training for researchers with learning difficulties?*

What is too much - too little? All people involved in evaluation need certain skills to do the job properly whether they are people with learning difficulties or anyone else. But we need to make sure that the unique

insight of people who experience services do not become submerged in the desire to make sure they are properly 'trained as researchers'.

? ***What is the appropriate partnership between user and professional researchers?***

People with learning difficulties bring to the work particular skills and the value of their own personal experience. Researchers have methodological skills/research experience/probing skills.

It might be thought a good idea to divide the work. For example, users look at people's everyday lives and professional researchers take on management and organisational issues. But many people with learning difficulties are very aware of management and staffing issues and make relevant and important comments on these aspects of services.

If both are taking part in the evaluation, it would be important for everyone in the team to decide beforehand how to share the work, recognising each person's particular skills, knowledge and interests. It might help to ask each other questions about different areas, for example: staffing - interviewing - the manager's job - to help decide who should take the lead on particular topics.

In our examples users and professional researchers worked together in two different ways:

- both taking part in the actual evaluation (as in Portsmouth and Bristol).
- acting as advisers and helping with administration and training but otherwise staying in the background (as in London People First and Dundee).

? ***Longer-term follow up - finding out what has happened***

Of course, the most important question to ask after the evaluation is: has it made a difference in people's lives?

Has anything changed? One way to find this out is to go back to where you did the evaluation say, 6 months afterwards and then a year afterwards and see what has happened. During these visits you could:

- interview some of the people you met the first time and see if their lives have changed;
- ask questions about your report - find out how much it was discussed at meetings of various committees responsible for services (e.g. look at their Minutes)
- ask managers
 - what came out of the report that was or wasn't helpful?
 - what have they done as a result?
- ask some people you didn't meet the first time how they have used the report.

This sort of detailed follow-up obviously means more work. You would have to plan it at the beginning and make sure there was money and time enough to do it. You might have to make choices of what is important - leave something out in order to do this? Would you have the energy? Would you need to refresh your memory about what happened the first time?

The report of People First's evaluation of community housing in Hillingdon includes an independent report of the evaluation itself. This discusses many issues relating to this work, including some of the above, in more detail.

PEOPLE TO CONTACT

Groups who have done similar work



'Free Speech' Wigan and Leigh Advocacy Group.
Contact: Bridget Whittell (Adviser)
11 Brook Drive, Astley, Tyldesley, Manchester, M29
7HR. **Tel: 01942 877088.**



Hackney People First. **Contact: Paula Mitchell**
11 Lovell House, Shrubland Road, Hackney, London,
E8 4NS. **Tel: 0171 241 2265.**



Liverpool People First.
Trade Union Resource Centre, 24 Hardman Street,
Liverpool L1 9AX. **Tel: 0151 709 3995 x 224.**

Manchester People First.
Fourways House, 57 Hilton Street, Manchester M1 2EJ.
Tel: 0161 236 6418.

Northamptonshire People First.
4 Hazelwood Road, Northampton NN1 1LN. **Tel:**
01604 37233. Fax: 01604 603503.

Organisations

Aural History Society. **Contact: Rob Perks**
National Sound Archive, 29 Exhibition Road, London,
SW7 2AS. **Tel: 0171 412 7405. Fax: 0171 412 7441.**

Charities Evaluation Services, 4 Coldbath Square,
London, EC1R 5HL.
Tel: 0171 713 5722. Fax: 0171 713 5692.

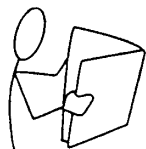
National Development Team.
St. Peter's Court, 8 Trumpet Street, Manchester, M1
5LW.
Tel: 0161 228 7055. Fax: 0161 228 7059.

Norah Fry Research Centre. **Contact: Ken Simons**
University of Bristol, 3 Priory Road, Bristol BS8 1TX.
Tel: 0117 923 8137. Fax: 0117 946 6553.

Open University. **Contact: Jane Walmsley, Dorothy Atkinson**

Department of Health and Social Welfare, Walton Hall,
Milton Keynes, Bucks MK7 6AA.
Tel: 01908 654256. Fax: 01908 653744.

FURTHER READING



Atkinson, D. Research interviews with people with mental handicap. In *Making Connections: reflecting on the lives and experiences of people with learning disabilities*. Brechin and Walmsley. Hodder and Stoughton, 1989.

Atkinson, D. Life history work with a group of people with learning disabilities. *Groupwork*. Vol 6, No. 3 pp199-210. 1993.

Barnes, M. Beyond Satisfaction Surveys. *Generation Review*. Vol 2, No.4 Dec p15-17, 1992.

Barnes, M and Wistow, G. Eds. *Researching User Involvement*. Nuffield Institute Seminar Series, University of Leeds, 1992.

Beresford, P., Harding, T. Eds. *A Challenge to Change: practical experiences of building user-led services*. National Institute of Social Work, 1993.

Connor, A, and Black, S. Getting and Using User Views for Performance Review. In *Performance Review and Quality in Social Care*. Research Highlights in Social Work 20. Jessica Kingsley, 1994.

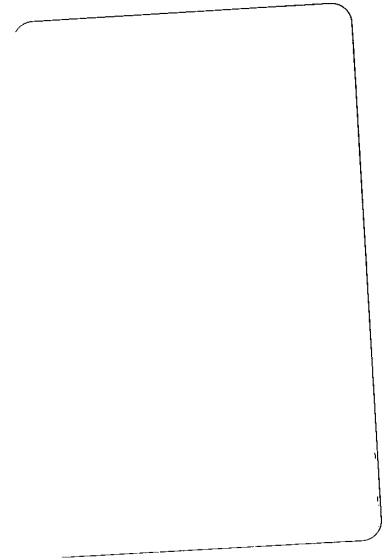
Open University. *Learning Disability: working as equal people*. Open University, 1996.

Townsley, R. Avon Calling. *Community Care*, 12-18, January, 1995.

Walmsley, J. Life history interviews with people with learning disabilities. *Aural History*. Vol 23, No. 1 pp71-77, 1995.

Whittaker, A., Gardner, S., Kershaw, J. *Evaluation by people with learning difficulties*. London, King's Fund Centre, 1991.

Whittaker, A., Ed. Involving people who have multiple disabilities. In Information Exchange on self-advocacy and user participation. No. 6, November, 1993. King's Fund Centre, London.



King's Fund



54001000649650



0000 048572 02000

