

## Front Cover

King's Fund

Andrea Whittaker

Changing our Days: Finding ways to get what you want from life

Cover illustration shows a sun rising

## Title Page

Changing our Days

Finding ways to get what you want from life

Handbook and Audio CD for people with learning difficulties

Andrea Whittaker

## Title Page

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## Thanks to:

Hereford Changing Days Group, who commented on the words in this book when it was first published. Taking Control Group, Knowsley, who helped with a lot of the suggestions for Things to do.

Our particular thanks also go to Bridges (formerly APMH). Bridges started in 1974 and was one of the first organisations to work for the right of people with learning difficulties to speak up for themselves. When the organisation closed down in 1998 they decided to give their remaining money to the King's Fund to be used in some special way for people with learning difficulties. This money has helped to pay the cost of producing this book and CD.

## Introduction

This book is about getting better day opportunities for people with learning difficulties. This means helping more people

to:

- get paid jobs
- do courses at college and get certificates
- make more friends
- have more interesting things to do in their spare time
- get help when they need it - e.g. in evenings and at weekends

and much more!

The book was first published as part of the King's Fund book Days of Change. Days of Change is a big book with a lot of information in it about day opportunities. This shorter, easy-to-read version is printed in the front of the big book. Here it is printed as a separate book to make it easier to use.

We hope that being able to listen to it on the CD will help.



## Tips on using this book and CD

- Some people might like to read and listen to the book on their own to think about how they can change their own lives. Then they could talk things over with a supporter, a keyworker, their parents or an advocate
- Self-advocacy groups and centre committees may like to read/listen to parts of the book in their meetings. This could be helpful in working with supporters and staff to change services
- The track numbers on the CD match the chapter numbers in the book to make it easier to find the chapter you want to listen to. The CD will play on any CD player
- At the end of each chapter are suggestions of 'things to do'. These are just to give you some ideas to start with. You will find that lots of other ideas come out as you talk about the topic with other people and think about what's happening in your own local area
- You don't need to read/listen to all the book at once. You can work on one chapter at a time.
- For example, if you want to help people get out and about more in the community, use Chapter 6 - Getting involved in your local community
  - talk about what it says. Do you agree? Do you disagree? What do you know about your own community? How could you find out more? Use the suggestions at the end of the chapter
  - add your own ideas
  - decide what action to take
- Get - or borrow - a copy of Days of Change. Many services and day centres will already have a copy. If not, your local library should be willing to get it for you. This will be helpful because:
  - the big book has much more information in it
  - it has good stories about people's lives
  - it has names and addresses of places and people to contact or visit.
  -

## Using the pictures and symbols

Most of the pictures and symbols in this book are easy to understand, but the ones below might need some explanation.

[picture of a hand making a fist]	help/support
[Stick person with fist symbol]	needs
[fist symbols and a picture of a hand placing a coin into an open palm]	services
[stick person pointing to themselves and a thumbs up symbol]	strengths
[Two overlapping circles]	together
[Stick person at a table hammering]	work/job
[stick person hammering a nail]	do

Pictures and symbols taken from: A Guide to Using Symbols, Phoenix NHS Trust; Rebus Glossary; Picture Communication Symbols, Mayer-Johnson, People First publications, The Drawings Pack (NACVS, Sheffield).

**The following chapters in this book originally appeared with accompanying symbols. To make it easier to follow the version below includes only the original text.**

## Chapter 1 The most important things to do

This chapter is about the most important things we need to do to make good things happen in the lives of people with learning difficulties. These important things include:

- persuading managers and other top people that it must be done!
- making sure that the changes are what people with learning difficulties want
- organising services and the money that pays for them in a way that helps staff support people properly
- making sure that each person with learning difficulties has the chance to speak up for themselves and say what they want
- • supporting people a lot more to be involved in their local communities having a plan to make all this happen.

### Start to make changes now!

Some people say things are okay and don't have to be changed. Other people want to change things but think it is too difficult to give it a go. A lot of people find change frightening and threatening. So people who are really keen to start making changes - parents, staff and people with learning difficulties - need to work together and show they are determined to make things better.

People with learning difficulties have a big part to play. Many who are going to day centres are unhappy with the services they are getting at the moment. A People First National Conference in Edinburgh passed a motion: '**day centres should not waste people's time or people's lives**'. Parents of children leaving school want their sons and daughters to go to college and have jobs.

### Listen to what people want

Changes in services must be based on what men and women with learning difficulties say they want to do in their lives. People who can't speak for themselves must have someone who knows them very well to speak for them.

In Essex, 750 people with learning difficulties talked about how they would like their lives to be. They put the information into a report and presented it to the Social Services Committee. This helped social services set out a plan for services that was truly based on the views and wishes of the people who used them.

### Help services to change and grow

Services often have too many rules. This can make it difficult for staff to help people. It can mean that people with learning difficulties get less choice, are not allowed to take risks, or make changes in their lives from time to time. It helps if everyone

working in services can keep learning, growing and developing and not get stuck in a rut!

### Planning for each person's needs - person-centred planning

Every man and woman with learning difficulties should have a personal plan for their life. This should say:

- what is good about their life now
- what needs to change
- their hopes and dreams for the future
- what help and support they need to make their dreams come true.

### Being included in the community

Many women and men with learning difficulties are now out and about in the community, using cafes, shops, restaurants, colleges and leisure centres. But often this still only happens in large groups, in separate places, special classes at college, special times at swimming pools, etc.

We still have to work hard to support people to be a part of the community like anyone else. This means, for example

- : • not only going to watch the football match but perhaps being a member of the supporters' club and helping to run it
- not only playing snooker or table tennis at the Gateway Club but also having a game at the local youth club, or neighbourhood centre alongside other citizens
- not only going to a rock concert with a member of staff but with a friend who also likes rock concerts!

It is also important to help the community to welcome people with disabilities and let them join in more with everyone else in the community. Services need to work with housing, employment, education, leisure and other organisations to make this happen.

