MAKING CHANGE HAPPEN

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CHAPTER 1: INTRODUCTION.

A new law - the Health and Social Care Act 2001 - says we must give Parliament a report on learning disability once a year. This is the first report under the new law. It says what we have done to make things better for people with learning disabilities and their families. We said what we would do in *Valuing People: A New Strategy for Learning Disability for the 21st Century* (called *Valuing People* for the rest of this report) in March 2001.

This report says what has been done so far to make change happen. It gives our reply to the first Annual Report from the Learning Disability Task Force *Making Things Happen* published in January 2003. It says what work has been done so far on the “key tasks” (the really important things we said should happen) listed in the delivery plan and in each chapter of *Valuing People*.

We have tried to write this report in a very clear way so that learning disabled people and others can understand what it says. We have made a shorter version. We have also produced CD ROM and tape versions.

The report uses the words “we” and “our” a lot. When it says “we” or “our”, that means the Government.
TEN BIG THINGS THAT ARE BETTER SINCE VALUING PEOPLE CAME OUT.

- More families with severely disabled children are getting family support
- More advocacy groups are being helped, and local councils are spending more on advocacy
- More people with learning disabilities are getting direct payments
- The Helpline is being well used (nearly 6,000 people called it in 10 months - from December 2001-October 2002)
- All areas with people living in long stay hospitals are making plans to move them to something better
- The National Forum is making national government hear what people with learning disabilities think
- The Learning Disability Task Force is successfully co-chaired by someone with a learning disability
- The Learning and Skills Council is working with people with learning disabilities to look at what they need for the future
- More people with learning disabilities are getting jobs
- 3,000 people are registered on the Learning Disability Awards Framework, so more will get qualifications
CHAPTER 2: MAKING CHANGE HAPPEN
WHAT HAS BEEN DONE?

*Valuing People* set out our ideas and plans for making things better for people with learning disabilities and their families. These were based on four beliefs:

- Legal and civil rights;
- Being included;
- More choice;
- Independence.

The ideas and plans were for children, young people, adults and older people and covered everything about their lives. There were new objectives for services for people with learning disabilities.

People with learning disabilities and carers helped with the ideas and plans in *Valuing People*. We try to involve people with learning disabilities in everything we do because they are central to everything done to make *Valuing People* happen.

People with learning disabilities helped to interview people who wanted to work in the Valuing People Support Team. They are working with us in many other ways including:

- planning the big survey of people with learning disabilities;
- being part of the working group looking at how to help with job opportunities.
Valuing People set a big programme for change. To make change happen we have:

- Set up the National Forum of People with Learning Disabilities; it started work in June 2001;

- Sent out guidance in August 2001 on what local councils and health authorities needed to do to start making Valuing People happen. One of the main things was to set up Learning Disability Partnership Boards in each local council area. These were set up by October 2001;

- Found people to work in the Valuing People Support Team; the National Director started work in November 2001 and the whole team was together by February 2002; and

- Set up the Learning Disability Task Force; it had its first meeting in December 2001.
The National Forum of People with Learning Disabilities.

The National Forum provides the voice of people with learning disabilities at national level. It tells us what people with learning disabilities think about services, plans and changes. It has members from all over England. There are Regional Forums in each of the 9 areas in England and they elect people to go onto the National Forum.

Members control the National Forum. Brian White from Newcastle and Joan Scott from Norwich chair it. Members tell the Forum about concerns in their area. Other people come and talk to the Forum about these things and the Valuing People Support Team report to it regularly.

The Forum elected five members to go on the Task Force including the Task Force co-chair, Michelle Chinery. They report Forum concerns to the Task Force. The Forum is trying to make sure it represents groups such as people with higher support needs and people from minority ethnic communities. At present their voices are not being heard enough.

The Forum's website www.valuingpeople.org.uk has more information.
Learning Disability Partnership Boards.

Partnership Boards do important work to make change happen locally. The members come from local organisations (the council, the National Health Service, voluntary organisations, education, training, local employers etc), people with learning disabilities and carers. They draw together ideas and plans for making things better in their area.

In January 2002 we got plans from Partnership Boards showing what they would do over the next three years to make services better for people with learning disabilities and their families (these are the Learning Disability Joint Investment Plans). The plans included ideas for spending money from a Government fund of up to £42.6 million, set up to help people change how they do things.

This money is in the Learning Disability Development Fund - £22.6 million for things that need to be paid for every day and up to £20 million for buildings or equipment.
For the everyday things the money is for advocacy, person centred planning, supported living for people living with older carers, services for people moving out of long-stay hospitals, modernising day services, and helping to make people better leaders.

The money for buildings and equipment is for: helping people who have challenging behaviour; services for children and young people with complex needs; and supported living for people living with older carers.

We thought most plans were good, but a few needed more work. In March 2002 we told Partnership Boards how much of the new fund they could spend on the things that need to be paid for every day.

Partnership Boards have had the advice and guidance promised in Valuing People. We say more about this in other parts of this report.
The Valuing People Support Team and National Director.

We found a National Director (Rob Greig) to lead on making *Valuing People* happen with the Valuing People Support Team to work with him. There are 11 people in the Support Team and each covers a different part of the country. The whole team have lots of experience in making change happen in learning disability services either for local councils or the National Health Service or the independent sector. We are spending £2 million on the Support Team this year (April 2002-March 2003).

The National Director reports to Jacqui Smith, the Minister for Health, on how things are going. He leads the Support Team. He provides national leadership for *Valuing People*. He talks to Government Departments and national bodies like the Disability Rights Commission and Connexions, he makes speeches at conferences and other events, and he visits places around the country.

The Support Team works on making things better for adults with learning disabilities, but the National Director also keeps an eye on what is happening with services for children and young people with learning disabilities. He is helping with the work on the National Service Framework for Children.
The Support Team's main role is to help Partnership Boards make the changes proposed in *Valuing People* and provide a link to what is happening at national level. It gets Partnership Boards together to talk about things. It sends them things like advice and toolkits.

The Team cannot do everything it would like to do to help make things better for people with learning disabilities and their families. This year it did a lot on these things:

- Helping Partnership Boards understand what they should do;
- Getting person centred planning going;
- Working with self-advocacy groups.

Next year, to give the Team more time for some really important things, they are paying for 'Expert Advisers' to work with them for 12 months from April 2003. These people will work on advocacy (two people - one has a learning disability), families, ethnicity, housing, work and education.

The Support Team's web site [www.doh.gov.uk/vpst](http://www.doh.gov.uk/vpst) has more information.
The Learning Disability Task Force.

The Learning Disability Task Force has met regularly since its first meeting on 19 December 2001. It is there to:

- Check how things are going in making the ideas in *Valuing People* work;
- Find out what things are getting in the way.

It is trying to do 4 things for learning disability:

- Champion change nationwide;
- Show how people who use learning disability services are part of everything it does;
- Check that *Valuing People* happens everywhere;
- Report to us on how things are going and what it thinks we need to do.

The Task Force has joint chairs. One of the chairs has a learning disability. Its members include people working for local government, the National Health Service, voluntary organisations, universities and government departments. As well as the co-chair four other members have learning disabilities and there are two carers. The Learning Disability Task Force has sent us its first annual report *Making Things Happen*. We reply to it in Chapter 3.
The Implementation Support Fund.

This Fund of £2.3 million a year is paying for: advocacy grant schemes; the Learning Disability Helpline; the Task Force; the National and Regional Forums of People with Learning Difficulties; and the Learning Disability Awards Framework. We say more about these later in this report.

Information and Research:
We already collect some information about services for people with learning disabilities. This does not tell us everything we want to know. So we have a programme of work to get better information about people with learning disabilities.

Research:
We asked people who are experts in doing research to study different things about learning disability. This is the Department of Health Learning Disability Research Initiative called Services, Inclusion and Partnership. We are already paying for 10 studies and we say more about these later in this report.

