Let me in – I’m a researcher!

Getting involved in research
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Getting involved in research

The Learning Difficulties Research Team

with assistance from Catherine Bewley and Linsay McCulloch

MARCH 2006
# Contents

- The Learning Difficulties Research Team 6
- Thank you 7
- Foreword 8
- A comment from the Learning Difficulties Research Team 10
- A quick summary 14

## Chapter 1: Introduction
- How this research happened 16
- Who we are 19
- Who can be a researcher? 20

## Chapter 2: About Our Research
- Our aims 24
- How we did our research 25
- How we managed our project 37
- Managing the money 43
- Ethical research and ethical issues 47
- The role of black team members 55
Chapter 3: What We Found Out

- Our findings 57
- People with learning difficulties getting paid to do research 57
- People with learning difficulties involved as unpaid advisors 62
- Involving people with learning difficulties as research participants 68
- Involvement of people from black and minority ethnic communities 71
- Accessible information 73
- Telling people 76
- Making changes next time 77

Chapter 4: Conclusions and Recommendations

- Conclusions 81
- Recommendations 85
- Think outside the box 85
- Be prepared to change 85
- Plan 86
- Get the right funding 86
- Get better at accessible information 87
- People with learning difficulties make a difference 87
Chapter 5: Our Final Thoughts

- The Project: A poem by Brian White  89
- What we learned from doing the research  91
- What will change as a result of our work?  97

Extra Information

The research projects we visited  99
Our Interview Questions  105
Our Project Information Leaflet  109
Glossary – Some words explained  113
Useful References and Contacts  115
The Learning Difficulties Research Team was made up of the following people:

Jackie Downer MBE
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Our supporters were:

Pam Dale
Katherine Dobbs
Linette Farquarson
Dee Harrad
Jane Ellis Morgan
Marie O’Sullivan

and Catherine Bewley from Values Into Action who provided practical and research support to us as a group.

Disclaimer note:

This report uses the term ‘learning difficulties’ rather than ‘learning disabilities’ because, if a label has to be used, this is the one the Learning Difficulties Research Team prefers.
Thank you

We couldn't have done this research by ourselves, so we would like to say thank you to the following people:

• The people with learning difficulties who took part in our research

• The researchers and others who took part in our research

• Our supporters

• The team from Values Into Action

• Carol Lupton at the Department of Health

• Gordon Grant and Paul Ramcharan from the Learning Disability Research Initiative

• Penny Mendonca for the illustrations in this report and CHANGE Picture Bank

We would also like to acknowledge the work done by Swindon People First before this project started, with help from Carol Lupton at the Department of Health. Swindon People First started to think about people with learning difficulties doing research and prepared a project proposal. Discussions about this led to the idea for this research and our group being brought together and commissioned to do the work. Swindon People First has been a part of our group.
Foreword

by the National Director for Learning Disabilities

One of the most important phrases linked to Valuing People is ‘Nothing About Us Without Us’. What this simply means is that anything being done about the lives of people with a learning disability should only happen with learning disabled people themselves being fully involved. This applies to research as much as anything else.

In the past, decisions about what research should be done, carrying out that research and then looking at and judging its quality, have all been done without the involvement of the most important people – people with learning disabilities. The DH funded Learning Disabilities Research Initiative (LDRI) decided to challenge this. By funding and supporting the ‘Learning Disability Research Group’, the LDRI has successfully challenged this traditional way of working.

The Research Group has been impressive in what it has done. They have demonstrated that people with a learning disability can be full and effective partners in academic research. They have importantly helped to highlight good practice and expose where the commitment to the involvement of people in research does not go beyond the words in the application process. They have helped keep everyone involved in the LDRI ‘on their toes’ in terms of genuine involvement and empowerment.

I hope that this report marks the start of what, in a few years time, will be seen as the only proper way to do academic research – that there is indeed ‘nothing about us without us’.

Rob Greig
National Director: Learning Disabilities
Can I be a researcher?
You are not ready yet.

1985

Can I be a researcher now?
Sorry, you're still not ready.

1995

So why can't I be a researcher now?
Well... maybe next year?

2005

****!
A comment from the Learning Difficulties Research Team

This report is about how to involve people with learning difficulties in research. It is for anyone and everyone who does research, takes part in research or pays for research. It is for people in universities, people in government, people in policy organisations, those who give grants for research and, of course, people with learning difficulties.

We think this is an important topic. If people with learning difficulties really get involved in research, then we can start to influence what research is done, how it is done, what is found out and how people are told about it. We can become good researchers and start getting good paid jobs as researchers. We can ask the questions about our lives that we want to know more about. We can start to gather information that helps change the things we want changing.

This report is for you!
This report tells you about us, the Learning Difficulties Research Team. It tells you how we got started and how we ran the project. We talk about what we learnt as researchers and research managers.

The report also tells you about the research we did, our ‘methodology’ (how we did our research), and what we found out. We come to some conclusions (this is what we think) about people with learning difficulties getting involved in research and we make some ‘recommendations’ (suggestions for change).

Sometimes reports are written in complicated language, with accessible summaries in separate documents or sections. We decided that it was important to make the whole of this report easy to read for everyone.

But we also thought it was important to show people that our research was a proper research project, with ‘fieldwork’, ‘methodology’, independent review and ‘analysis’ done to a high standard.

This means that we have sometimes used jargon words that researchers in universities know about. We have learnt what these words mean and, as researchers, we can use them when we’re talking with academics.
But we know the words are jargon and so we have explained some words as we go along. There is also a ‘glossary’ – a list of words and what they mean. You can find this in the Extra Information at the end of the report.

This report is quite long. We know there will be too many words for some people but we need to put in enough detail so that researchers can learn and change what they do. We need to explain exactly what we did and what we found out.

We have put some information in boxes, in case you only want to read about the most important things we found out. We have also put in some illustrations and pictures. You can read the report from start to finish or just dip into the parts you are interested in.