They must help these organisations to understand that people with learning difficulties have the same rights as anyone else.

### Moving from services to support for individual people

So the most important messages are:

- we must change from just helping groups of people to helping each person live the way they want with the support they need

- we must start by asking each man and woman with learning difficulties what they want in their future. Then give the support that each person needs.

#### Things to do

- Hold a conference. Look at what's good and what's not so good about your services and what you could do to change them.
- Do a survey or a questionnaire to find out what people who use services want in their lives and what they really think about their services.
- Give a talk to your Social Services Committee about what people want from their services.

## Chapter 2 Getting started

Many services are changing the way they work. They are moving away from big, separate day centres to supporting people to spend their days, evenings and weekends in the same places in the community that everyone else uses. How are services making these changes? They are doing it by

- listening to what people with learning difficulties say they want in their lives,
- listening to parents and staff say what changes they would like to see,
- getting a group of people together to lead the changes,
- making sure there are strong leaders to support people,
- getting top people to believe in these changes and give their support,
- making sure that each person with learning difficulties has a personal plan,
- using these personal plans to build better services, training staff to have new skills,
- employing staff to work when people with learning difficulties need them - in the evenings and weekends as well as the day time,
- getting jobs for people, using money in different ways.

### Things to do:

- Do a presentation to councillors, managers and care managers on what you want to happen in your services. Tell them how you could help.
- Make your own list of things you feel should be done and send this to councillors, managers and other top people.

- 

## Chapter 3 Staying on track

This means sticking with it, even when it gets very difficult! Sometimes it is easy and exciting to make changes and see good things happening in people's lives. At other times, it is very difficult, people get upset and want to give up.

What helps?

- Hold meetings to see how people are getting on and to support and encourage each other
- Celebrate success - tell people when they do something good and when good things happen
- Make special efforts to work with people who don't want change
- If you get stuck, try getting help and support from someone outside your local service

When managers and staff are trying to make big changes in services, it can be particularly difficult for those who are leaders. They need to make sure they get personal support for themselves.

It is important to work out a way of checking that the new service is doing what it set out to do. Managers and staff need to keep in touch with what is happening in the lives of people who use the service.

A good way of doing this has been developed by the Quality Is Our Business Too project. The project staff asked people with learning difficulties what was most important in their lives. They chose ten important statements about the kind of life people want. Here are five of them.

1. I make decisions about my life
2. People listen to me and treat me with respect
3. I have friendships and relationships
4. I take part alongside ordinary members of the community
5. I get the chance to do a paid job and the help I need to do it well

Things to do

- Talk about the five statements above. Are they your most important statements?
- Make a checklist of things that are important in your life. ?
- Find out how you could get involved in checking services. Strategic planning and commissioning

## Chapter 4 Strategic planning and commissioning

This chapter is particularly about commissioning services. People who commission services (commissioners) are sometimes called purchasers or buyers of services. But commissioners are more than that. They:

- find out how people with learning difficulties want to live their lives
- find out what help they need to do this
- use money and good ways of working to make sure people get the support they need
- keep in touch with people to make sure that they get what they want.
- 

For commissioners to do their job well they need to:

- believe in the right of people with learning difficulties to have the same choices and opportunities as other citizens
- plan services based on what people with learning difficulties say they want and need
- use money in different ways according to what different people want. For example, instead of putting all the money for transport into contracts for big buses, use it for a variety of transport like taxis, cars which take wheelchairs, mini-buses, travel training, helping people use public transport or ride a bicycle safely
- work closely together with all their colleagues from different services
- make sure that planning is about a person's whole life - where they live, what they do during the day, getting a job, having a social life and friends
- write contracts which can change if someone's needs change
- make sure that the people who provide services - e.g. managers and staff in people's homes, staff who support people at work or college – understand very clearly how they should help men and women with learning difficulties.

It is important that commissioners keep in touch with people with learning difficulties who use the service. They can do this by:

- getting to know at least one person with learning difficulties very well
- taking part in service reviews that involve spending time with people
- setting up a way of getting regular comments and feedback from people who are using the service.

### Things to do

Find out who your commissioners are. Invite them to come and speak with you. Talk about how you could work with them.



Get a copy of 'Putting People First' and learn how Newham People First works with commissioners. Write to: People First, Instrument House, 207-215 King's Cross Road, London WC1X9DB.

## Chapter 5 Getting a life, not a building

Many men and women with learning difficulties don't go to a day centre any more or perhaps go for just one or two days a week. This is because they have a job or go to college or do voluntary work or other activities during the day. This chapter is about how to support people to have interesting days without going to a day centre.

### Using buildings differently

We cannot stop using big day centres overnight. Day centres are important places for people to meet their friends. Parents know that their sons and daughters are safe there. But it is difficult to make big changes for a lot of people while we still use all our big day centre buildings.

One way to start to make changes is to look at how we are using our buildings. Could they be used differently? Does your local area have a community centre? Could your day centre become a community centre for local people as well as people with learning difficulties?

### Working without a day centre base:

More people with learning difficulties are now being supported entirely in the community. The only special place is a small office for staff. Staff meet people at their homes and then go off together to do whatever is planned for that day.

It takes a lot of good planning, enthusiasm and commitment from everyone involved to make sure this type of support works well.

### What helps?

- Staff who can work on their own, are good at meeting people, who know their own community.
- A manager who trusts staff to take responsibility, manage their own time and get on with the job on their own.

### Linking with family and carers

Working in this way, staff get to know the person's family better. They see the family more often because they meet the person at their home rather than only seeing them at the day centre. This often means that staff can help people take part in more family activities.

They can get to know the person's cultural background. They meet friends of the family. They can help the person meet up again with family members they might not have seen for years.

It also means the support worker gets to know the neighbourhood where the person lives and where there may be new opportunities for the person.