We will soon start paying for two more studies - one looking at ways to measure the effect of Valuing People. The other will find out how people with learning disabilities use ordinary health services. We have set up a group to keep an eye on how the studies develop. People with learning disabilities are involved in this group. We will also look at how people with learning disabilities are involved in the studies. We are spending £2 million on this.
A Big Survey:
We have asked BMRB, Central England People First and Professor Eric Emerson, University of Lancaster to start work on the first ever survey of people with learning disabilities. This will ask people with learning disabilities what their lives are like, what they think about things and what they want for the future. The work began in May 2002. The first part involves testing how to find a wide range of people with learning disabilities, what questions to ask and how to ask them. We are due to get a report on this first part in May 2003.

Checking what is happening at local level

The Department of Health's Social Services Inspectorate checks what is happening locally by:

- Looking at what local councils with social services responsibilities are doing and writing reports on this;
- Getting information from local councils about what they are doing.

During 2001 the Inspectorate looked at what 9 local councils were doing for people with learning disabilities. Their report *Fulfilling Lives* (published February 2003) found great enthusiasm for *Valuing People* and good work in making people understand its beliefs and setting up Partnership Boards. It also said really big changes were needed in the quality of services to meet the objectives in *Valuing People*. 
Over the next 12 months the Social Services Inspectorate will look at learning disability services in between 10 and 12 local councils.

Each year local councils tell us what they have done to make services for adults with learning disabilities better and their plans for the future. We study all this information along with information about services for other groups such as older people when we are deciding how many stars to give each local authority. (The number of stars a council gets tells local people how well their council is doing to provide good quality services).

This year we got information from local councils on what they had done about the things they had said they would do in their Learning Disability Joint Investment Plans sent to us in January 2002.

Most councils are doing a lot of the things they said they would do to help people with learning disabilities have:
- More control over their lives;
- More choice over with where and how they live.
Most councils were doing some of the things they said they would do to make planning with young people with learning disabilities as they leave school better. Most were doing well in getting lots of new workers to register on the Learning Disability Awards Framework. Most say they are working hard to help Learning Disability Partnership Boards understand how they should work.

Some councils were finding it more difficult to meet the deadlines to:

- Help carers;
- Make it easier for people with learning disabilities to get the health care they need;
- Set up good arrangements for checking on the standards in health and social care services;
- Make plans about the number of people they need to work with people with learning disabilities and the training they should have.
CHAPTER 3: OUR REPLY TO THE LEARNING DISABILITY TASK FORCE ANNUAL REPORT MAKING THINGS HAPPEN.

We welcome the Task Force's first report and congratulate them on their excellent work. The Task Force really involves learning disabled people in everything it does. Its meetings are accessible and so is its report. This has been recognised internationally. The Task Force has also successfully involved carers in its work.

The Task Force has worked on many things in its first year and begun to get the people in Government who work on ideas for new ways of doing things to listen to them and to respond. We saw this happen with the agreement to increase advocacy budgets and the Lord Chancellor's Department agreeing to do accessible versions of the leaflets about Making Decisions.

We welcome the Task Force's ideas for what it should do next year. We want to hear their suggestions for changing things and we will try to reply positively to their ideas. We will continue to support the work of the Task Force.
We agree with the Task Force that:
- People across Government as a whole are not taking Valuing People seriously enough when they make new plans and changes to ways of doing things;
- Partnership Boards have had to do a lot of things very quickly. This has made it hard to work well with people with learning disabilities.

We will try to do something about both these things as we work to make Valuing People happen in the future. We think the Task Force itself can also do something. For example, it can make sure its own members from Government Departments know what to do when they are making plans and changes.

We are glad that the Task Force wants to build links with Partnership Boards next year. We think this will help Partnership Boards to understand how they can work well with people with learning disabilities.

Response to Chapter 10 of the Task Force Report: What we would like the Government to think about

Care Standards
The report says:

“We were pleased the Department of Health listened to us when they were working on the new rules about the difference between supported living and residential care. But we are still worried about how the rules will work in practice. The Care Standards Commission has agreed to keep in touch with us about that.”
The comments from the Task Force were very helpful and helped us get this guidance right. The guidance was sent out in August 2002 and the National Care Standards Commission are using it to help them in their work. We will check how this is working out and make sure the Task Force knows what is happening.

Making Decisions
The report says:

“The Lord Chancellor's Department is asking people what they think about when people with disabilities can make decisions and how they can be supported in a better way. But it is very important that any changes do not go against Valuing People. They must not take independence or rights away from people with learning disabilities.”

The Lord Chancellor's Department was concerned that people with learning disabilities could not say what they thought about the proposals in the paper *Helping people who have difficulty deciding for themselves*. They made an accessible version of this paper and an audio CD-Rom with help from the Task Force and the National Forum, so people with all levels of disability could say what they thought. They had a good response. They are looking at the responses and hope the final version of the leaflets will go out in the spring.
The Lord Chancellor’s Department wants to use this work to make sure everything it produces which concerns people with learning disabilities is accessible to them. Proposals that affect people with disabilities should not go against the *Valuing People* beliefs.

The Lord Chancellor’s Department is now working on ideas for a new law about people making decisions for other people. There is a “Consultative Forum on Mental Incapacity” with members from different organisations who represent people who sometimes have difficulty making decisions, including some learning disability organisations. The Lord Chancellor’s Department and the Department of Health are working together to make sure that people with learning disabilities know what is going on and can take part in meetings of the Consultative Forum. We are also seeing how to involve the Task Force.

**Funding:**
The report says:

> “*We believe Government should look into how much money is spent on services for people with learning disabilities and think about whether it is enough.*”

The Task Force says it found it hard to get clear information about how much is being spent locally on learning disability services. It is setting up a group to look more closely at funding and we are willing to join in this work.
We know about the money spent on learning disability up to last year. The amount of the social services budget across the whole of England spent on learning disability has been going up for a long time. In 1983 for every £100 spent on social services, £7 was for learning disability. By 1993, for every £100 spent, £10 was for learning disability. Last year, for every £100, the social services amount rose to £14. We are glad we will be able to have a closer look at this.

We have given local councils more money to spend on social services. Over the last 6 years, up to 2002/03, this money went up by over a fifth (over 20 per cent) - a rise of over 3 per cent above inflation each year. Over the next three years the money given to local councils will go up by around 6 per cent above inflation each year.

In the National Health Service the money is going up by an average 7.5 per cent a year in the next three years. Local councils, Primary Care Trusts and other National Health Service bodies have to decide how much of this extra money should be spent on learning disability services. We expect Partnership Boards to say what is needed locally, to help them make these decisions.

The Valuing People Support Team produced information last year and organised workshops about the money in the National Health Service and how to make sure it can help people with learning disabilities.
Valuing People said that between them the National Health Service and local councils spent £3 billion each year on learning disability but the quality of services was not the same across the country. It is important that Partnership Boards work out how to spend this money better. We hope the Task Force study will be able to look at examples of how some local councils and the National Health Service manage to spend their money well.

Minority ethnic communities:
The report says:
“The Government should make sure that it talks with people from minority ethnic communities with learning disabilities and their carers. Otherwise many will continue to be missed out by services and not gain from Valuing People.”

We support this fully. When we were working on the ideas for Valuing People we asked the University of Leeds to study the needs of people with learning disabilities from minority ethnic communities. Their report Learning Difficulties and Ethnicity shows what people from different minority ethnic communities said about their lives and the services they used. We have used this report to tell the statutory bodies (local councils and the National Health Service) involved in learning
disability that they must listen to the needs of people from minority ethnic communities. The new law - the Race Relations (Amendment) Act 2000 - says they must do this.

We support what the Task Force and the National Forum are doing to make sure they represent the views of minority ethnic communities. We look forward to seeing their ideas for what to do next. We will look at what they say the Government should do. All Government Departments are looking at how to make sure they think about the needs of minority ethnic communities when making plans and introducing new ideas.

**Long-stay hospitals:**
The report says:

“We fear that the 2004 target for closing all old long-stay hospitals will not be met.”

We are keeping a close eye on this. *Valuing People* said all people living in long-stay hospitals should have good plans and support to live in the community. This is the important thing, not just closing the hospitals, which could happen without people having better lives after they close.
We get regular reports about this from the National Director of the Valuing People Support Team. Lots of work has been done already to help people make plans for people with learning disabilities living in long-stay hospitals move to better places in the community. Every area with a long-stay hospital is now doing some planning - some weren't doing this before last year.