We also decided to make this report personal by saying ‘we’ rather than 'the Learning Difficulties Research Team' or 'the researchers'. We think this is a more direct and accessible way for us to write this report.

We have tried our best to write a good report that is easy to read. There are probably some things you think we could have done better. We’re still learning about research and how to tell people about it. We hope you like what you read.
Thank you for being interested in what we’ve done.

Good luck with your own research! Happy reading!

The Learning Difficulties Research Team
A quick summary

When Valuing People started, the government decided to pay for research looking at some important things that affect the lives of people with learning difficulties. £2 million was put on one side to pay for thirteen research projects in England. Each project was asked to involve people with learning difficulties in what they did. All these projects are part of the Learning Disability Research Initiative (LDRI).

Our project is one of the thirteen funded by the Department of Health. We were paid to find out if people with learning difficulties were involved in the other twelve projects and to share the lessons of what makes good involvement work.

Our project was groundbreaking because the research and the management were done by people with learning difficulties. A management group of people with learning difficulties from around England was brought together by the Department of Health. We worked on this research between June 2003 and May 2005.

Very few people with learning difficulties are paid as researchers but what makes good involvement work is the right people, the right money, the right planning and time, and imagination.
“We all worked together as equals, we all felt like part of the team!”
How this research happened

People with learning difficulties are getting more and more involved in decisions about the policies and services that affect them. This is happening nationally, through the Task Force and the National Forum.

It is also happening locally, as self-advocacy groups get stronger and more powerful. The government’s white paper, *Valuing People* (2001), lists four ‘key principles’, things that are really important to everyone: rights, independence, choice and inclusion.

When *Valuing People* started, the government decided to pay for research to look at important things that affect the lives of people with learning difficulties.

£2 million was put on one side to pay for thirteen research projects spread out over England. Each of the research projects was asked to involve people with learning difficulties in what they did, their ‘research process’. All these projects are part of the Learning Disability Research Initiative (LDRI).

What is research?

Research is about finding answers to questions and doing it in a planned way.

There are different types of research. We did research about what people think and feel and what has happened to them.
Our project is one of the thirteen funded by the Department of Health. We were paid to find out if people with learning difficulties were involved in the other twelve projects and to share the lessons of what makes good involvement work.

Our research is a first!

In the past and still today, most social research is done by people without learning difficulties. People with learning difficulties sometimes take part but usually don’t have a say about the research itself.

Some researchers are challenging this. They are helping people with learning difficulties to take part as researchers, advisors and consultants, as well as participants.

Organisations like the Norah Fry Research Centre, Values Into Action and Swindon People First have done research with people with learning difficulties as researchers, consultants and advisors.

Other researchers and policy makers have produced good practice guidelines about the wider subject of involving people who use services.
Some of this work looks at services (Aitchison et al 2001). Some looks at community development (Croft & Beresford, 1993). And some looks at research itself (e.g. Cupples, 2001).

Our project was groundbreaking because the research and the management was done by people with learning difficulties. Research is often something that is ‘done to’ people with learning difficulties not ‘done by’ us. But this project gave us an active and independent role in the process of research.

It has also provided information about how good involvement works, which will be useful for more general work on user involvement.

This is the first time a project like this has been done with people with learning difficulties. Because of this, we want to show how we did it. So this report will be about how we did the work, as well as what we found out.
We are seven people who have learning difficulties. We live all over the country: in Swindon, Newcastle, Abingdon, Shrewsbury, London, Norwich and Nottingham. We don’t usually work together but we came together to do this research project.

Usually we all do different things. Some of us work as independent consultants. Some of us work for organisations as advisors. Some of us are paid staff members. Some of us don’t get paid for the things we do.

For most of us this was the first time we had done research. We all took part in training before we started the project. The training covered good practice in research and interviewing.

We have learnt how to work together as a team. We have worked with six supporters, people who have worked alongside us as colleagues. The total number of people in the team is 13. We took the decision at the start that the researchers and the supporters would be
equal members of the team. We were all paid at the same rates and all made a contribution to the team.

From the very beginning of this project, we had very good support from our supporters, from the team at Values Into Action and from the Department of Health. We have also supported each other. We have been through some difficult times and the support for that was brilliant. We have been working really hard to get the research done, write up the analysis, do the report and run our conference. We could not have done this without support.

The training helped us to get practice interviewing. We also had to learn about confidentiality. The training made us think about difficult questions that might come up in the interviewing. It helped us feel more confident. Research uses a lot of new and difficult words, and we had to practice these. The training was really important.

Who can be a researcher?

We were brought together as a group by the Department of Health. We were lucky enough to get involved because we are part of networks that the Department of Health knew about. We also selected
ourselves by being interested in research and, after some first meetings, deciding to join in.

We worked hard as a group to get to know each other. We decided not to give individual group members specific tasks to do: we all had a go at everything. But we also worked hard to use people’s individual talents and strengths and to support each other where we needed it. This went for supporters as much as group members.

Instead of focusing on what we can’t do (some of us don’t read very well, some forget things a lot and get lost, some of us need things repeating often before we understand, some of us are not very confident) we took all of this in our stride and focused on what we can do (chair a meeting well, write brilliant poems, ask good questions, tune into what someone is feeling, make everyone laugh).

Sometimes people are nervous about including people with learning difficulties because they think mainly about what people might not be able to do. But all these things can be got round with a bit of imagination and planning. It is more helpful to find out what (often
hidden) talents, experiences and views people do have and find creative ways to use these.

In some circumstances it might be appropriate to interview people for research roles, if they require specific experience or approaches.

Certainly, people with learning difficulties will need to go through a selection procedure for paid research jobs. But it is important to remember that many people have not had the chance to do research before so we can’t prove that we can do it. We need to be given the chance to try and the support to develop our skills.

