

## Creating more choice for people with learning difficulties

Government policies across the UK challenge service providers to make sure that people with learning difficulties are central to planning the services that affect them. 'Helping Each Other For A Better World' is a consultancy team of six people with learning difficulties. They visited five places in England and Wales where new things were happening for people with learning difficulties during the day to find out what had changed and how change had happened. The team found that:

- f** People with learning difficulties were seldom involved in the early stages of change, or in running and making decisions about the organisations and projects.
- f** People with learning difficulties were in charge in only one of the five places visited.
- f** In some places, people with learning difficulties could go to staff team meetings or board meetings.
- f** Some people with learning difficulties were paid the same as non-disabled people. Some people were not paid anything at all.
- f** In most of the places visited, staff in social services departments had an important role in starting or supporting change.
- f** The team concluded that:
  - people with learning difficulties should have the same chances and choices as non-disabled people;
  - modernising services should involve people with learning difficulties from the start and at all stages;
  - the current benefits system and rules made it more difficult for people with learning difficulties to do paid work.

## Background

'Helping Each Other For A Better World' is a team of six people with learning difficulties. The team was interested in finding out for themselves what different things people with learning difficulties do during the day. They visited and interviewed people at five well-known and innovative projects in England and Wales to learn about what was on offer and how people with learning difficulties were involved in the projects. This information formed the basis of a training pack to tell people with learning difficulties about different and interesting things they might do during the day and how they could get these opportunities for themselves.

## Policy context: new strategies for people with learning difficulties

The Department of Health recently published a White Paper on services for people with learning difficulties: *Valuing people: A new strategy for learning disability in the 21st century* (March 2001). The White Paper is based on four core principles:

- rights;
- independence;
- choice;
- inclusion.

The Government's key objectives include:

- modernising day services for people with learning difficulties to help make services more 'person-centred';
- increasing the number of people with learning difficulties in work, including paid work;
- promoting the active involvement of people with learning difficulties in local planning processes through Learning Disability Partnership Boards and increased support for citizen advocacy and self-advocacy.

Implementing the proposals outlined in *Valuing people* at the local level will require local partnership working across: people with learning difficulties, carers, social services, health, employment, education, housing, community development, leisure, and local voluntary and private service providers.

In Scotland, the Scottish Executive's Learning Disability Review, *The same as you?* (May 2000), recommended making day services more person-centred and less segregated, and investing in supported employment for people with learning difficulties.

In Wales, the Learning Disability Advisory Group

has now submitted its final report to the National Assembly. The report, *Fulfilling the promises: Proposals for a framework for services for people with learning disabilities* (June 2001), recommends further investment and action to help more adults with learning difficulties gain paid employment or participate in meaningful day-time activities.

## Changing services and supporting employment

The team found out about how the projects started; how they were funded; whether and how people with learning difficulties were involved in projects and benefited from them.

### Getting started

The team found that people with learning difficulties were seldom involved in the early stages of change.

Some organisations conducted surveys to find out what people with learning difficulties wanted to do. Some got their ideas by visiting other projects. In one place, a small group of staff developed an idea and worked together to set up a new project. In another place, staff from a voluntary organisation spent a lot of time talking to people with learning difficulties about what they wanted; they supported people to set up their own co-operative firm.

The staff involved in making changes worked for a range of organisations, mainly social services, voluntary organisations and (sometimes) health authorities. They always had strong beliefs in the rights of people with learning difficulties to have the same opportunities to live and work as other people.

### Organisations involved in supporting change

In all the places visited, social services departments had an important role in starting or supporting change. In three places, the health service or social services department led the change as part of a larger strategy such as a hospital closure plan. In two places, a small number of staff from health or social services departments set up new voluntary organisations. They employed new staff with new skills and lots of enthusiasm.

### Funding change

The team found that funding to change things came from a wide variety of sources.

All of the projects received some funding from the local authority. Other sources were: European Social Fund (two projects); charitable trusts (two projects); National Lottery Arts for Everyone (one project); 'All Wales Strategy' (one project); and a local

health authority (one project). Two projects were partially self-sustaining through generating their own income.

### **Involving people with learning difficulties**

The team found that people with learning difficulties were not often involved in starting, running or making decisions about organisations and projects.

In only one project were people with learning difficulties in charge (this was a workers' co-operative). In four projects, staff (not people with learning difficulties) decided what services were on offer. However, people with learning difficulties could decide what work or activities they did.

Different ways of involving people with learning difficulties were evident in the five places. Some places used several different ways of involvement:

- filling in questionnaires;
- going to staff team meetings;
- participating in an organisation's planning weekend;
- attending board meetings (but not being company directors);
- being in service user groups.

Staff at all five projects stated that they included people with a variety of skills and support needs, including people with high support needs.

### **Getting paid**

The team found that most people did not get paid the same as non-disabled people for doing the same job.