We are disappointed some places are saying they may still not be able to help everyone move out of long-stay hospitals to better places by April 2004, but we want them to go on trying. Rob Greig, the National Director, and the Valuing People Support Team are continuing to help people with their plans. The Learning Disability Development Fund can be used to help with this. Jacqui Smith, the Minister, is looking at how things are going. Rob Greig reports on this when he meets her.
CHAPTER 4: CHILDREN AND YOUNG PEOPLE.

*Valuing People* said that children and young people should have lots of help so they can do everything they want to. Young people's move to adult life should be smooth and help them into further education, training or work.

**What we promised would happen:**

*Valuing People* said we wanted disabled children and young people to have lots of opportunities to do the things they want to do. We have lots of programmes to make things better for all children and we are using these for the things proposed in *Valuing People*. We say here what has happened for each topic in Chapter 3 of *Valuing People*. Things are starting to get better for some disabled children and their families, but we need to do more, particularly to help them as they move into adult life.

**Quality Protects:**

We said that in 2001/02 and 2002/03 local councils should spend £15 million from the money in this programme on disabled children. Plans by local councils (these are called Management Actions Plans) show this money paid for more family support services such as short breaks. It is helping different organisations work together better, so services are better organised. The money will double to £30 million in 2003/04.
**Family Support:**
Since April 2001 Local Education Authorities have to provide parent partnership services for families of children with special needs. In that year (2001/02) they could spend £18 million from the Standards Fund to help set up these services. The new Special Educational Needs Code of Practice says what parents and families could expect from a parent partnership service.

15,800 more families with severely disabled children had more family support in 2001/02. Local National Health Service bodies and local councils worked together to combine services for these families.

The money in the Carer’s Grant goes up each year; so more parents are getting short breaks. In 2001/02 we spent £15 million helping over 52,000 carers get this help. We have already said the Grant will go up each year until at least 2006.

The Carers and Disabled Children Act 2000 started in April 2001. Carers and disabled young people aged 16 or 17 can now get direct payments. By September 2001, 66 carers and 8 young people were getting direct payments. By January 2002, over 50 local councils said they were giving some families direct payments. They expected this number to go up during 2002 and 2003.
Contact a Family opened the new national information centre with a free national telephone helpline in June 2001. Lots of people have called the helpline - nearly 9,000 by the end of March 2002. By the end of 2004 the number will have gone up to 21,000 a year.

We are giving more money to the Family Fund Trust, which provides grants to help families with severely disabled children. In 2001/02 we gave £26.4 million and the Trust gave grants to over 45,000 families. The Trust has £28.4 million this year (2002/03). It will go up to £31.4 million in 2003/04.

**Play, Leisure, Culture and Sport:**
The Management Action Plans show that the money for disabled children in the Quality Protects programme is helping more of them use ordinary sport, cultural and leisure services. There are more services around, so they have more things to choose from.

**Education:**
We are spending £220 million over three years from 2001 to 2004 on making schools accessible to disabled children. We spent £50 million in the first year (2001/02) and £70 million this year (2002/03). From September 2002, schools and Local Education Authorities have to have a plan showing how they propose to make it easier for disabled pupils to go to ordinary schools.

**Residential Places:**
A working group is finding out more about disabled children living away from home in residential schools or children's homes. We have already had one report with suggestions about how to make these places better. They are carrying on with this work in 2003. This will include a seminar to ask different organisations and people with a special interest what they think should be done to make services better.

**Early Years:**
In May 2002 we asked people what they thought about draft guidance on how to find out about the special needs of children aged under 2. We had lots of comments. Final guidance is due to go out in March 2003.

**Cross Government Programmes:**
We said £4 million from the National Childcare Strategy should go on children with disabilities and special educational needs, so people providing services could have more staff to support disabled children. We are looking to see what more should be done for
childcare services used by disabled children. Disabled children are one of the important groups for Sure Start and the Children's Fund. We sent guidance to Sure Start Partnerships about services for disabled children and their families in 2002.

**Financial Support:**
Since April 2001 families with disabled children can get higher benefits. The extra money for a disabled child in benefits that take account of parents' other money has gone up by twice the rate of inflation. It will go up by a further £5 above inflation in April 2003. Parents with disabled children aged 3 or 4 can now get the mobility allowance as part of the Disability Living Allowance. This gives extra money to families who meet the conditions for this benefit.

**Health Services:**
As part of the work on the National Service Framework for Children a working group led by Contact a Family has been looking at the quality and range of things that disabled children and young people should get when they use health and social care services. Families and disabled children and young people have been asked to tell the working group what they think needs to be changed. The Framework will be published by the end of 2003.
We said an extra £48 million from the New Opportunities Fund should be spent in 2001/02 to help children with severe disabilities who need special help with daily living - this is called palliative care. This money made these services better. The Management Action Plans show that in 2001/02 more councils were working closely with the National Health Service to help children with complex health needs. Some of the money for buildings and equipment in the Learning Disability Development Fund in 2002 is being spent on things to help these children.

Connexions:
Disabled young people are one of the important groups for the new Connexions service. We sent guidance to Partnership Boards about the new service and to Connexions Partnerships about supporting young people with learning disabilities. We will send advice on how Connexions Partnerships and learning disability services can work together. The national Connexions Unit is checking what is happening locally. The Valuing People Support Team is working closely with Connexions. The new Special Educational Needs Code of Practice has advice on making plans for disabled young people about to leave school.
Person Centred Planning:
Young people are one of the important groups for Partnership Boards as they draw up plans for a person centred approach to providing services. We say more about this in the next chapter.

What else has happened?

Mencap has a grant to study support services for children with learning disabilities from Asian families in Bradford.

The Council for Disabled Children has a grant to help local councils setting up direct payment schemes for families of disabled children.

The Institute of Applied Health and Social Policy has had a grant for work with Connexions Partnerships on providing support for disabled young people.

Information from local councils shows that by late 2001 social services departments were supporting 29,700 disabled children - 2 per cent more than the year before.
Stories

In Windsor and Maidenhead last year, the team dealing with children with special needs in the local council and the people working in the Child Development Centre at St Marks Hospital became one team. They provide a “one-stop shop” service for disabled children and their parents and carers.

In Gateshead the local council has set up a 'Leisure Link' service, working closely with the Out of School Network to make it easier for children with severe and complex disabilities to go to ordinary out of school and leisure clubs.
CHAPTER 5: CONTROL OVER YOUR OWN LIFE.

Valuing People said that people with learning disabilities should have more control over their own lives.

We are starting to see more advocacy services, more people with direct payments, more interest in using a person centred approach to providing services. We need to do more to give people with higher support needs more control over their lives.

What we promised would happen:

**Action:** Funding for citizen advocacy network and self-advocacy work comes on stream

**Target Date:** Spring 2001

In summer 2001 the British Institute of Learning Disabilities and Values into Action agreed to run schemes to give grants to local advocacy groups and help them develop. They had between them £1.19 million in 2001/02 and £1.44 million in 2002/03 to run the grants scheme. Over 150 local advocacy groups have been given grants. Nearly 250 more people have volunteered to become citizen advocates. Next year (2003/04) there will be £1.44 million for the grants scheme.

This year (2002/03) local councils are spending about a third more on advocacy than the year before (2001/02). Some councils spend a lot more than other councils.
Action: National Forum for People with Learning Difficulties set up

Target Date: Summer 2001

The National Forum first met in summer 2001 and is getting better and better. It meets regularly. There are 9 regional forums that elect its members.

Action: Good practice advice on involving people with learning disabilities in decision making

Target Date: Autumn 2001

We sent this advice out in October 2001

Action: Good practice advice on person centred planning

Target Date: Autumn 2001

We sent this advice out in December 2001
By September 2002, 736 people with learning disabilities were getting direct payments - an increase of 100% since September 2001. Some councils are not giving anyone with learning disabilities a direct payment.

The new law - the Health and Social Care Act 2001 - has allowed the Department of Health to produce new regulations which will begin on 1 April 2003. Someone who asks for a direct payment and meets the conditions for getting one must be given one.