Finally, sometimes research is difficult because it is about a sensitive topic or with people who are very vulnerable to abuse. Two of the research projects we covered were about the very sensitive topic of sexual abuse. It is important that both researchers and participants are not put in vulnerable positions. Researchers with learning difficulties may need to go through the same checks as researchers without learning difficulties.

We discuss the challenges of doing research on sensitive subjects that we experienced in Chapter 5.
Chapter 2: About our research

At first you said I was just an advisor and only paid me £20.

I was surprised that you did such a good job!

Now we work as partners, planning and deciding together.

It’s so much easier if you involve people from the start.

... and I get paid properly for all the research I do.

She does a great job and is worth every penny!
Our aims

The aim of this research was to find out what the twelve research teams funded by the Department of Health had been doing to involve people with learning difficulties: what worked and what didn’t.

The research aimed to:

• make contact with the twelve research projects funded under the Learning Disability Research Initiative and with people with learning difficulties involved in each project;

• do semi-structured interviews with a selection of academics, advisors, participants and others at each research project to find out the ‘who, what, where, when and how’ of how people with learning difficulties were involved;

• work out how good projects were at involving people with learning difficulties, bearing in mind the aims of each research project;

• keep diaries to reflect on our own experience of doing and managing research, and use these as data for our research;
• work out what all this information tells us about involving people with learning difficulties getting involved in research.

How we did our research

How you plan and do research is called the ‘research process’. The way you gather information and your ideas about what you are trying to do is called ‘methodology’. We used what’s called ‘qualitative’ methodology. This means we mostly looked at people’s experiences and opinions, rather than numbers.

Stage 1: setting things up

We started the project by spending six months setting things up. This included sorting out the research proposal and the contract with the Department of Health.

This was more complicated than we expected because it was the first time the Department of Health had given such an important research contract in this way to a group of people like us. We had to sort out things like the legal responsibilities, insurance cover, how the project...
would be managed, the bank account and how the money would work.

This was quite a difficult stage for us and it all seemed to take a long time. We were lucky to have the support of Values Into Action, which helped with practical and financial support while everything was being sorted out.

We also spent this time learning about research and preparing for the fieldwork stage. This included getting to know each other and agreeing how we would work together as a group. We also did some training in research and how to do interviews, organised by Values Into Action. We wrote up all the notes from the training into a research pack and ‘help sheets’ which we could use when we went out and about.

We planned the fieldwork stage, prepared the interview questions, produced an information leaflet about the project and got all the paperwork prepared. We also made links with the Learning Disability Research Initiative.

Stage 1 took from June to December 2003. This is the list of tasks we achieved:

- we planned the process, timetable, workplan and dissemination for the project;
• we worked out how we would work as a group and how we wanted to be supported;
• we did our proposal and answered the questions of the independent reviewers;
• we did training in research and interviewing techniques;
• we did a presentation about the project at the annual Learning Disability Research Initiative conference in November;
• we prepared the interview questions, and practised them;
• we put together our research pack;
• we set up our support systems.

Stage 2: gathering the information

We decided that the best way of getting information about what people experienced in the twelve research projects was to ask them questions in an interview. We also wanted to give them the chance to influence the discussion, so we used a ‘semi-structured’ interview. This means we had a list of questions but we didn’t have to stick to the order of questions. People could speak
freely and we could let the conversation and questions flow around them.

We did semi-structured interviews. You can find our list of questions in ‘Extra Information’ at the end of this report.

We used this way of gathering information because we thought it would give us the best information we could get and we felt it respected the opinions and experiences of the people we interviewed.

On the other hand, it was important that we were quite disciplined in the questions we asked and how we ran the interviews. Otherwise we would not have been able to compare what people said in different interviews.

It was a challenge to come up with a list of interview questions that suited all the people we wanted to interview in all twelve research projects. The twelve research projects were all at various stages in their research. They also had different aims and processes. And they had different methods and different aims about the involvement of people with learning difficulties. So it was a challenge to get a list of questions that was suitable for everyone.
You can find our list of interview questions in Extra Information section at the end of this report.

We also used a ‘reflexive’ methodology. This means that we recorded information about our own experiences of doing the research and used this information in the analysis. We did this because we were also people with learning difficulties getting involved in research, so our own experiences of inclusion were useful data for the research.

We recorded this reflexive information by keeping diaries that we filled in on our way back from interviews and at other times. We also shared and recorded our stories each time we met as a group.

This was a very useful source of information for us but it was very important that we were clear what was our experience and what people in the interviews told us. We had to be careful not to let our own experiences influence what we asked or how we interpreted what people told us in interviews.
There were twelve research projects to cover and we decided that at each one we would try to interview between three and six people. We wanted these people to include a paid researcher, an advisor and a participant. In some of the twelve projects, all three of these roles might be filled by someone with a learning difficulty. In other projects, maybe none of the roles would be done by someone with a learning difficulty.

We also decided to do an initial visit to each site and then go back to do interviews. On average we visited each of the twelve projects two or three times. Sometimes we stayed at a site for more than one day to do interviews. We usually did one or two interviews in a day but sometimes we did up to six interviews in one day. Sometimes this was on top of two or three hours of travelling.

One of our challenges was to coordinate the interviews. We decided to visit research sites in pairs, with one or two supporters. We also decided to work in different combinations of pairs for each site, so that we all had a chance to work together. We are based all over England and we are all busy with
other commitments too, so sometimes it was quite a difficult job to coordinate our diaries.

The other factor was that the people we wanted to interview were based all over England too and they were also very busy. So often it took many telephone calls, emails and letters to fix dates we could all make.

We mostly relied on the researchers at each of the twelve projects to put us in touch with advisors and research participants. This mostly worked very well. But on a few occasions it held us up because the researchers were slow in organising interviews or contacts for us.

We gave all of our interviewees an information leaflet about our project. We talked about confidentiality with them and how their information would be used. We tape recorded interviews and took notes, with their permission.