## Making it work for people with complex needs

Some of these community-based services support people with complex needs - women and men who need a great deal of support in their lives. Sometimes these are people who don't like going to the day centre because there are too many people or they find it noisy.

Often they are people who had so many problems they were not getting any service at all. It might be someone who is too afraid even to leave his/her own home. All these people can be helped by this kind of service.

### Kevin's story

Kevin is a young man in his thirties. He lives at home with his mother. He had not received any services for 15 years, had no regular activities and no social life. He couldn't talk or hear very well.

Then he began to get help from staff who work with people by going to their homes. He had a lot of help with speech and language and learned to use symbols. This meant he could make real choices about what he wanted to do.

Kevin particularly enjoys art and has joined mainstream art and pottery classes at his local college. He goes out for cups of coffee with his classmates. He is good at computers and has learned to hold conversations with people using typed messages. He goes swimming regularly and visits a neighbour.

Kevin had an exhibition of his artwork and pottery at the cafe he often goes to. Family and friends came to see the exhibition and his picture was in the local newspaper.

### Things to do

- Talk to people who used to go to a day centre but now have a job or do other things during the week. Ask them how they felt about leaving the day centre and what their life is like now.
- Talk about your day centre building. Is it used in the evenings as well as the daytime? Do any community groups use it?
- Organise an open day and invite people from the local area to come and see what you do.

## Chapter 6 Getting involved in your local community

Every person with learning difficulties, no matter how severe their disabilities, should have the chance to live in the community and take part in local activities. Services should always work to make this happen.

Many people with learning difficulties are now getting out and about to a wide range of places in the community - leisure centres, colleges, pubs, shops, theatres and restaurants. But many people still go out in big groups and join in activities in the community only at special times - for example, they go swimming only at special sessions for disabled people, or attend special classes at college which are only for disabled people.

We need to do much more to help people also have the chance to go out with just one or two friends - for example, to see a film, to go to a concert or to join a photography club together.

We need to do much more to help people do things in the community alongside other citizens.

### Friendships and relationships

Friendships are very important to all of us. When a day centre is closing, people who go to the centre often ask:

'How will I keep in touch with my friends?'

'How can I make new friends?'

Services must make sure that people can keep in touch with their friends and help them make new friends. In the past, services have not been good at doing this. They need to realise how important it is. They need to make sure staff understand it is an important part of their job.

### Helping people make friends

Helping someone make new friends is not always easy. Many men and women with learning difficulties are separated from their families. They have not had opportunities to learn how to make friends. They may have lived with the same group of people for many years. The only people they know are staff. Staff are often so busy looking after people that they don't have time to help them make new friends.

### What helps?

Ask the person with learning difficulties what she/he would like to do. Then find somebody who wants to do the same thing so that they could do it together. For example, going for walks, joining a steel band, making pottery. Many services have set up schemes to help this happen. They are sometimes called leisure partnerships or befriending schemes.

The Hereford Changing Days group has written a book about making friends. It is entitled Talk About Friends and has pictures as well as words.

For more information contact:

Changing Days User Group, Hereford Citizen Advocacy, 25 Castle Street, Hereford HR1 2NW. Tel: 01432 263757.

### Circles of support

Every man and woman with learning difficulties should have at least one friend - one person in their lives who cares about them and wants to be with them. But most of us have friends - some close friends and some friends we don't see so often. This should happen for people with learning difficulties too.

A good way to make this happen is to ask a few people to get together to help a particular person. This is called a 'circle of friends' or a 'circle of support'. The person with learning difficulties should choose who they want in their circle. It might just start with two people. Those two people also have friends who might like to join the circle. So, over time, the person with learning difficulties has several friends who they can see socially and call on for help if necessary.

### A different job for staff

Staff need to work differently to make these things happen. It must become one of the most important parts of their work. They need to think of ways that will help men and women with learning difficulties meet more people and make more friends.

This is more than just finding a person 'something to do' in the community. It is about taking the time to help people make friends, to know their neighbours, to become members of leisure and other community organisations, to help others as volunteers. Staff will need to:

- be willing to speak up for people - to challenge prejudices.
- Be enthusiastic- want to make things happen for people
- Be creative – able to think of new ways of doing things, find new opportunities
- Be patient – it can take a long time – but stick to it!

### Taking risks

Many parents, staff and carers worry about people taking more risks when they are out and about in the community. They worry about people having accidents, or meeting the wrong sort of people, or not knowing how to live safely away from the security of the day centre or hospital.

Some people with learning difficulties already know how to look after themselves very well. Others will learn quickly. Others will always need someone with them to make sure they are safe.

But whatever help people need, it should not stop them trying out new things and taking part in activities they enjoy in the community.

It is good that already so many more men and women with learning difficulties are out and about doing interesting things in the community. But we need to do much more to help people take part in their local community – just like other citizens do.

### Things to do

- Plan social evenings and coffee mornings to keep in touch with old friends
- Arrange a day to show photos and videos and tell stories to help people keep in touch about old times and old friends
- Find out who are the bosses (yop managers) in your leisure services. Arrange a meeting to ask them how they could help more people with learning difficulties use swimming pools, sports parks, libraries etc.
- Make a book about local places to go and things to do in your community that are accessible and friendly to people with learning difficulties.
- Find out about circles of support. Contact: Circles Network, Pamwell House, 160 Pennywell Road, Upper Easton, Bristol BS5 0TX Te; 01179393917
- Invite someone who has a circle of support to come and talk about it to your group.

## Chapter 7: Planning for individuals

Each man and woman with learning difficulties should have their own plan of what they want their life to be like. This chapter is about how to draw up a lifeplan. The plan should set out:

- the person's hopes and dreams,
- what they want to do in their lives,
- the support they need to do it.

There are a number of different words used to describe people's plans:

Person-centred plan (PCP),

- Lifeplan,
- Assessment,
- Profile,
- IPP,
- Community care plan.