In August 2002 we asked people to tell us what they thought about a draft of the guidance about these changes. We also sent out accessible information about the changes. We will send final guidance in April 2003. The Valuing People Support Team is paying Swindon People First to send out a free video on how to use direct payments. We plan to provide a guide in the near future for people working for local councils, to help them understand how to make it easier for people with learning disabilities to get direct payments.
Most councils now have plans about introducing a person centred approach to providing services. Nearly half are now using this to plan services with people with learning disabilities and their families. The Valuing People Support Team worked with Partnership Boards who were finding it difficult to make a plan. The Valuing People Support Team has run training events so in each Partnership Board area there will be someone who has done training on using a person centred approach.

What has happened with other things we promised?

**Disability Rights Commission:**
The Commission has a learning disability action group. It is looking at making things more accessible for people with learning disabilities, publicising their rights and using its Practice Forum to tell people about good practice.
People with preserved rights, local councils and direct payments:  
The law - the Health and Social Care Act 2001- says local councils should assess the needs of people in the group.

Community equipment services:  
The new guide on these services working together says that really meeting the needs of people with learning disabilities helps them become independent.

What else has happened?  
The British Institute of Learning Disabilities is getting money to look at new kinds of advocacy.

Central England People First are getting money to look at good practice in self-advocacy.

Two of the research studies are working in this area:

- Values into Action is studying the effect of the Human Rights Act 1998 on people with learning disabilities.
- The University of Lancaster is looking at what happens when local councils use a person centred approach to planning services.
Stories

Around Wigan people running supported living wanted a better way to tell people with learning disabilities about direct payments. They put together a presentation called *Who wants a direct payment*. It is based on the Chris Tarrant show and gives information in a fun way. They are putting on a roadshow using the game.

In Lincolnshire people with learning disabilities stopped going to Partnership Board meetings because they found them boring and inaccessible. The Board took this criticism seriously and had a close look at how they did things. They are now working in lots of different ways. People with learning disabilities now go to the meetings and find people listen to them and take notice of what they say.
SUPPORTING CARERS.

Valuing People said that carers should get more support and be able to look after their families including their learning disabled son or daughter properly.

More carers are getting short breaks and they are using the new helpline. Making plans to meet the needs of carers needs to be better.

What we promised would happen:

Action: Begin work with Mencap to set up National Information Centre

Target Date: Spring 2001

The Department of Health and Mencap are paying for the Learning Disability Helpline. It opened in December 2001. Between then and October 2002 nearly 6,000 people used it - over a quarter (27 per cent) were carers, a fifth (21 per cent) 'unknown', a quarter either professionals (15 per cent) or students (10 per cent) and a few (2 per cent) people with learning disabilities.
What has happened with the other things we promised?

**General carer initiatives:**
We introduced the Carers Grant in 1999 to help local councils give carers more support by paying for more short breaks. Most carers say short breaks help them care for their relative with learning disabilities and keep well and fit themselves. During the first three years (up to 2001/02) we provided an extra £140 million for short breaks. This year (2002/03) it is worth £85 million. It will be going on until at least 2005/06 and will go up each year. It will more than double to £185 million. This money has given lots of carers short breaks, including carers of people with learning disabilities.

Information from local councils shows the number of people with learning disabilities getting short breaks was about 1 in 5 of the people known to be getting services last year (2001/02) and the same this year (2002/03).

**The Carers and Disabled Children Act 2000:**
This new law started in April 2001. Each carer now has the right to ask local councils to make a plan about his or her needs. More work is needed to find out about good practice in making a plan.
**Exclusions from services:**
The August 2001 guidance on making *Valuing People* happen said Partnership Boards should look into this.

**Older carers and those from minority ethnic communities:**
The Social Services Inspectorate found some councils were trying to make things better for carers from minority ethnic communities, when they looked at learning disability services in 9 local councils. Information from local councils shows more older carers (those aged over 65) now have a plan. Last year (2001/02) just over 40 per cent had a plan. This year (2002/03) it has gone up to 50 per cent.

**Carers and carers organisations on the Learning Disability Task Force:**
Two carers are on the Task Force along with people from Mencap and Rescare. The Task Force is doing some work on carers with the *Valuing People* Support Team and the people working on ideas for ways of doing things in the Department of Health. The Support Team will lead on to a new carers programme in the spring.
What else has happened?

The Foundation for People with Learning Disabilities has a grant for its Older Family Carers Initiative. It also has money for its Valuing Families: A Training Pack. The pack is to help carers train people working in learning disability services.

The North West Training and Development Team has money to produce training to help carers get involved in local planning and policy making.

Stories

In the West Midlands there is a regional network for carers who are members of Partnership Boards. It wrote a guide 10 Top Tips for Partnership Boards.

In Warwickshire carers are active members of the Partnership Board. Someone is paid to help carers prepare and take part in the meetings. There is a carers forum and a regular newsletter.
CHAPTER 7: GOOD HEALTH.

*Valuing People* said that health care for people with learning disabilities should be provided on the basis of their individual needs.

We have sent advice on Health Action Plans. We need to find ways to see whether the health of people with learning disabilities is getting better.

**What we promised would happen:**
This is what has been done to make things happen by target dates in 2003 and 2005.

<table>
<thead>
<tr>
<th>Action:</th>
<th>Target Date:</th>
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</thead>
<tbody>
<tr>
<td>Partnership Boards to agree framework for Health Action Plans</td>
<td>Summer 2003</td>
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</table>

We sent Partnership Boards good practice advice in July 2002. The Valuing People Support Team put on events to talk about this.

<table>
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<tr>
<th>Action:</th>
<th>Target Date:</th>
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<tbody>
<tr>
<td>Health facilitators to be found (they help people with learning disabilities use the National Health Service)</td>
<td>Summer 2003</td>
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</table>

The good practice advice said something about this.
What has happened with other things we promised?

**Confidential inquiry into deaths among people with learning disabilities:**
The Department of Health has worked with the National Institute for Clinical Excellence to see whether this is possible. We will be able to decide about this soon.

**Stopping discrimination against people with learning disabilities from minority ethnic communities:**
We paid for *Speaking up for Myself* in the Books Beyond Words series. This is about how difficult it is for a person with learning disability from a minority ethnic community to get a good service. The advice on Health Action Plans has a section about people with learning disabilities from minority ethnic communities. The Valuing People Support
Team is working on a toolkit for Partnership Boards so they know how to make sure people with learning disabilities from minority ethnic communities get services that meet their particular needs.

**Registration with a GP by June 2004:**
We are talking to the people working on the Primary Care Information System (PRIMIS) about whether this could help doctors find out whether people with learning disabilities are registered with them.

**Ordinary hospital services to be accessible to people with learning disabilities:**
The Valuing People Support Team wrote *All Means All* for Primary Care Trusts and the new Strategic Health Authorities. This helps them understand about including people with learning disabilities in their plans for making the National Health Service better over the next three years. *All Means All* describes the evidence for the poor state of health of people with learning disabilities compared to the rest of the population.

The National Patient Safety Agency wants to understand more about the safety of people with learning disabilities using health care. They will be talking to people with learning disabilities, carers, health professionals and academics to look at ways of improving the safety of services in the future.
Local specialist services:
Most of the money for buildings and equipment in the Learning Disability Development Fund was spent on local specialist services for people with severe challenging behaviour.

The National Service Framework for Mental Health and people with learning disabilities:
The Institute of Applied Health and Social Policy has money for a project to make training materials on including people with learning disabilities in mental health services. This year we asked teams making the National Service Framework happen (the Local Implementation Teams) to check how they are making sure people with learning disabilities get the mental health services they need.

New role for specialist learning disability services:
People working in specialist learning disability services are looking at their future role. We will be sending advice on the role of specialist learning disability services later this year.
What else has happened?

One of the research studies will study how people with learning disabilities use ordinary health services.

The Institute of Applied Health and Social Policy has money finishing in March 2003 for a project on the general health of people with learning disabilities. It set up a network for Primary Care Groups and Primary Care Trusts to get them involved in learning disability. It has made training materials and accessible information about going to the doctor or hospital. The Valuing People Support Team is helping the Institute to tell local organisations about this project.

The British Institute of Learning Disabilities had a grant for a booklet on older people with learning disabilities staying healthy. It will be published later this year as part of the *Your Good Health* series.