We always asked that we had a private room for interviews and we did not share the information we were told with other people in that research project.
There are a lot of things to think about when you set up an interview:

- how do you reach the people you want to interview?
- how do you tell them about your project?
- how can you make it private and confidential, even when people need supporters to help them?

We spent some time discussing whether people’s supporters should be allowed into interviews. We decided that supporters could be there, if the person with a learning difficulty wanted them there. We thought this was important in helping people with higher support needs or people who felt nervous about the interview to take part.

However, we decided we would make it clear that we wanted to hear the views of the person with learning difficulties. We would also stop the interview if we felt the supporter was overstepping their role or dominating the interview. This fieldwork stage lasted from January to September 2004. It involved:

- making initial contact with the twelve research projects;
- recruiting participants in each research project;
• setting up interviews, and organising travel and accommodation;

• doing the interviews;

• listening to the tapes of the interviews and writing up notes;

• writing our reflexive diaries.

### What is a researcher?

A researcher is someone who tries to find answers to questions.

A researcher asks questions and listens to the answers they get. Being a researcher is about listening to what people are really saying, even if what you find out disagrees with your personal opinion or experience.

Being a researcher is about being organised, having a plan. You try to meet people with all points of view, ask them the same questions, record their answers very carefully, and then you have to work out what all this information is telling you. To do this, you must have a plan.

### Stage 3: doing the analysis

We started to look at our notes and work out what the interviews were telling us in July 2004. This continued throughout the summer.
We started with some training about research analysis and then spent some full days working on the notes and materials we had gathered. We started shaping our notes into themes and looking at the patterns in the information. We looked at the answers people had given us and what was similar and different about what they said. The technical words are that this is a qualitative method of analysis, using ‘triangulation’ to find the most important points. We looked for patterns in the information: what was different or similar between each site? What stories were being told time and time again? What stood out as a very positive or a very negative example?

We then went back and added information from our reflexive diaries and from other materials we had gathered, like reports and leaflets.

We worked on this material from July to September 2004. We all did the analysis together. First we got into the groups that did the interviewing at each research project to work out the answers to the interview questions. Then, all together, we put all this information onto one big plan (this took lots of pieces of flipchart on the wall!). This process took a few sessions.
A lot of us found this stage the hardest. It was quite difficult to understand at first but it became easier the more we practiced it. We started to see the findings, what the data was telling us and it became easier to see how analysis worked. We worked on the material a few times to test our findings.

The analysis stage covered:

- learning about analysis, what it is and how to do it;
- doing the analysis;
- working out our key findings.

**Stage 4: telling people**

This is the ‘dissemination’ stage, which lasted from September 2004 to March 2005. We did a lot of tasks to pull things together and tell people about what we found.

Our main ways to tell people about our findings were a conference and a report. We also put information on useful websites and wrote articles for magazines and journals.
We had a number of challenges in telling people about the research. It is difficult for a group to write a report together, especially when we didn’t meet very often to go through drafts and designs together. It was also a lot of work to organise the conference.

For both of these ways of telling people we wanted to show how information can be shared in interesting and accessible ways. For the conference we organised creative workshops and presentations using drama and imaginative visual examples.

One presentation involved a giant snakes and ladders board, the height of the room, to show the ups and downs of doing research. Another presentation involved a real washing line, with various items pegged onto it, to describe the journey of the researcher.

We mixed a real cake in one workshop to show the mix of ingredients needed for good inclusive research and did a ‘crystal maze’ game in another to show how you can overcome barriers to inclusion.
In terms of the report, as we mention at the beginning of this report, it is difficult to write a long report and keep it accessible. We have tried to find ways to make this report easier to read but it will not suit everybody.

The dissemination stage included:

• making decisions about a conference, organising it and running it;

• working out the structure of the report, writing it, deciding on illustrations and design, getting it published;

• running presentations at the LDRI annual conference and the Involve conference in November;

• preparing articles for relevant academic, policy and self-advocacy journals, magazines and websites;

• This is what we did. You can find out more about how we felt about the research and what we learnt in Chapter 5.

How we managed our project

As well as going out and doing the research, we also had the job of managing our research project. As a group we were responsible for:
• making sure the research happened in a proper way to a high standard
• finishing the project on time
• doing everything that our contract with the Department of Health said we should do
• managing our budget of £107,000 with good financial procedures.

We managed the project and the budget. It was a big challenge but we did it

This was a big responsibility. What made this even more challenging was that group members were spread out all over the country, only meeting once a month. And we had less than two years to do it all from start to finish, even including the set-up time.

We have completed a good piece of research, on time and on budget!

How did we do it?!

Team work

First, by working very hard. Everyone in the group really threw themselves into the work. No one took a back seat. And we stayed committed to the project to the end.
Perhaps these things happened because we worked hard to grow as a group, to get to know each other and work together. We became friends and were committed to each other, as well as the project.

Part of this was about supporters working as team members, having an input in their own right and being prepared to support colleagues and the research itself, not just the individual they came with. We also worked in different pairings for the interviews, rather than always working with the same one or two people.

It also helped that we stayed together when we travelled to London for meetings or around the country for interviews. We spent valuable time outside of meetings, just relaxing together. We ate together, drank together, sat many hours on trains together, swam, bowled, went to see shows and visited the London Eye together.

Although we didn’t realise it at the time, looking back we can see that this was a very important factor in becoming a group. We got to know and trust each other, we helped each other out, we shared personal information. We were there when one group member’s Mum died. We were there when two group members...
had a tough time in an interview. We helped each other when we were ill. We were there when one supporter’s grandson was seriously ill and when another supporter had a baby.

This level of trust and commitment meant that when we did have disagreements and upsets, we were able as a group to get through them.