There are a number of different ways of describing how to draw up these lifeplans:

- Whole life planning,
- Personal futures planning,
- Essential lifestyle planning,
- PATH (Planning Alternative Tomorrows with Hope).

Each person should have a copy of their own lifeplan. The plan should be easy for the person to understand, use and share with other people as necessary.

Ways of doing this are:

- use words the person understands,
- use signs and symbols,
- include photographs and drawings,
- use videos and computers.

The lifeplan should look at the whole of a person's life and include

- where they live,
- what they do in the day time, evenings and weekends,
- what should be done to help them make friends,
- how to help them become members of local organisations and take part in their local community.

## Making the lifeplan

Everyone who knows the person well - family, friends, staff, advocates and support workers - should be involved. The person should choose who they want to help them make their lifeplan.

It is important to record small details about the person, particularly if it is someone who can't easily say what he/she wants. 'Getting up' and 'going to bed' routines are important, but also smaller details like:

'Does he like to face towards light or away from it?'; 'Does she like to be fed a mouthful of meat before the vegetables - or vice-versa - or both together?' What sign does he use to say 'yes'? How do we know she is saying 'no'?

Make a life history book, including as much detail as possible about the person's past. This is very important in helping to understand what has happened to a person through their life. It can also tell us about interests or skills the person used to have which everyone has forgotten about.

For example:

A lady who lived at home until she was an adult was used to doing cooking, ironing and washing. She was put into an institution when her mother died and didn't use these skills. When she moved out again into a house in the community, staff were surprised that she could do all these things.

The lifeplan should be the first step in developing a person's community care assessment. Information in the community care assessment is used by managers to decide what services a person needs. The people who do the community care assessment - the care managers - should know the person with learning difficulties very well, to make sure the person gets what they want and need.

## Things to do

- Talk about lifeplans. Are they a good idea? (Note: lifeplans might be called by a different name in your area.)
- Have you (and people in your group) got a lifeplan? If not, would you like one? Talk about who might help you.
- Help someone you know who can't speak up for him/herself to make a life story book. Use the ideas in this chapter.



## Chapter 8: Keeping users central-involving user groups

Services must work in partnership with men and women with learning difficulties.

Everyone - from top to bottom of an organisation - must believe in working with users, understand why it is important and work to make it happen.

Money and staff for user involvement should be part of the main budget of the service, not just given when there is some 'spare money' or rely on staff to support user groups in their own time.

There should be opportunities for staff and users to train together.

A service that really wants to involve users will have:

- senior managers and other 'top people' regularly meeting with men and women with learning difficulties;
- planners and policy-makers attending user meetings;
- users attending council meetings;
- managers meeting with user representatives regularly;
- users on committees and sub-groups with good support
- parallel user groups with negotiating power and a clear process for joint working with staff/professional groups
- users actively involved in checking and evaluating services;
- user involvement written into contracts with providers.

To make sure individual users are involved the service will have:

- an individual lifeplan for each person and use the lifeplans to develop services;
- a well-used complaints procedure
- users choosing their own support workers;
- active user groups which have power to change things in residential homes, day centres and clubs;
- user groups for people from minority ethnic groups
- staff specially appointed to support user groups to work to change services; easy-to-understand information about services in different languages and using signs and symbols, photographs, tapes, video and computers.

### How users were involved in Changing Days

Three Changing Days user groups were set up - in Cambridge, Hackney and Hereford. These groups worked alongside the professional Changing Days groups.

Some of the good things the groups did

- taking part in Changing Days steering groups alongside professionals
- speaking to social services committee members about their ideas for future day services

- visiting different parts of their own and other people's services
- making videos of their lives and services
- searching out new opportunities locally - places to go, things to do
- taking photographs to help people identify new staff and their new roles in services;
- creating a booklet on things to do in the community which cost little or nothing
- writing a booklet on helping people make friends
- organising an activity day at the centres and inviting people from the community.

### What helped?

The things that helped these groups grow strong were

- regular support from staff willing to give generously of their time, in and out of working hours
- strong support from management - in writing and with money; easy-to-read papers using everyday language and pictures
- managers keeping in regular contact with users
- professionals being willing to change the way they run meetings, the times and the places to fit in with users' needs.

This is what members of the Cambridge group thought was good about being involved in Changing Days:

"Being able to meet new people and make new friends"

"We have spent time out of the centre"

"We have worked well in groups. It has been somewhere to talk about problems and worries"

"We have worked with the steering group"

"We have talked to managers about what we want"

"We have invited guest speakers to talk to us"

"We have had free lunches and drinks at meetings"

### Hereford user group:

This is what members of the Hereford group said was good about being involved in Changing Days:

"looking at what we like and do not like about our lives and the services we use"

"Finding out about what others think and feel about things"

"We want the user group to keep meeting and to grow"

“We want to find out the views of service users and take them back to management and social services”

“We want to go to centres and tell users what is possible and help them to stand up for themselves.”

### Involving people with complex needs:

Services should also listen to people who need a great deal of help, every day in their lives.

These people may need extra help to speak up. In Hackney, one young man was a member of the Changing Days user group right from the beginning. Although he could not speak, he could show how he felt about what was going on. He also helped the group remember the needs of people who have greater disabilities than themselves.

Some services are good at asking people with learning difficulties what they think about their service and changing things because of what they say. This should happen in all services.

### Things to do

This chapter talks about a lot of different ways people with learning difficulties can be involved in services. Which ones are already happening in your area?

Choose three others which you would like your group to do. Decide what is the first thing you need to do to make them happen.

## Chapter 9 Involving parents and families

It is very important to work with parents.

Parents want to talk about and be asked about changes in services.

Many parents worry about big changes like closing a day centre. They are afraid that services are being cut and their sons and daughters will not receive the support they need.

Parents want a reliable service. They want things to work properly. When their son or daughter has been attending a day centre five days a week, parents can be afraid of what he or she will be doing out and about in the community at different places, at different times, and on different days.