Books Beyond Words will be getting a grant to do a book on heart disease.
Stories
In Barnet, people working in the National Health Service on keeping everyone healthy, people with learning disabilities and people working in learning disability services got together to produce some accessible information about cancer screening for women with learning disabilities. This was so good that other women - people who could not read very well and people whose first language was not English - liked using it as well.

In Manchester they now include learning disability in their ideas for making the Cancer Plan happen. People working in learning disability are working closely with the person who is the PALS (Patient Advocacy and Liaison Service) officer in the South Manchester University Hospital Trust. They always include learning disability when they are talking about anything to do with the National Health Service.
CHAPTER 8: CHOOSING WHERE AND HOW YOU LIVE.

Valuing People said that people with learning disabilities and their families should have more choice and control over where and how they live.

Local organisations now have guidance on housing, care and support options to help them produce a plan. It is possible that not everyone living in a long-stay hospital will move out by April 2004.

What we promised would happen:

<table>
<thead>
<tr>
<th>Action:</th>
<th>Target Date:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Issue new guidance on housing care and support options</td>
<td>Summer 2001</td>
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Lots of learning disability and housing organisations helped us write the guidance. It took much longer to do because we decided Partnership Boards needed advice and support for their work on housing strategies. We put the guidance on our website in July 2002 and Partnership Boards have been using it. We also asked people what they thought about it. We got lots of comments and will publish the final version soon.

Supporting People is our big programme to help vulnerable people live independently. Local plans being made for this programme will give people with learning disabilities the support they need to live independently in a wider range of housing.
What has happened with the other things we promised?

Local housing strategies for people with learning disabilities:
By February 2003 Partnership Boards have to have plans about housing for people with learning disabilities. The new guidance is helping Partnership Boards work with housing departments and social services on their plans. Information from local councils shows that most councils (60 per cent) were meeting most or all the deadlines in their Learning Disability Joint Investment Plans. The Valuing People Support Team organised events across the country for local people to talk about working on these plans.

Action: Plans for closing remaining long-stay hospitals agreed
Target Date: Spring 2002

There are 21 long-stay hospitals with 1,000 people living in them. Every area with a long-stay hospital is now doing some planning. Some areas have not yet agreed plans but the Valuing People Support Team is working with the local organisations to help them do this. Some areas may not be able to help everyone move out of long-stay hospitals to somewhere better by April 2004. The National Director and the Valuing People Support Team will continue to help people with their plans.
Supported living for people living with older carers: 
The money in the Learning Disability Development Fund can be used for 
supported living for people living with older carers. We told organisations it was 
important to look at this in the guidance on making Valuing People happen sent out in 
August 2001.

What else has happened?
The Learning Disability Task Force sub-group on housing is keeping an eye on what is 
happening with the housing objectives in Valuing People. People working for important 
housing organisations are on the sub-group. Its programme for next year includes keeping 
an eye on what is happening as people leave long-stay hospitals.

Housing Options has a grant for its Housing Options Advisory Service project. This will 
provide regional advisers to help people with learning disabilities choose where and how 
they want to live, provide training, support and information for local groups, families or 
professionals.

KeyRing has a grant for its Neighbour Networks project. This will offer an 
opportunity for up to 18 people with learning disabilities to live in ordinary homes with help 
from the community.
West Sussex had traditional ways of providing housing and support for people with learning disabilities. The Partnership Board decided to change this. They got together social services, housing departments and other important organisations and people interested in housing to make a plan for housing for people with learning disabilities. There is now a plan for supported living that will give more choice for around 300 people with learning disabilities.
CHAPTER 9: LIVING A FULL LIFE.

Valuing People said that people should be able to lead full lives in their community with friends, relationships and things to do.

Some things are beginning to help people with learning disabilities go to college and use buses and trains. There is still a lot to do before people with learning disabilities really lead full lives but more people are starting to have good things to tell about how their lives are getting better.

What we promised would happen:

**Action:**
Day service modernisation programme agreed

**Target Date:**
Winter 2002/2003

The Valuing People Support Team sent Partnership Boards a toolkit to help them make plans for modernising day services. The first part went out in November 2002, the second will come soon. The Support Team will put on events in each region to help Partnership Boards. Some local councils are using the Learning Disability Development Fund to help them bring their day services up to date. Some are using the Private Finance initiative (where councils and private companies share the costs) to do this.
What has happened with the other things we promised?

**Further Education:**
The Learning and Skills Council wants people with learning disabilities to have the same opportunities as everyone else to go on with their education. Currently, the Council pays for around 2,500 learners with learning difficulties and/or disabilities to go to 68 specialist colleges. Not everyone with a learning disability wants to go to specialist colleges. Lots of learners go to further education colleges near where they live. There is some money called Additional Learning Support that pays for extra support for learners who go to further education colleges. The new law - the Learning and Skills Act 2000 - says the Council must consider the needs of people with learning difficulties and make sure there are suitable facilities for their education or training.

The Disability Discrimination Act now covers all education. This will make sure people providing education services know how to help people with disabilities get education.

The body that reports on how well colleges and others who are providing education and training are doing - Office for Standards in Education (OFSTED) - must say what is being done for people with learning difficulties or disabilities in its reports on places providing further education and training and Connexions services.
The Learning and Skills Council is working on describing what is provided at the moment for learners with learning difficulties and/or disabilities. This will help it plan for the future. It will involve local Learning and Skills Councils. The Council has set up a Forum on learners with difficulties and/or disabilities to look at this group’s specific needs. People from different organisations working with and for learners with learning difficulties and/or disabilities come to the meetings. Learners with disabilities are going to join the Forum.

**Transport:**
The Department for Transport has been asking people what they think about changing the law so that people who work for transport companies (like bus or taxi or train drivers) cannot refuse to help a disabled person. We hope we can change the law by next year to make this happen.

We already have laws that mean disabled people can use new buses and trains. On new trains there have to be spoken and written announcements to tell everyone what the next stop will be. We have been testing this equipment on buses and we hope that many buses will soon also be making announcements.
We are working with the people who run transport to help them train all their staff to understand what disabled people need. There is now a video and an information pack, which most bus companies use to train drivers. The video includes people with learning disabilities talking about their problems using public transport.

Local councils get money to spend on making transport better. They have to tell us how they are going to spend the money before we decide how much to give them. One of the things they have to tell us about is what they will do to make transport easier for disabled people. We will soon look at whether they have done what they said they would do. We have a committee of disabled people to tell us what people need and how to make things better. One person on the committee has a learning disability. This helps us do our work.

Leisure services:
We asked local councils to make sure everyone in their areas can use leisure services. When local councils ask people what they think about new leisure plans we want them to pay special attention to people or groups who are difficult to contact. This would include people with learning disabilities.
Parents with learning disabilities:
3 projects are doing things to help parents with a learning disability. The Joseph Rowntree Foundation has a project to support disabled people in their parenting role and share good ways of working. Respond has a grant for a project about assessing the risk of abuse to the children of parents with learning disabilities. Circles Network has a grant for their Supported Parenting project. This offers support and development in self advocacy to couples where one or both have learning disabilities.

Staff working on social security benefits:
People in the Department for Work and Pensions have made some training materials about making people really understand about disability and what it means for people with disabilities. These materials are to help people when they are working with people with disabilities who are asking about social security benefits for people with disabilities.

The people in the Department are organising training courses using these materials. The bits in the training materials about learning disability repeat the important messages in Valuing People. They have also made some training materials about mental health. By the end of 2003 all the people in the Department who make decisions about social security benefits for people with disabilities
will have done training using these materials. When new people start working on making decisions about benefits they will always have training in understanding about disability.

**What else has happened**

We are giving a grant to the Association for Residential Care for their *My Money Matters* project.

**Stories**

In North Lincolnshire, the Partnership Board saw transport was important for people with learning disabilities. They are looking at the specialist transport system and working with transport planners, providers and others to find the best ways to meet people's transport needs. They are linking this work with the Local Strategic Partnership in North Lincolnshire. It had found transport was important for the whole community.
Leicester Road Day Service in Melton Mowbray was set up as an old-fashioned day service for people with learning disabilities. In the last few years there have been big changes to give people more choice about what they do in the day. 90 people use the day service. They used to spend most of their time there.