In two places people were not paid anything. Benefits rules made it difficult for people to do paid work. People sometimes got told that they could only earn £15 a week or nothing at all.

### **Transport issues**

People with learning difficulties travelled to work in different ways. In some places, people used 'special transport'. In one place, everyone went to work using ordinary public transport.

### **Involving parents and carers**

In some places, parents and informal carers of people with learning difficulties supported the projects by helping to reassure other parents about the changes.

### **Lessons from the research process**

The way the team undertook the research provides additional lessons for practice, policy and research on people with learning difficulties.

### **Setting up**

The team came together because they wanted to make things better for people with learning difficulties. Four members of the Team had been working together since September 1998.

In July 1999 the team advertised for new members to join them. The two new members were chosen through interviews. A facilitator from the Leeds Coalition, an independent advocate from Leeds Advocacy, and a Project Advisory Group supported the team to carry out this work.

### **Employment**

The team was employed by the Leeds Coalition - a not-for-profit organisation working with and for people with learning difficulties.

Each team member was employed to work 3 hours per week at £5 an hour. In this way, potential difficulties such as losing benefits entitlements or having one's entitlements reviewed and reduced were avoided.

### **Deciding where to visit**

The team wrote to many organisations and projects that had been written about or recommended to them by well-known researchers and practitioners. From those that replied, the team chose to visit:

- **Making Waves:** a theatre apprenticeship scheme set up by *mind the... gap* in Bradford;
- **A Clean Sweep:** a workers' co-operative of people with learning difficulties in Bristol;
- social enterprises set up by **Co-options** in North Wales;
- **Sabre Employment Service** in London;
- **Trowbridge Day Centre** in London.

### **Visiting each project**

Visits took place in December 1999 and January 2000. Two team members and the facilitator went on each visit.

Before starting the visits, the team wrote a list of questions to ask. The questions were written in large print, alongside a picture or symbol for each question. They decided which team members would go on each visit and practised asking the questions. The team sent the questions to all the places they planned to visit in advance, so that people with learning difficulties would have a chance to talk about the questions before being interviewed. At each of the five places visited, team members asked the questions. At each visit, the facilitator took some photos, audio-taped the

interviews and made a short video recording of the places visited.

Team members were not able to interview people with learning difficulties on all the visits. For example, at one organisation people with learning difficulties were all out doing their jobs in different places and it would have been intrusive to visit them at their places of work. No one with learning difficulties worked in that organisation's office.

### **Analyzing the information**

At the Leeds Coalition office, the whole team looked at the photos. They also watched the videos so that everyone could see the places and people involved. The whole team listened to the tapes together. They listened to them a little at a time, pausing the tape and discussing what people had said.

The team agreed what they had heard and the facilitator made a written record on large sheets of paper, using drawings and symbols as much as possible. It took a long time (several months) to listen to all the tapes.

Then the team looked at the notes from the tapes to agree what they meant. They looked at the information place by place, and decided what they wanted to put in the training pack about each place. Then they looked at all the answers to the same question from the different places. They looked for patterns, and agreed what the main findings were.

### **Producing the 'Making Your Days Better' training pack**

The team developed a training pack to tell other people with learning difficulties about the different things they might want to do and to give people ideas about how they could change things themselves. The training pack uses photos, pictures, words and symbols. It includes information about the five places visited during the project and the team's findings.

### **Conclusion**

The Helping Each Other For A Better World Team found that people with learning difficulties were seldom involved in getting new ideas started, or in running and making decisions about organisations and projects. They hope the 'Making Your Days Better' Training Pack will help to change that.

## How to get further information

**Helping Each Other For A Better World**, The Leeds Coalition, Bridge House, Balm Road, Leeds LS10 2TP. Tel: 0113 270 3233. email for the team: Better.World@leeds-coalition.uklinux.net; email for Leeds Coalition: cathy.wintersgill@leeds-coalition.uklinux.net

**Making Your Days Better: A training pack for people with learning difficulties**, is written by Margaret Baines, Mary Brayshay, David Norman, Durbali Roy, Mark Wallis and Philip Walsh with Cathy Wintersgill and Sue Lindsay. It is designed for use by self-advocacy groups and their supporters, as well as relevant practitioners and service providers. The team is currently preparing to use the training pack to run training sessions for groups of people with learning difficulties. It is published for the Foundation by Pavilion Publishing (ISBN 1 84196 050 0, price £55, £20 for self-advocacy groups). It is available from Pavilion Publishing (Brighton) Ltd, 8 St George's Place, Brighton, East Sussex, BN1 4GB, Tel: 01273 623222, Fax: 01273 625526 (please add £2.50 p&p).

The team has also written a summary of their findings for people with learning difficulties. It is available in print and on audio tape from **Plain Facts** at the Norah Fry Research Centre in Bristol, Tel: 0117 923 8137 ([www.bris.ac.uk/Depts/NorahFry/PlainFacts](http://www.bris.ac.uk/Depts/NorahFry/PlainFacts)).