Parents need to be sure that staff know where people are and what they are doing. They want to be sure that their son or daughter is safe and not being put at risk.

Often parents who, at first, are angry and very much against any changes end up saying it is a good idea because they see how much better it is for their son or daughter.

### Communication - talking together

Communication is very important to parents.

They say:

'Consult us right from the start',

'Listen to us',

'Be honest',

'Communicate regularly with us'.

### Ways of parents and staff working together

- Meetings - one-to-one (parent and staff member), small meetings (like workshops), larger meetings (like conferences), social events (when people can talk about other things besides services).
- Arrange visits for parents to go and see different services in other parts of the country.
- Give parents jobs to do - for example, in one new service, a parent whose everyday job was in transport chaired the sub-group looking at different kinds of transport.

Many parents are looking for and welcome changes for their sons and daughters. But they also want to make sure that the new service will work for them too as well as their sons and daughters.

## Things to do

- Do presentations to parent groups about what you want to do in your life and what you want services to be like.
- Tell a story or show a video about someone who has done well to show parents what is possible.

## Chapter 10 Transition – moving towards adulthood

### Transition means

- getting ready to leave school,
- thinking about what you want to do when you leave school - e.g. go to college, get a job,
- planning how to make this happen.

It is a time when many important decisions about the future are made. To help make these decisions, young people with learning difficulties need to

- talk to family, friends and staff about things they enjoy doing and would like to try,
- talk to family and friends about college and work to get to know what it is like to be a student or an employee,
- visit workplaces and colleges to see what is on offer and what sort of place would suit them best.

Young people need to learn about being an adult and being a good citizen so that they can take part in the life of their community.

### The importance of information:

Families need to be able to find information when they need it. The information must be correct and easy to understand.

The information should be about things like

- a statement of rights,
- a description of services available,
- details of benefits and financial help,
- where to go to talk to other people about transition,
- how to make comments, suggestions or complaints.

### Listen to people with learning difficulties

Sometimes young people with learning difficulties are not listened to properly. It's as if adults think they are still small children who don't have opinions of their own.

But when a young person is growing up, it is very important they are listened to by their parents, friends and staff. If they are treated with dignity and respect, they feel good about themselves and can look forward to the future with confidence.

Sometimes there can be problems when helping someone plan for their adult life

e.g. the young person with learning difficulties wants one thing but the parents want something else. Parents have strong ideas about what their son or daughter needs. Staff have equally strong but perhaps different ideas about what the young person needs.

The young person is pulled in different directions. When planning for the future, young men and women with learning difficulties, their parents and families and staff must talk together about what they want and listen to each other.

### Beth's mother tells her story

When Beth was coming up to school-leaving age, I was really worried. As a single parent I felt very responsible for getting it right. The social worker called and explained about doing an assessment of Beth's needs. We all got together, including Beth, with a teacher from school and talked about the things she liked to do, what she was good at and where she needed help. I was pleased - it felt that people were really interested in her.

Beth now enjoys a full week of activities. We meet every six months to see how she's getting on. Beth would like to attend the local college with her friend and we are looking for a volunteer to support her with the travelling. It's amazing - I never imagined I would have the confidence to consider these things were possible. We have all worked very well together.

### How can managers help?

Involve young people with learning difficulties in all decisions about their life.

Appoint an advocate to help people who can't speak up for themselves.

Invite parents, relatives and carers to come to transition planning meetings.

Hold the meetings at times and in places that are convenient to families.

### Things to do

- Find out which member(s) of staff are employed to be a link between schools and the day centres. Invite them to your group to talk about their work.
- Visit your local special school and give a talk to people who are ready to leave school. Tell them about your life and how services can help.

## Chapter 11 Supported employment

Having a job is very important to many men and women with learning difficulties.

Even people with very severe learning difficulties can get jobs, provided they are given the right training and support.

In recent years, we have learnt a lot about how to help people

- get a job,
- learn how to do the job,
- keep on enjoying the job and doing it well

Supported employment is a good way to help people get jobs because

- it is person-centred,

It finds out what the person's interests are. It then finds the right job for the person in the right organisation, in the right work surroundings.

- people get real jobs,

They are jobs that employers need to pay somebody to do. The worker must do the job to the standard the employer needs. So the worker is helping to make the business a success.

- it is an ordinary working life,  
on-the-job training is very important. The person learns the skills necessary for that job
- it helps the person learn to take risks,

it provides opportunities for people with disabilities to spend time with non-disabled workmates,

- it increases the amount of money people have to spend.

### How supported employment can improve services

Although supported employment can cost a lot at the beginning, after a few years it costs less because

- as workers need less support, less money is spent in paying staff to support them,
- as workers need less support, staff can work with more people in the same amount of time.

As more people get jobs and move out of day centres, fewer people go to the day centre. This gives day centre staff more time to work with people who don't wish to - or cannot - get a job.

Services can get extra money for supported employment. For example, from the European Social Fund, the Access to Work Scheme and Training and Enterprise Council funding.

Through a job people can make new friends and get involved in new leisure and recreation activities.

### Problems in providing more supported employment

A number of things stop services being able to get jobs for more people. Sometimes it is because employment agencies aren't working well, but more often it is because of government policies about work and benefits.

Too often, the person with learning difficulties has to choose between having a job or having benefits. It is difficult to gradually reduce benefits as a person earns more in wages.

If a person loses his/her job, it can take a long time to get back on benefits.

The system for employing people does not allow for the fact that some disabled people can work well at some times but may be too ill at other times.

Sometimes there are problems because services don't understand what employers want. Services may think employers should give a person a job out of pity or charity. But employers need people who can do jobs well and help to run their businesses successfully.

### What helps?

We need to

- make sure that services and employers work together and learn to understand each other,
- change the way money is used to provide supported employment,
- change the way benefits are organised so that disabled people can more easily take up job opportunities.