Now, 60 people spend all their time doing different things out in the community. They go straight from home to their activity without stopping off at the Day Centre. 20 people have some things they do out in the community and some at the Centre. 10 people are in the Day Centre all day.

The things they do in the community include going to college, using leisure services, and social interests. Everyone at Leicester Road Day Service is working to give people more choice about what they do during the day. By 2005 all the things people do will be out in the community.
CHAPTER 10: WORK.
Valuing People said that more people with learning disabilities should have the chance to work.

The number of people working is going up, but it is still small. We are beginning to get more information about things that help and things that make this difficult. We need to do more about jobs in the public services.

What we promised would happen:

Action:
Ask an organisation to study the relationship between day services and work

Target Date:
Summer 2001

The study From Day Centres Onwards is being done by the Learning Disability Employment Research Partnership. It started in May 2002 and it will give us a report in autumn 2003. It will help us find out what stops people with learning disabilities getting jobs and what helps them do this.
10

Action: Set up working group on employment

Target Date:
Summer 2001

The working group held its first meeting in June 2002. Its members include people with learning disabilities, employers, local councils, voluntary organisations and researchers. People running supported employment agencies gave talks about things that help and things that make it difficult for people with learning disabilities get jobs. People from Connexions and the Learning and Skills Council gave talks about their work. We had a talk about the *Pathways to Work* Green Paper (about changes to incapacity benefits) and decided to send an accessible version of the paper to people with learning disabilities so they could say what they think.

What has happened with the other things we promised

*Increasing numbers in work:*
Two years ago (2000/01), information from local councils showed that 10 in every 100 people with learning disabilities known to social services departments had jobs. Last year (2001/02) and this year (2002/03) it was about 11 in every 100 people with learning disabilities known to social services departments.
**WORKSTEP:**
This provides support for around 21,500 people with more complex problems to find and keep a job. Nearly half (40 per cent) have a learning disability. We have given WORKSTEP an extra £37.2 million over the 3 years (April 2001- April 2004) to modernise the way it works. This includes around £10 million for up to 2,000 more WORKSTEP places. These places became available from April 2002.

**New Deal Job Brokers:**
Job Brokers help people with health problems or disabilities find and keep work. People do not have to join the New Deal for Disabled People. Job Brokers help people with applying for jobs, preparing for interviews and supporting them when they have found work. They also work with people providing training and other things if more help is needed.

Between July 2001 and November 2002 over 33,000 registered with a Job Broker. Nearly 8,000 people found jobs.

**Disability Living Allowance:**
In November 2001 the Department for Work and Pensions sent out new guidance to people making decisions about Disability Living Allowance. This was to make sure disabled people do not lose this allowance unfairly when they start work.
**Partnership Board Employment Strategies:**
By February 2003 Partnership Boards should have made plans for helping people with learning disabilities get jobs. In June 2002 the Valuing People Support Team sent advice on how to draw up these plans. It put on events in each region for Partnership Boards to talk about this work.

**Employment Opportunities in Public Services:**
We need to do more work on this. Some people with learning disabilities work in the civil service or for local councils or in the National Health Service, but we do not know how many. We will look into this during 2003. That will include finding ways to make sure that people whose job is to find people to work in the public services, understand about learning disability.

**What else has happened?**
One of the research projects is a study by the University of Durham to find out about the sort of people who give people with learning disabilities support with work. It will look at their skills and what they know about social inclusion.
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What else has happened?
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Local councils have the chance to make local targets (known as “Local Public Service Agreements”) that reflect the specific needs of their area. They can ask for more money to tackle things we agree are particularly important. One of these is making better opportunities for work for disadvantaged groups. In Milton Keynes they are testing this and they have set big targets to help people with learning disabilities get work.

Remploy recently asked employers to double the number of disabled people they employ. This campaign will run during 2003 - the European Year of Disabled People. Already several household names - Asda, Comet, the Co-op, Marks and Spencer, Morrisons, Sainsbury, Safeway and Tesco - have backed this campaign.

Since April 2002 the rules about work for people getting certain benefits have been better. The new rules are part of our programme to make it easier for people with long-term health problems or disabilities to get a job, if they want to. Under the new rules the work no longer has to be agreed first by the person’s doctor. The new rules continue to allow the person to earn some money and not lose the benefit.
Stories

In Milton Keynes, Poole and Hartlepool the whole council wants more disabled people to be in work and is working with other organisations to make this happen. Many more people with learning disabilities have jobs in these areas and many others see getting a job as a real option. They are also making good plans to modernise their day services.

United Response has a grant for its Health and Social Inclusion project. They work with premier league, First and Second Division Football Clubs around England and encourage people with learning disabilities to live and work in mainstream society.
CHAPTER 11 QUALITY.

Valuing People said that organisations should make sure services for people with learning disabilities are good quality and worth the money spent on them.

We have worked on standards in residential care homes and adult placement schemes and sent out guidance on physical interventions. We need to do more to make sure people with higher support needs get good quality services.

What we promised would happen:

Action: Put out guidance on physical interventions

Target Date: Spring 2001

We sent out joint guidance in July 2002. It took longer to write the guidance because we decided it should cover schools as well as places where adults live. We have held 4 conferences to tell people about it.

The British Institute of Learning Disabilities had money for 3 years ending in March 2003 to work on good practice in physical interventions. It will be making a package of tools to help people providing services make the way they use physical interventions better.
What has happened with other things we promised?

Minimum standards in residential care:
People told us what they thought about changes to the minimum standards. We studied what they said and sent out revised standards in February 2003. We are asking people what they think about new regulations and standards for adult placement schemes.

Social Care Institute of Excellence:
The Institute is starting work on a database on learning disability for professional people and others working with people with learning disabilities. It is using the model made by the National Electronic Library.
Guidance on user surveys:
This is on the Department of Health's website www.doh.gov.uk/public/statret.htm and www.doh.gov.uk/pssuser2002-03/

Data on incidents of abuse:
Local councils put together information about adults being abused that is reported to them. We do not have any national information. We are looking to see whether we can use our system for checking how local councils are doing in providing services for people in their area to find out more about what is going on.

Giving evidence in court:
We have nearly finished our work to help vulnerable or intimidated witnesses give evidence in court. We made some changes to court procedures in spring 2002 including ways of supporting witnesses. We sent guidelines to the police on working with vulnerable or intimidated witnesses in summer 2002. In the spring we will be setting up arrangements for intermediaries to help vulnerable or intimidated witnesses give evidence.

What else has happened?
Two of the research projects are about abuse. The University of Kent is studying: men with learning disabilities at risk of sexual offending; and symptoms of abuse in people with severe learning disabilities.
Some local councils have tried to make the way they help carers from minority ethnic communities better. Some have tried to ask people with learning disabilities in minority ethnic communities themselves what services they wanted. We have not been able to find out much about how many people with learning disabilities from minority ethnic communities are getting services and whether more people are getting help.

We want people with higher support needs to have better lives. We are doing some things to help make this happen.

The advice on person centred planning and on Health Action Plans will help.

The National Service Framework for long-term conditions will help people with learning disabilities who have epilepsy.

The Medical Research Council has extra money (£2.5 million) for studying autism.

The Association Residential Care (ARC) has money for its *Challenged by Complexity* project on good practice in working with people with higher support needs.

The National Autistic Society has a grant for doing things about working with people with higher support needs.

The Valuing People Support Team will do some work with Partnership Boards next year about meeting the needs of people with higher support needs. The Learning Disability
Task Force has set up a sub-group to look at the needs of people with higher support needs.

The British Institute of Learning Disabilities, Choice Support and the Institute for Applied Health and Social Policy are receiving grants to work on quality issues.

**Stories**

Imran is a young man who was about to leave school. He is from a south Asian community. He only uses a few words, and he has a wheelchair.

He and the people close to him worked together to make an 'Essential Lifestyle Plan'. The Plan was separate from the assessments that he had from services, but it did help make the assessments better.

Communication was the key. People who knew him really well used different ways of listening to him and hearing what was important to him. This included using a 'communication dictionary'.

The first changes made things better at school, by changing what he did and what he ate. He got a new wheelchair, as they found out that his old one had been hurting him. His school and his family began to get on much better.
As the planning carried on, it began to say what he wanted as an adult. This meant that the people around him could find out what he really wanted, instead of just fitting him into services that were already there. It was not easy, and it was more difficult for him because of the extra barriers he faced as someone from a minority ethnic community.