**Meetings that we enjoyed**

We found a structure for our meetings that worked for us. We were able to cover a lot of ground each time we met. We also spent time preparing for meetings, with minutes and notes in easy English and with pictures. We always had time for feedback and discussion and about how the work was going and what we were feeling about it. We asked each other for advice. This was especially true during the fieldwork stage.
Contact between meetings

We all spent time on the telephone talking with each other, asking for advice and checking things out in-between meetings. Supporters helped organise travel and expenses and would check that individuals were prepared for the next meeting or interview.

I wasn't very confident but the training helped. We were videoed and seeing myself on the screen, I thought “this is something I can do!”

Member of our research team

Training

The training was very important in helping us develop skills and confidence about research. We all felt nervous before we started the interviewing, so it was important to practice. We used video and role play to practise interviewing.

We also had some training in analysis later on in the project.
Support

The Department of Health already funded an organisation called Involve to work on issues of involvement in Department funded projects. Involve is an organisation supporting consumer and public involvement in health and social care research. Involve was asked to support us in our work.

Values Into Action (VIA) was asked to do the day-by-day support of the project. Values Into Action is an organisation experienced in research and campaigning on rights issues with people with learning difficulties. VIA has employed people with learning difficulties as paid researchers on their staff team for a number of years.

Catherine Bewley, senior project worker at VIA, supported us. This involved any tasks that we needed doing to help the project continue smoothly. This often included organising meetings, writing up minutes, organising training, giving support on the day-by-day running of the project and offering expert advice about research processes. VIA’s role was only to support: we managed the project and the budget.
It takes a lot of experience and knowledge to run a large research project successfully. The support role that VIA undertook was very important in helping the research achieve successful outputs on time and on budget.

**Managing the money**

This was a challenge for us. At the start of the project we spent a long time agreeing a budget. This included working out:

- what we would all be paid;
- what we would spend on the fieldwork;
- what we would spend on monthly meetings;
- what we would spend on our conference and report.

There were some budget headings that we added later. For example, there were some childcare costs for supporters that we had not originally thought about. We also agreed some costs for extra support for some group members after they had a tough time in an interview.
Each time we met as a group we looked at the budget. We looked at:

<table>
<thead>
<tr>
<th>How much was allocated in the budget for that item of spending</th>
<th>How much we had spent under that heading, adding in all the spending since the last meeting</th>
<th>How much we had left under that heading</th>
</tr>
</thead>
<tbody>
<tr>
<td>£</td>
<td>£</td>
<td>£</td>
</tr>
</tbody>
</table>

We then made decisions about what we could afford. Sometimes we needed to move some money from one heading to another heading.

**Financial procedures**

We all came from different groups and the Learning Difficulties Research Team was not formally constituted as a group. This meant that we could not open a bank account ourselves. So VIA opened a separate account solely for the project on our behalf. We then set up procedures to authorise VIA to make payments. VIA only acted under our instructions. No payments were made without the written authorisation of the group.
We managed the budget. VIA opened an account on our behalf because as individuals rather than a formal group, we couldn’t do it ourselves. But we made all decisions about the money and no payments were made without our written authorisation had to be authorised in writing before payment could be made.

There were occasions when we questioned expenses. These discussions were carefully minuted to show that we were in charge of the decision-making about the money.

VIA also lent us some money for six months at the start of the project to pay for meeting expenses while our research process was being peer reviewed and the contract was being agreed with the Department of Health.
Pay

We had long discussions at the start of the project about fees. We eventually agreed the daily rate and how many days of work would be paid for. We also made the decision to pay ourselves and our supporters the same daily rate.

This was very important for us. We believe that our supporters worked as colleagues and were part of the team, not silent people sat apart. Our philosophy is that we worked together in a team. We thought this should be reflected in the fee level. This was perhaps an unusual decision but one that we all felt very strongly about. This was entirely our decision: we discussed and agreed it without the supporters being present and they did not influence our decision.

We were paid on a self-employed basis for the work we did. We all had different circumstances in terms of our income and each person sorted out their money in a different way. Some of us wanted the money to go to our organisations, where it was added to our salary. Some of us were self-employed already. Others made agreements with our local Benefit Office to receive the money in equal monthly or weekly amounts at a rate that did not affect our benefits.
We think it is very important to do ‘ethical research’. This means treating everyone involved in the research with care and respect. It is also important that the research should empower people, not put people down.

This is important because for many years research was done by people who had lots of power to say what people’s lives were like, even if they did not have the life experiences they were researching about. These researchers were called ‘experts’ and they made their careers by researching people who were called ‘subjects’.

Disabled people started challenging this. They demanded to be seen as the experts about our lives. Disabled people started to run research. We want to ask the questions and, even more important, get to decide what questions to ask!

This situation is changing but many people with learning difficulties are still the ‘subjects’ of research. Sometimes we get to be advisors. But it is still very rare for people with learning difficulties to get paid to run research.
We had to deal with quite a few ethical issues in this research. We discussed ethical issues in our training and came up with a list of standards to work by when we did our research. These were:

- People must not be harmed by taking part in our research. This means physical and emotional harm.

- We will always be kind and respectful, listen carefully, and thank people for sharing their expertise with us.

- People must know what the research is about and why it’s happening. They must know who we are, where we're from, and what will happen next. We will put things on tape or use pictures if people want us to.

- People must agree to take part in this research. It’s our job to make sure they understand what they are taking part in and how we will use their information. This is called ‘informed consent’. If people don’t understand, we will find different ways to explain who we are and what the project is about.

- We will not put people under pressure to take part or answer questions. People have the right to say no, to not take part, or not answer certain questions. We will respect their rights. Sometimes people just want to please and don’t have the courage to say no. We will make sure they know it is OK to say no.
• We will not use the thank you payment of £20 to bribe or encourage people to take part. People shouldn’t take part just for the money.

• People will be given a copy of the research report afterwards and invited to any events. We will not name people in our report.

• We will not promise to do things if it isn’t our role or we can’t keep our promise. If we do promise to do something, like send someone some information, then we will do it.