### Things to do

- talk to people in your group or centre who have jobs. What is it like for them having a job?
- Find out who helps people with learning difficulties get jobs in your area.
- Visit your local job centre and find out how they work.
- Talk about the problem of benefits to your councillor or local MP.



## Chapter 12 Access to continuing education

Many people with learning difficulties now go to college. Colleges are very important for helping people learn skills to get a job, make new friends and join in more leisure activities.

But we need to

- help more people do real courses with a qualification - for example, NVQs
- make sure they go to classes alongside other students in the college - rather than attend special classes
- support them in a way which makes it possible for them to make new friends
- increase the number of minority ethnic students with learning difficulties who are going to college.

### Renu's story

Renu goes to an Asian studies course for people with learning difficulties at college. The course looks at different Asian countries and cultures. Shopping for Asian food and looking at different festivals are among the topics they have covered. Renu says, 'It's important to learn about India because me and my sister haven't been before ... I've seen video, films but that's it.'

### Recent changes

Recent government documents have changed the way education authorities work. These documents also say what should be done to make sure that all people with disabilities have the chance to go to college.

For example, the Further and Higher Education Act 1992 made colleges independent from local authorities. It also set out what courses colleges could teach. The Further Education Funding Council was set up to make sure colleges do what the law says.

Some of these changes were good for people with learning difficulties. For example, more courses have to be about learning skills to get a job. More courses have to be planned so that people get a certificate at the end - for example, NVQ courses.

But some changes have not been good. For example, there are less courses on self-advocacy. There are less courses just for fun - things like music, art and drama groups. This means there are often fewer classes that people with severe or profound learning difficulties can go to and enjoy.

One of the problems is that if colleges don't teach the subjects that the Further Education Council says they should teach, they don't get their funding. So some courses which people with learning difficulties particularly like are the ones that have been cut.

### The Tomlinson Committee

This committee wrote an important report about what should be done for education for adults with learning difficulties. They asked colleges, local education authorities

and other people what they thought about what the report said. Everyone supported the report. So in 1997/98, one million pounds (£1,000,000) is being used to train staff and produce training materials to help colleges include more people with disabilities.

### Funding further education

There are a number of different ways of getting more money for education

- Further Education Funding Council,
- Local education authorities,
- European Social Fund,
- Health authorities and social services,
- Training and enterprise councils,
- Voluntary organisations,
- Joint funding.

### What helps?

- Support people to be involved in college committees and training staff;
- Make sure there are taster sessions so that students can try out different classes before making a choice
- Find the right class for each person, not just people to fill 'a class';
- Let the student choose something he/she is interested in and wants to learn;
- Ask for easy-to-understand information. Many colleges still do not have details of their courses in large print, easy words and pictures or photos. If a college hasn't done this, offer to do it together and involve people with learning difficulties
- Ask for self-advocacy courses to be put on
- Make sure that support workers know how to support students in class properly
- Offer to help education staff with training.

### Things to do:

- Talk about the ideas in the 'What helps' list. How many of these happen at your local college?
- Support someone you know who wants to start a college course.
- Ask your local college to do a survey to find out what courses people want.
- Have a committee of students, college staff, social services staff and outside people to check that all courses are going well.

## Chapter 13 Making it happen for people with complex disabilities

Every person with learning difficulties - even people with complex needs or multiple disabilities - should live in the community like everyone else.

By people with complex needs we mean people who can't speak, walk or do anything for themselves

They can also be people who

- get angry a lot,
- injure themselves,
- sometimes attack other people.

The starting point for helping people with complex needs is the same as for anybody with disabilities:

- start with the hopes and dreams of the person
- look at what they can do rather than what they can't do,
- give top priority to helping people communicate - to get over to other people how they feel, what they like and don't like, and what they want to do,
- support each person to have a say in their choice of lifestyle.

For some men and women with complex needs, these things are happening and their lives have improved a lot. But there are many others who have not yet had these opportunities.

Helping a person with complex needs to live like everyone else in the community is not always easy and takes a lot of time. But more and more success stories are proving that it can be done.

### Communication

Many people with severe learning difficulties don't speak or use signs and may even find pictures and photographs difficult. They rely on others to say how they feel and what they want to say. How can we help these people?

Other people with learning difficulties can help. For example, people who go to day centres often get to know people who are in the special care unit very well.

Managers must give staff enough time to get to know individual people very well.

Symbols and signing should be used more. Make sure that people have sight and hearing tests. Problems with seeing and hearing might be making communication difficult.

### Challenging behaviour

People who have a reputation for hurting themselves or others are often said to be 'not ready' to go into the community. But this is often because services are thinking only about what the person can't do, instead of what he/she can do.

If we get to know a person really well, we can learn how to help them. This may take a very long time but in the end the person's life can change for the better.

### John's story

John was a young man with a well-known reputation for breaking windows. Staff spent all their time stopping him from damaging buildings and hurting himself. Few people liked him. People were afraid of him. His behaviour didn't improve. Then it was agreed to try thinking completely differently about John. Could his enjoyment of breaking glass be turned into something useful? John wanted a job, like his brothers and sisters. A job was found in a local glass recycling plant and now, with the help of a job coach, John spends part of his week breaking glass. He enjoys the noise, the atmosphere and the fact he is doing something useful. He does not break windows at home as much. John is happier, has greater self-esteem and sees himself as a more valued person.

People with challenging behaviour often don't see their family and have no friends. So it is very important to get people in their lives who care about them. Sometimes it can be someone they knew in the past. Or it might be long-lost members of their family, or staff from an institution where they used to live.

### Brian's story

Brian was unhappy living in London and had no family to help him. Staff said the only thing he enjoyed was going for long walks but this was difficult where he lived. He had one friend who invited him to his home in the country for weekends and introduced him to more people. Here, Brian could go walking and quickly showed he had many other interests - e.g. cafes, music, pubs and travelling in the car. Brian's new friends all wanted to help him live his life as he wanted. They became his circle of support and worked together to make it possible for Brian to move out of London and start a new life in the country.