For example, his Essential Lifestyle Plan said it was really important that he had other men to help with his personal care. At first the Day Service could not promise him this, so he could not go there. The planning group did not give up. In the end the Day Service found men in another service who could come in to work with him. They got to know him and now he always has the right support.

Today lots of things in Imran's plan are happening. He loves to go swimming and he is part of community groups near where he lives. The planning group are looking at getting him a job, and getting a mortgage for his own home.

Three years ago Imran’s family and the people working with him did not think he would ever do these things. Imran’s mum now helps services get better for other people from her community. She says:

"Planning has changed our lives. My son receives a service that guarantees meeting his personal and spiritual needs in the way which is important to him. We now have hopes and aspirations for his future..."
CHAPTER 12: TRAINING AND PLANNING FOR WORKERS.

*Valuing People* said that people working in the National Health Service and social care should have the right skills for the job. People working in other places used by people with learning disabilities should know how to work with them.

The Learning Disability Awards Framework is working well, though we need to find ways to check that people working in the independent sector register for the awards. Some Partnership Boards are finding it difficult to make plans about the number of people needed to work in learning disability and the training they should have.

**What we promised would happen:**

<table>
<thead>
<tr>
<th>Action: Registration on the Learning Disability Awards Framework</th>
<th>Target Date:</th>
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<tbody>
<tr>
<td>Spring 2001</td>
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The new Framework was launched in spring 2001. Around 3,000 people have registered for the awards. Information from local councils shows that some councils need to do more to make sure they get to the target in *Valuing People* of having half the people working in learning disability with a qualification by 2005.

Some councils are doing really well, but some have a lot more to do.
What has happened the other things we promised?

**Health and Social Care Workforce Strategies:**
We are working with people planning the health and social care workforces to make sure these plans include services for people with learning disabilities.

**Leadership Initiatives:**
The Valuing People Support Team and the Leadership Centre are working together on a programme to help people working in organisations become better leaders. There are also things to help carers, people with learning disabilities, 'champions' on Partnership Boards and nurses become better leaders.

**Local Workforce Planning and Training Plans:**
Partnership Boards have started to draw up plans. Nearly half (43 per cent) will meet all or most deadlines in their Learning Disability Joint Investment Plans. A few (7 per cent) will find it difficult to meet quite a lot of deadlines. We gave Partnership Boards a framework with the topics that should be in a plan. The Valuing People Support Team organised events to help people use the framework.
What else has happened?

One of the research projects is a study by the University of Lancaster into the things that people working with people with learning disabilities in residential settings must be able to do as a minimum.

The Association for Residential Care has grants for two projects: one to look at ways of getting and keeping staff and the other at training for people working in adult placement schemes.

Stories

What people have said about the Learning Disability Awards Framework:

'It was our idea to make a book--- Everyone gets one in their induction pack ---. We do training too. We do a play about a nice support worker and a bad support worker. Then we ask people 'Which would YOU like?--- I quite like the idea of us training support workers. We don't want it to be us and them. It's better to work together.'
'Now that I’ve completed the Induction and Foundation Programme, I was amazed to find that the work I’d done had gone a long way towards completion of my NVQ Level II.'

'We're --- using the LDAF programme to encourage people to challenge practice.--- Interesting things happen when the programme is done by existing staff or new starters who already have experience and maybe an NVQ. Often they are reluctant or even resentful before they start---. Then they may go a bit quiet as they realise what they're learning. Then they love it! It's about personal development as well as good practice - the two go together'
CHAPTER 13: PARTNERSHIP.

*Valuing People* said that people and organisations should work well together to provide services for people with learning disabilities. They should work well together in deciding what services should be paid for and how they should be provided.

Some Partnership Boards are beginning to understand how they should work. The Learning Disability Joint Investment Plans were quite good. The Learning Disability Development Fund needs to be simpler to operate.

What we promised would happen:

**Action:**
Learning Disability Partnership Boards to be set up

**Target Date:**
Autumn 2001

Partnership Boards were set up by Winter 2001.
Action:  
Introduction of the Learning Disability Development Fund

Target Date:
To be available from 2002/2003

The Fund has £22.6 million for things that need to be paid for every day. £2 million of this money is paying for the Valuing People Support Team. There is also up to £20 million for things like buildings and equipment.

Action:  
Send out good practice advice on partnership working

Target Date:
Autumn 2001

We published good practice advice in November 2002. Each member of the Valuing People Support Team works with the Partnership Boards in their region. There is money for events and other things to help Partnership Boards.

We have sent Partnership Boards advice on good practice on lots of things - health action plans, person centred planning, partnership working and housing. The Valuing People Support Team has a website www.doh.gov.uk/vpst and has sent Partnership Boards materials like toolkits to help them.
What has happened with other things we promised?

**Partnership Boards and Health Act flexibilities:**
In October 2002 the Support Team found over half (54 per cent) the Partnership Boards were using the law in the Health Act 1999 to put money from the Learning Disability Development Fund into one budget. By autumn 2002 we knew that slightly less than half (47 per cent) of the local councils had already set up these budgets. By March 2003 another third (30 per cent) now have these budgets set up and nearly all the rest will have them next year (2003/04). By autumn 2002 nearly all local councils (93 per cent) had agreed with the health authorities in their area about how much to spend from the Learning Disability Development Fund.
**Partnership working and community learning disability teams:**

The Valuing People Support Team made a toolkit for Partnership Boards to help them look at community learning disability teams. It helps them check how well people from different professions were working together and with other people (including people with learning disabilities and carers) to make *Valuing People* happen everywhere.

**What else has happened**

The Department of Health sent out some advice on setting up Care Trusts (A Care Trust is a new sort of organisation in which the National Health Service and people from local council social services Departments work together to provide services to groups such as older people). This included some hints and advice for people thinking about setting up a care trust for services for people with learning disabilities.

The Support Team and the National Health Service Leadership Centre have drawn up a programme to help leaders in different ways. There are programmes for example for self-advocate and family leadership and leadership from ethnic minorities.

Many Partnership Boards have members representing Job Centre Plus. Where there is a Job Centre Plus Pathfinder Pilot
members are more active. Some Partnership Boards are starting to work closely with their local employment agencies and the Learning and Skills Councils on the modernisation of day services.

Stories

The Norfolk Partnership Board was set up in April 2001. It has members from all the organisations working with people with learning disabilities. The top person from each organisation is on the board.

The Director of Social Services for Norfolk chairs it. 8 people with learning disabilities and 3 carers are on the board. People with learning disabilities have their own support worker at the meetings so they can follow things and everyone involved can take part.

The papers, minutes and agendas use simple words and pictures and papers go out three weeks before the meeting. People with learning disabilities contribute to really important things and help make decisions that get results.

All the organisations on the board have learnt a lot about involving people with
learning disabilities and this helps other parts of their organisation. People with learning disabilities and their carers feel really part of helping make Valuing People happen.

Next year they plan to have someone with a learning disability as co-chair. There is more information on their website www.norfolk.gov.uk/learningdifficultypb
CHAPTER 14: LAST WORDS.

We said it would take five years to make the changes in Valuing People start to happen. There is still a long way to go but already we have made good progress on the things promised in Valuing People:

- Partnership Boards, the National Forum, the Task Force, and the Valuing People Support Team headed by the National Director, have been set up and have had a year to make plans and start to make things change;

- We have sent out the money. Local Councils and the National Health Service have had the Learning Disability Development Fund to spend on local ideas. The Implementation Support Fund has been spent on advocacy groups, the Learning Disability Awards Framework and the Helpline run by Mencap;

- We have sent out guidance and support materials on important things like person centred planning, health action plans and housing

Things haven't always happened how we said they would in Valuing People. Some things happened slower than we planned. And not all the Learning Disability Development Fund for buildings and equipment has been spent because of these delays. We have sent out £16.7 million, less than the £20 million we planned.
Some things are starting to work really well. The Task Force and the National Forum have given a real voice to learning disabled people. These good things helped the Department of Health get to the finals of the 2002 IPPR/Guardian awards for Public Involvement. We got an award for our work with learning disabled people.