• We will be careful when we talk to other people about who we have interviewed and what we find out. Our notes are confidential and will not be shown to anyone except other members of the team.

• We will not start or continue an interview if we haven’t got privacy.

We found it was not too difficult to keep to these standards. But there were some other ethical dilemmas that were more difficult. For example, we relied on the research managers and workers in the 12 projects to find people with learning difficulties for us to interview. This meant that they selected who we talked with. They could have selected people with particular opinions and this would have influenced what we found out.
We couldn't see another way around this for our project and we do feel we interviewed a range of people at each project. But it is a potential problem.

We also found that not everyone who was selected to meet us knew who we were or why we (or they) were there, even though we'd sent information beforehand.

There were also some research projects that worked with people with high support needs who did not use speech. We did not interview these people directly. We met people and we gathered views from family members and researchers.

This is a problem faced by many researchers and could be seen as a weakness of our research.

We did not find it difficult to ask our questions to interviewees with learning difficulties. Although only one of our team had done research before, we are all familiar with doing employment interviews or hosting events or taking part in national consultations. All these things gave us experience of how to welcome people, put them at their ease and ask questions.

We also trained hard beforehand so we really knew what we were doing in the interviews.

Finally, we had excellent relationships with our supporters. We worked together to prepare for interviews and we discussed beforehand how the supporter would help us if we got stuck in the interview.
We also used individual feedback time and our group meetings to reflect on how things were going and talk through things we felt we could do better.

However, in two situations people we interviewed went way beyond what we asked them and poured out their experiences to us in a way we could not have prepared for. This does happen in interviews from time-to-time. However, what we were told was very sensitive, difficult information for us to hear, which we then had to deal with emotionally. This had consequences for us as individuals and as a team, which we discuss later in this section and in Chapter 5.

We also had to do interviews in a secure unit in one site. Again, we had to prepare for this and choose carefully who did the interview and how it was set up so that we and those we interviewed would feel safe but we would also do good interviews.

In both these situations, good preparation before the interview, good support in the interview and good de-briefing afterwards are important.

We did not approach NHS trusts for formal ethical approval as most of the research projects were social research. In any case, our research was with the projects about inclusion and was not about the topic that the projects themselves were researching.
We did reflexive research and we are people with learning difficulties ourselves. We think this is an advantage and helped our project. However, there are two potential dilemmas with this situation.

First, it's a small world and we might know someone we want to interview. We dealt with this by sharing out the research projects so that we did not work with any team or individual we already knew. We agreed that, if we turned up at an interview and there was someone there we weren’t expecting, then we would talk with that person about postponing the interview or, if we were in a pair, just one of us would do the interview. It doesn't always matter that you know someone already but it can influence how they answer the questions, so we tried to avoid that situation.

Second, we might get our own experience mixed up in our minds with the answers given to us in interviews. This was particularly so for us because we were researching what we were doing too, so it could get confusing. Our experiences and those of our interviewees might be the same but might be different, so it was important to keep them separate in our minds. Reminders from our supporters were helpful. It also helped to have an experienced researcher (our supporter from VIA) keeping an eye on things and talking it over if we got confused.
What to do to set up interviews

Preparation is very, very important! Do this bit right and the interview has every chance of going well!

Before you go to an interview, you should have made a first contact with the researchers at the project you are studying. They should know who you are, what your project is about and what you need from them. They should have received some information from you and they should know how to contact you.

The next step is to work out who you need to interview. Ask the researcher who is on the team and if they have the names of people with learning difficulties who got involved in their research. You may want to do a first visit, just to see the head researcher and work out with them who to interview and how you will ask these people if they want to take part.

When you have a list of names, write or telephone people beforehand explaining who you are, what the project is and why you want to meet them. Tell them a bit about the interview – how long it will take, where it will take place, what sort of questions you want to ask them.

Then arrange your dates, times and venues for the interviews. Try to make best use of your time by seeing two or three people each time you visit.
How to do an interview
Interviews can be divided into three parts.

Part 1 is about introductions
Introduce yourself fully and go over again what will happen in the interview, how long you’ve got, and how you will record and use information. Make sure the person knows why they are there and that they agree to take part. Make sure they know they have rights and can stop at any time or ask you not to record certain information. You should put people at their ease and make sure everything is comfortable.

Part 2 is the section when you ask questions and people tell you their answers
This section takes the most time. In part 2, you do most of the listening and the person you are interviewing does most of the talking. Use body language to encourage people, rather than lots of words. In this section, you don’t give your personal opinions or look like you agree or disagree with what people are saying. Just listen carefully and record what you hear.

Part 3 is about ending the interview
In this section ask if the person you are interviewing has got anything else they want to say or any questions to ask you. Remind them what happens next and how to get in touch with you if they think of anything afterwards. Thank them very much for their time and help. Then end the interview.
The role of black team members

Two members of our team were black, one person with a learning difficulty and one supporter. Their involvement in the project was very important in helping black and Asian participants feel comfortable in getting involved in the research.

Both team members were also women and this was particularly valuable in one research site in which interviews took place in people’s homes. Participants felt more relaxed and so felt comfortable in sharing information with us.

One participant said that it was inspiring to meet a black person with learning difficulties who was doing such work, as it gave her hope for her child’s future.

Cultural and regional differences were valued by all of us but it was particularly helpful for the project to have black team members, as the importance of issues affecting black people with learning difficulties was always on the agenda. Black team members had personal insights about discrimination and real ideas about how to tackle it.
Chapter 3: What we found out

I’d love the chance to do something really challenging!

It’s not fair on her, she might get upset when she hears people’s stories.

People will tell me things that they might not tell other people.

But will she ask the right questions?

Involve us to get the right answers!