### Things to do

- Name three people you know who need a great deal of help in their lives. Are their lives different from yours? Do they have someone who can speak up for them?
- Think about being a friend of one of these people. How could you speak up for them? Who do you know who already does this?
- Talk about advocacy. What does it mean? What is it like to be an advocate? Find out if there is a citizen advocacy project in your area.
- Find out about circles of support. Contact: Circles Network, Pamwell House, 160 Pennywell Road, Upper Easton, Bristol BS5 OTX. Tel: 0117 939 3917.

## Chapter 14 Keeping fit and healthy

People with learning difficulties should be able to get the same good quality health care as everyone else in the community. This means:

- going to a GP who knows the person well and is helpful,
- taking part in health screening programmes (e.g. blood tests, allergies, tests for cancer),
- learning about healthy lifestyles (e.g. diet, exercise, sexual health).

People with learning difficulties often don't get good health care. For example:

- some doctors and other health care staff don't understand what their special needs might be,
- they don't get so many health checks, such as immunisation, blood pressure checks, sight & hearing tests,
- they sometimes find it harder to say how they feel or what's wrong with them,
- people who have lived in long-stay hospitals often don't have good medical records. Important information about things like childhood diseases, seizures and drugs is often missing.

### What helps?

Each person's individual profile or lifeplan should include a section on health care needs - the support he/she needs in order to keep healthy and fit.

People who find it difficult to say how they feel - to let others know when they feel sick - should have help with communication. Staff need to watch out for signs of pain or distress and keep a note of these to help others who don't know the person so well.

Every person should have a yearly health check with their GP.

When people go to their GP, they should be able to go with someone they choose who knows them well.

The National Development Team has developed an easy-to-use personal health record for people with learning difficulties. It is called Advocating for Health and is available from Harlow Print Ltd. Telephone 0191 455 4286.

### The need for services to work together

Men and women with learning difficulties can get good health care only if doctors, physiotherapists, social workers and care managers work together to make this happen.

West Surrey Health Authority organised a week of health activities for people with learning difficulties and their families and carers. There were workshops and classes about personal safety, healthy eating, keep fit, sports and women's health. People

with learning difficulties were involved in organising, advertising and taking part in the week.

You can find out more about this Health Week by contacting: Training and Information Officer, Health Promotion Service, West Surrey Health Authority, The White House, Crouch Oak Lane, Addlestone, Surrey KT15 2AN. Tel: 01932 854476 Fax: 01932 828397.

The Healthy Way is a helpful booklet with tape and game especially for people with learning difficulties. It is available from: Dept of Health, PO Box 410, Wetherby LS23 7LN.

#### Things to do:

- Talk about your experiences of going to your doctor or GP. What makes a good GP? What helps people when they need to go to a doctor?
- Do you have a women's group/men's group to talk about how to keep fit and healthy?
- Organise a Health Week like Surrey did.

## Chapter 15 From hospital to community

Planning how people moving out of hospital will spend their days, evenings and weekends should begin at the same time as planning where they will live.

The person's individual lifeplan should be used as a starting point.

Hospital managers must make sure that money is in the budget specially to pay for daytime and weekend activities.

People who live in hospital are mainly looked after by health services. But when a hospital closes, other services like social services and voluntary organisations get involved.

Staff from these services often work in different ways. They need to learn how to work together to make sure the people moving out of hospital will be happy in their new homes in the community.

In order to help overcome this problem, Ely Hospital employed two managers and two day services staff who usually worked in social services. These people had their office at the hospital so they could get to know residents and work closely with hospital staff.

### Keeping person-centred

In order to make sure that each person living in Ely Hospital was treated as an individual, the following things were done:

- Planning circles were set up to help each resident have a say in their choice of lifestyle in the community.
- Money was given directly to ward managers to make it easier to take people to places outside the hospital. Before this, staff had to fill in a lot of forms or go to the petty cash office before people could, for example, go out for a day trip at the weekend.

### Mike Hooking's circle

At my first planning circle meeting, there were lots of people who I knew. They asked what I wanted to do with my time.

I told them that I like to be busy and that most of all I'd like a job as a security guard but I know that jobs are hard to come by. I also told them that I'd like to:

- learn how to use a computer,
- learn how to manage my money a bit better,
- go to pottery classes, art classes and photography classes.

In my spare time I said that I'd like to:

- go bike riding,

- play football,
- go to watch Barry Town football matches, do outdoor pursuits like walking, camping, climbing, abseiling and caving.

I've been told that I'm starting outdoor pursuits tomorrow. I think that's wonderful and I'm looking forward to it. Mike Hookings, former resident, Ely Hospital.

### Recording past life history

Unfortunately, when people have lived in hospital for many years, information about their lives - their family backgrounds, people they have known - is often lost when they leave hospital. Sometimes this is because their records have been lost. Sometimes it is because staff in the hospital who have known them for many years don't have a chance to pass on information.

It is very important that as much information as possible is written down before people leave hospital. It is also important that photographs and other links with their past go with them.

### Life outside hospital

When people leave Ely Hospital, they are not going to day centres. Each person has a programme of activities which use ordinary places in the community.

In Cambridge, a number of young people who need a great deal of support in their lives and who used to live in Ida Darwin Hospital are now living in an ordinary house in the community. Each day they go out to different places in the community with staff who are specially employed to help them with their days, evenings and weekends.

### Things to do:

- Find out if there are people in your area still living in hospital. Ask if they would like you to visit them.
- Find out if there are people living in your area who have recently moved out of hospital. Ask if they would like you to visit them. Invite them to your activities.
- Think about whether you (or your group) could become an advocate for someone who has just moved out of hospital.



## Chapter 16 Finance

New-style day services will mean that managers need to work out new ways of using money.