The Valuing People Support Team have also done very well in helping Partnership Boards and other local groups plan and carry out their work. We have had lots of good comments about their work.

There are some things we think did not go too well that we want to improve.

A lot of good things have been done by different Government Departments. This report tells you about some of the good things. But we know we could do more. That is what learning disabled people, carers, and the Task Force are telling us.

The Disability Branch in the Department of Health will talk to people in other Departments about this report and what more can be done to make what we said in Valuing People happen. They will write a report about it that will be looked at by Ministers by the end of 2003. The Disability Branch will include learning disabled people and carers in this work.
The Task Force have said they are worried that Partnership Boards have been given too much to do. We think this report shows a lot of good things have happened since *Valuing People* came out. A lot has been done in almost every local council area to plan how to improve the lives of learning disabled people and their carers. The really important thing now is to support Partnership Boards and other local groups to make change start to happen in their areas.

We will help with this. We are going to continue our support for Learning Disability Partnership Boards next year and through to 2006 for the full five years we said *Valuing People* needs to make it work.

- The £42.6 million Learning Disability Development Fund will continue for next year until March 2004. We are also making the way we send out the money simpler. We are not asking people to put in bids and plans. During the next year we will talk to the Task Force about how the fund should work in the future.

- The Implementation Support Fund will be continued for next year at £2.3 million. It will support the same things as this year mainly advocacy and the Mencap Helpline. We intend to keep the budget at £2 million each year for 2004/05 and 2005/06 and we will talk to the Task Force about what to spend it on.
We have a budget of £100,000 for 2003/04, which we intend to keep at this level for 2004/05 and 2005/06. It is used to train people who provide services and support to people with learning disabilities. We will try to spend it on training for person centred planning, including family carers.

The work of the National Director and the Valuing People Support Team will go on until 2006. Their contracts are due to run out in 2004 but we will extend them. They will concentrate on helping partnership boards and making change happen at local level.

We have decided to continue our support until 2006 because that is the best way to make sure that what we promised would happen in Valuing People is really done.
We believe the Government needs to go on working with people:
In local councils;
In the National Health Service;
In voluntary bodies;
And with people with learning disabilities and with carers.
This is to make sure we do everything possible to improve the lives of people with learning disabilities.

This is what we promised to do in Valuing People. We said it would take a lot of hard work by everyone. People have been working very hard for the past year. They now have good plans and can start to make real changes. It will take a lot more hard work and that is the job we must all do together over the next few years.
WHAT THE WORDS MEAN.
Here is a list to help explain some of the words we have used in this report.

**Advocacy**
Speaking up or speaking out for yourself.

**Advocate**
A person who speaks up for someone else.

**Autism**
When someone has difficulties talking or relating to other people.

**BMRB**
BMRB (British Market Research Bureau) is a research company that finds out what people think or want.

**Care Standards Commission**
The National Care Standards Commission is a new, independent group set up to make sure services meet their rules for care.

**Challenging behaviour**
Where a person has a lot of support needs or may get cross if they cannot get what they need.

**Champion**
Leading the way to make things change.

**Connexions**
A new service to help young people leave school and move on to work, training or further education. Personal Advisers will support young people into adulthood.

**Consultative Forum on Mental Incapacity**
This is a group of people who are being asked by the Lord Chancellor’s Department for their views on decision-making issues.

**Code of Practice**
A list saying what should be done.

**Cross Government Programmes**
A plan that includes a lot of the different bits of Government, not just one department.

**Culture**
A way of doing things.

**Department of Health**
The Government department who make national plans and ideas for most care services.

**Direct Payments**
Having money to arrange your own service.
<table>
<thead>
<tr>
<th>Term</th>
<th>Definition</th>
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<tbody>
<tr>
<td>Disability Discrimination Act (DDA)</td>
<td>A law to stop unfair treatment in work, shops, housing and services. It also applies to information and public transport.</td>
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<tr>
<td>Disability Living Allowance</td>
<td>A benefit for disabled people. It has several different levels to help with care and getting about.</td>
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<tr>
<td>Discrimination</td>
<td>Being treated unfairly.</td>
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<tr>
<td>Employer</td>
<td>The person or company who pays you for work.</td>
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<tr>
<td>Ethnicity</td>
<td>People from black &amp; ethnic minority groups.</td>
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<tr>
<td>Family Carers</td>
<td>Your family who help you with your needs.</td>
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<tr>
<td>GP</td>
<td>Doctor.</td>
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<td>Health Action Plan</td>
<td>A personal plan about your health needs.</td>
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<td>Incapacity Benefits</td>
<td>A benefit if you cannot work.</td>
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<tr>
<td>Inclusion</td>
<td>Being part of something.</td>
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<tr>
<td>Initiative</td>
<td>A new scheme or idea.</td>
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<td>Intimidated Witnesses</td>
<td>People who feel threatened by someone to not say what they have seen, especially when a person has been abused.</td>
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<tr>
<td>Intermediaries</td>
<td>People who can help support others to say what they have seen or what has been done to them, especially to the police or in court.</td>
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<tr>
<td>Job brokers</td>
<td>People who can help you get a job.</td>
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<tr>
<td>Joint Investment Plans (JIPS)</td>
<td>Local plans that look at providing the services in this strategy.</td>
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<tr>
<td>Leadership</td>
<td>Being guided or having someone to look up to because of the way they act.</td>
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<tr>
<td>Learning and Skills Council</td>
<td>A group making sure there is equal access to education for everyone.</td>
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<tr>
<td>Term</td>
<td>Description</td>
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<td>---------------------------------------------------</td>
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<tr>
<td>Learning disability</td>
<td>The official term used by the Department of Health.</td>
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<tr>
<td>Learning Disability Awards Framework</td>
<td>This is a list of things that workers should know. It helps people get qualifications to work with people with learning disabilities.</td>
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<tr>
<td>Learning Disability Development Fund</td>
<td>A new fund to pay for some of the new ways of working in the White Paper.</td>
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<td>Learning Disability Partnership Boards</td>
<td>A new group who will work on the local Joint Investment Plan. The group should make sure they include the views of people with learning disabilities.</td>
</tr>
<tr>
<td>Mainstream</td>
<td>Like everybody else.</td>
</tr>
<tr>
<td>Minority Ethnic Communities</td>
<td>Groups of people with their own language or culture.</td>
</tr>
<tr>
<td>Modernise</td>
<td>To bring up to date.</td>
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<tr>
<td>National Forum of People with Learning Disabilities</td>
<td>The National Forum is a new group of people with learning disabilities from all over England who tell the TaskForce and Government about how local services are making Valuing People happen.</td>
</tr>
<tr>
<td>Objectives</td>
<td>These are the new things or targets in Valuing People that services need to meet.</td>
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<tr>
<td>Palliative Care</td>
<td>Care when you are very ill and Doctors can no longer make you better.</td>
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<tr>
<td>Person Centred Planning</td>
<td>A way of planning where you say what you want your life to be like.</td>
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<tr>
<td>Physical Interventions</td>
<td>A set of rules that say when staff might be able to stop somebody from hurting themselves.</td>
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<tr>
<td>Preserved Rights</td>
<td>Money for people who were in care homes before changes in 1993.</td>
</tr>
<tr>
<td>Professionals</td>
<td>People who are qualified and paid to work in one area.</td>
</tr>
</tbody>
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Quality Protects
A new Government programme helping make services and support for children better.

Represent
Speak up for others.

Services
Support provided for you in a number of different ways.

Social Inclusion
Being included in everyday life.

Social Services Inspectorate
A Government group who check up on Social Services Department's and help them get better.

Strategy
A Government plan of how things should be. If very important it can also be a White Paper.

Supported Employment
Support for you to find or keep work.

TaskForce
The TaskForce is a new group of people set up to check on how things are going in making the ideas in Valuing People happen. It includes people with learning disabilities as well as carers, professionals and people from Government.

Valuing People
Valuing People is the Governments new plans for services for people with learning disabilities. It came out in 2001 and has accessible versions.

Valuing People Support Team
The Support team is a new group of people around England who help make the changes in Valuing People happen.

Vulnerable
Someone who may be likely to be hurt or at risk.
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