But we don’t have enough time or money to involve her properly...
Our findings

This chapter tells you about our ‘findings’, what we found out, and what we learnt about involving people with learning difficulties in research. We have added thoughts from our own experience of doing research too but we also cover this in more detail in Chapter 5. In Chapter 4 we draw all this together to make recommendations or suggestions for change.

People with learning difficulties getting paid to do research

The largest research team had eleven members and the smallest had one but our most striking finding is that, out of all twelve research projects, only two projects actually employed a person with learning difficulties as a paid researcher working as an equal with others in the research team.

We only met two people with learning difficulties with paid research jobs

This is surprising because the twelve research projects were selected for funding by the Department of Health partly on the basis that they would be good at involving people with learning difficulties.
But this finding is perhaps not news to people with learning difficulties, who know that they are usually seen as the ‘subjects’ of research and as research participants. It is clear that there are major barriers to people getting jobs and making careers as paid researchers.

**What could these barriers be?**

1. **Not planning before your proposal**

A lot of the teams had not really thought about involving people with learning difficulties as paid researchers. This needs to be thought through when a grant proposal is being developed, as it requires the right budget to make it happen. One researcher said she would now involve people in writing proposals, but also recognised that this requires more time to put the proposal together.

**Projects, plans and ways of working need more time**

Having enough time was mentioned by many of the researchers we interviewed. Most of the teams thought that a lot more time would be needed if people with learning difficulties were involved in projects as researchers. More time is needed to develop grant proposals and more time needs to be built into the
proposed research to help people with learning difficulties to take part fully.

This raises a question about how grant funders assess whether a proposal has involved people with learning difficulties in its development and how good it is in terms of involvement.

2. Making assumptions about what people with learning difficulties can do

One research project had not included people with learning difficulties as researchers or advisors because they felt that the topic was too difficult and upsetting for people to deal with. However, the fact that we dealt with this project and undertook interviews with some participants showed them that it was possible for people to deal with difficult research issues.

As far as we could tell, none of the research projects had involved people with learning difficulties in deciding what to do the research on, in designing the research or in writing the grant proposal.

This is certainly possible to do, as our experience shows, but it does take more time and requires a team way of working. Some researchers
recognised this issue but said they didn't feel they had the experience to work in this way with people with learning difficulties.

Those projects that did involve people with learning difficulties said they enjoyed and benefited from the involvement. There was also surprise at how much people with learning difficulties could offer.

3. Fixed ways of doing research

What is important is that researchers have to change how they do research if they want to really involve people with learning difficulties as colleagues. Most of the teams said involving people as paid researchers means:

- using different methods and materials;
- finding different ways to explain things;
- working with longer and slower timetables;
- and presenting information in more accessible ways.

Preparations must be made at the proposal stage and funders must be prepared to pay for the required methods, materials and timescales.
Some researchers also thought that they would have to organise the project differently in order to include people with learning difficulties properly. They thought that it would take more work on their behalf to work alongside colleagues with learning difficulties. The need to have more time to plan and do the research was mentioned in many interviews.

One research site said they had enjoyed working with people with learning difficulties but had found it difficult because it demanded a different way of doing things.

4. Feeling confident about working as colleagues with people with learning difficulties

Most research projects had not taken advice from any self-advocacy or advocacy groups on how to involve people with learning difficulties. One research project said it would now involve people as advisors.

Some researchers were also thinking about what sort of support people with learning difficulties might need to get involved in research. Issues that came up in interviews included practical things, such as getting the right transport organised. Researchers had also found that people needed positive support from their families and services if their involvement was to be sustained.
5. The benefits trap

It can be difficult for people to get paid work that doesn’t affect their benefits or gives them a good enough wage to risk coming off benefits. This means that most people end up being paid a nominal amount.

We were surprised that some people with learning difficulties we interviewed often couldn’t remember or were not sure if they got paid. This suggests that they were not. When we asked researchers about this, they said that sometimes people got a small amount (like £10, either to an individual or a group) for each time they came to an advisory group but often a sum of money was given to the self-advocacy group that people with learning difficulties were connected with.

People with learning difficulties involved as unpaid advisors

All but one of the research projects had advisory groups that included people with learning difficulties. Some research projects had fairly traditional advisory groups, made up of a range of professionals and relevant people. These groups usually included one, two or three people with learning difficulties. For example, one
research project had a group of 26 advisors, 2 of whom were people with learning difficulties.

Those we interviewed said that the big gaps between meetings meant it was hard to work with others as a team. Professionals on an advisory group may know each other and meet outside of meetings and may be more used to speaking up in advisory groups.

Advisory groups are better at involvement when they:

• meet regularly
• are personal and friendly
• have social time together
• include more people with learning difficulties
• pay people
• find more creative ways of discussing issues, asking questions and speaking up

The people with learning difficulties we interviewed often felt on one side in advisory groups. Some were not sure what the group was for or what the research was really about. In fact, one group of people did not even know that they were the advisory group!

And in another project, even the researchers recognised that people didn’t realise they were advisors.

People with learning difficulties told us that they often didn’t feel connected with other advisory group
members and there was little chance for an advisory group to form and work as a team. For example, one project had an advisory group of twenty six people, with only two of those being people with learning difficulties. In this situation, people with learning difficulties can feel at a disadvantage and may not contribute to the extent that they are able.

On the other hand, some people with learning difficulties we interviewed said they were worried about being an advisor at first but became more confident as the advisory group got going. People with learning difficulties involved in advisory groups in six of the projects said they enjoyed the experience. They ended up wanting to do more. They learned new things and new skills.

At one project, people said they felt they had been listened to. At another they felt very involved and this made people feel good. They said they felt proud that their views had been listened to and, importantly, their opinions had led to the researchers changing things in the project. “It’s good to work with people you trust” said one person.
Other research projects separated the paid advisors from service organisations and voluntary groups from people with learning difficulties, who often had separate focus groups. Sometimes the research project went to the local self-advocacy group as a whole for advice. People with learning difficulties felt they had a bigger input when advisory groups were set up like this but they also didn’t have the chance to influence what the group of ‘professionals’ discussed.