At present, a lot of the money for services is used up in buildings. But new services are much more about people than buildings. It is also about people going to a number of different places during the week instead of just one place - the day centre. This means that it is more complicated to run the service. So the way the money is used will be more complicated.

Also, money is coming from different places. Not just social services, but health, education, European Social Fund and many others. This also makes things more complicated.

There are no easy answers on how to organise the money better.

Some of the questions are:

- When a person needs help to manage their money, who should take responsibility? Family, friends, advocates, health, social services, voluntary agency?
- If someone wants to change their personal plan and do something different, how do we make sure they will be able to use their money to pay for the different activities?
- We need money for making more opportunities for people in the community. We need money for supported employment services. We want people to be included in their local community.
- The funding to make all this happen could come from many different places. How can we sort this out?

What will help?

Everyone believing that people come first and sticking to it!

All the different services working together to make the best use of their money and skills.

Helping men and women with learning difficulties get more money. This can be done by helping more people get jobs and by giving good advice about benefits.

Commissioners and providers need to have a plan to get the new service going and then work closely together to find the best ways of using money for the benefit of people who use the service.

## Direct payments

Social services can now give money to disabled people to buy their own services and support. This money is called a 'direct payment'. Direct payments can give people more independence and choice about how to live their lives.

A few people with learning difficulties already get direct payments. Some people use the money to buy help they need to live in their own homes. Other people use it to help them get to work or go out in the evenings or weekends.

### It's your right:

- to ask for information about direct payments,
- to ask if you can have a direct payment,
- to get help to use your direct payment.

You can get more information about direct payments from 'Plain Facts'. Ask for a copy of Issue 10, June 1997. Write to: Plain Facts, Norah Fry Research Centre, 3 Priory Road, Bristol BS8 ITX. Tel: 0117 9238137.

A useful book about money is: It's My Money by Catherine Bewley, a book and tape for people with learning difficulties. £3.00. From: VIA Publications, Oxford House, Derbyshire Street, London E2 6HG. Tel: 0207 729 5436.

### Things to do:

- Find out how your service is making sure that everyone gets the benefits they should be getting.
- Collect stories of how benefits can be a problem to people who want to work and send them to your MP.
- Get copies of 'Plain Facts' Issue 10 and learn about getting direct payments.

## Chapter 17 Staff development

Training is a very important part of making changes in services.

Staff, service users and carers should all be included in training.

Training can:

- change the way people think about their organisation and their work,
- introduce new ideas,
- help people develop new skills,
- make it easier to change services.

There should be a training plan which says what training will be done and how it will be done.

### What training needs to be done?

It is important to find out what skills people will need for the new service. Ask people what they think their training needs are.

It is important to organise training which people need - not just about things they know already!

### Including service users and carers

It might be necessary to run training for service users or carers in the evenings or at weekends.

Send out letters to make sure that service users and carers know the training is available.

Service users and carers might find it helpful for trainers to visit them and explain what the training is and why it might be useful.

### Different ways of training

Conferences are good for getting everyone together and collecting people's ideas. But many people find it hard to speak up in a large group.

Training which runs over several days is good for helping people work as a team and for learning new skills.

Workshops are also good for helping people learn new skills. They are usually for one or two days.

### Was the training successful?

At the end of the training session, it is important to ask participants what they thought.

Good training can be a great help to staff, service users and carers and it does not have to cost a lot of money. But it does require support from all those who want to change services for the better.

#### Things to do:

- Make up your own training pack with training sessions that are important to you.
- Work out ways of involving people with complex needs in training.
- Invite someone from the staff training department to come and talk about their training plan. Ask them how people with learning difficulties are involved in staff training.
- Think about training you could do with staff. What training sessions could you lead?
- Learn how to do training by using a pack like 'Training for Change'. You can buy a copy of 'Training for Change' from: Publications Sales, NIACE, 21 De Montfort Street, Leicester LE1 7GE. Chapter 18

## Chapter 18 Transport

People's transport needs should be a part of their individual plan and also be set out in their community care assessment.

Every person with learning difficulties should have the opportunity to have good travel training.

Public transport must be designed to make it easier for people with learning difficulties.

The Hackney Plus Bus is a service which is something like an ordinary bus and something like a Dial-a-Ride service. All the information about the service is designed to make it easy to understand. Each bus stop along the route has a different symbol.

The symbols are printed on timetables and other information and are inside the bus itself on a display panel. As the bus goes along the route, the place name and the picture light up to show where the bus is and what the next stop will be.

### Using service transport differently

In other parts of the country, for example Devon, Kent and West Norfolk, health and social services, education and voluntary organisations are working together to make transport better. For example, they share the use of the different vehicles they own. The buses travel to different places and at different times according to what disabled people need.

### Buying your own transport

Many more people are now buying or leasing (hiring) their own vehicles - cars or vans - using mobility allowance and other personal savings. The vehicle may be used by one person or by two or three people in the same house, putting all their money together. At Ely Hospital a vehicle was bought for one ward using the money of the people living on that ward.

### Things to do

- Make a list of the kinds of transport you and your friends use - e.g. public buses and trains, taxi, mini bus, bicycle!
- Talk about what's good and not so good about the transport you use.
- Find out who has had the chance to learn to use public transport. Does everyone who wants to get this chance?

## Back Cover

Changing our Days is an easy-to-use handbook and CD to help men and women with learning difficulties have better day opportunities. It is about working with services, families and other supporters to help people to:

- get paid jobs,
- do courses at college and get certificates, make more friends,
- have more interesting things to do in their spare time,
- receive help when they need it - at home and at weekends and much more!

Changing our Days is easy to read and the words can also be listened to on the CD. It gives a lot of good ideas and ways of working to help people with learning difficulties become fully active citizens in their local communities.

Other King's Fund books which could be helpful:

Changing Days edited by Alison Wertheimer,

Days of Change edited by Barbara McIntosh & Andrea Whittaker,

Looking at Our Services: Service Evaluation by People with Learning Difficulties by Andrea Whittaker