The researchers at one project told us that they had learned that people with learning difficulties can offer more than they expected. Another time they would ask their local self-advocacy group for advice.

Researchers at another project told us that they had some problems with a consent form, which participants with learning difficulties hadn’t understood. The researchers hadn’t asked any people with learning difficulties for their comments about the form and, afterwards, they realised that they might have produced a better form if they had asked for some advice.
Some people we interviewed, both people with and without learning difficulties, said that advisory group members without learning difficulties need help to work well with colleagues with learning difficulties. We didn’t come across any examples of mixed advisory groups being given training in how to work together or time to explore their ground rules and group processes.

The same issues about involving people as paid researchers come up when involving people as advisors: researchers and research projects are not designed with enough time and money to really enable people with learning difficulties (and others) to take part fully.

People with learning difficulties seem to have to prove their professionalism and their expertise, whereas this is assumed to be present for those without learning difficulties.

Some researchers we interviewed did recognise that people must be involved in ways that suit them, especially in ways that respect their culture. People we interviewed also said to us that more should be done to include people with high support needs, and people from black and minority ethnic communities.
Two projects in particular were very good at reaching out and including people with learning difficulties from black and minority ethnic communities. At one project, this had involved extra money for carer support and transport, as these were things that helped people get involved.

At the other project, what counted was a very personal relationship between the researcher, people with learning difficulties and their families. This project also put a lot of effort into finding accessible ways to share information. These efforts paid off: a lot of advisors and participants with learning difficulties, many of whom had high support needs, stayed involved for over two years.

They are also some practical issues that limit people’s involvement as advisors. Often these are around transport. Some people with learning difficulties need accessible transport and personal support to attend meetings. People are also restricted by the transport that’s available in their area or attached to their service.

We also experienced this as researchers. The practical arrangements of travel, accommodation, where you are going to eat, have you got your papers with you, and all the things that need to happen to take part in a
meeting are often big issues for people with learning difficulties. Unless these are planned for and dealt with, people will not be able to get to meetings or contribute properly when they are there.

Three of the projects paid people with learning difficulties as consultants. One project consulted people with learning difficulties on the design of their materials and website. They also consulted on what should go in their newsletter, and on producing information for visually impaired people.

**Involving people with learning difficulties as research participants**

A research participant is someone who is interviewed by a researcher or who takes part sharing information or trying things out so that researchers can gather the data they need. People with learning difficulties were included as participants in all the research projects except one.

This one project did not include people because they had high support needs, often didn’t use speech, and the subject matter was distressing. However, having seen how we handled our research, they said they would reconsider this another time.
Researchers at another project thought that the participants with learning difficulties were not really aware that they were taking part in research. They knew they were taking part in the activity involved but not that this was research.

Some of the research teams found it hard to make contact with and involve people with learning difficulties. It was difficult to know who would be the right people to ask. The teams often had to rely on other people and organisations to act as ‘gatekeepers’. This did not always work very well. In one research project, care home managers did not distribute questionnaires, so people with learning difficulties were prevented from taking part.

Other projects used questionnaires to get the views of a large number of people with learning difficulties, from 30 or 40 people up to 400 people.

How was information gathered from participants? We found that researchers mostly used interviews to get their information. Sometimes interviews were with individuals, perhaps with a supporter or family member present, but sometimes interviews were with groups.
Group interviews were often called ‘focus groups’ by the researchers.

Researchers said that small groups and one-to-one meetings were often the best way to involve people well. Some projects found it was very important to develop a personal relationship with participants and their families, to build trust and continuity so that people felt safe enough to give their views.

This seems to be especially important when people have higher support needs and need support to get involved and when research takes place within minority ethnic communities. In this case, knowledge of the community and its culture and language, plus time and effort to build relationships, seems particularly important.

Most of the research projects used fairly traditional techniques to get their information: interviews and, in two research sites, questionnaires. Even when there was outreach to self-advocacy groups, this was usually in writing or by a visit and meeting with the group.

There was particular criticism about the effectiveness of sending letters to people. People we interviewed said letters weren’t read or understood. When visits to groups or homes happened there was often so much time between visits that people had forgotten about the project.
There were some examples of more unusual and interesting ways of getting people involved and finding out their views and experiences. One project organised a day out as a way of meeting people and getting them involved. In another project, the people with learning difficulties involved had produced a video to recruit more people.

The issue of support was also recognised as important. Three projects used other people with learning difficulties to act as peer supporters for people in interviews but in only one of these projects did the peer supporters get paid.

One project gave £100 to a self advocacy group that acted as a focus group. Individuals got £10 per interview but most participants did not get paid.

**Involvement of people from black and minority ethnic communities**

Several of the projects made extra efforts to include black and minority ethnic communities as participants. One project did this by focusing on an area where people from black and minority ethnic communities lived. Another focused on a particular ethnic community and used family and community networks to contact participants.
In another project, an independent black consultant was paid to advise the project and help with their outreach to black and minority ethnic communities.

Another project set up a focus group of people with learning difficulties from black and ethnic minority communities.

Several other projects did nothing special to attract people but still had people from black and minority ethnic communities involved.

One research participant said:

“In an English culture when a child or a young person becomes an adult, they just leave them to do what they want whereas in our culture it’s not like that. Things like going to pubs and clubs, we wouldn’t allow it.

My son’s just recently started going to an adult respite centre, and the people there get taken to the pub, but we wouldn’t allow him to go, it wouldn’t be right for our religion and culture.”

As noted in the previous section, researchers found that it was knowledge of communities, cultures and languages was very important in creating links to potential participants. Using community networks to contact people also worked, such as through relevant faith organisations. Spending time building personal relationships of trust, often focused around the home, also proved important in some research projects.
Accessible information

Overall, most research projects had made some effort to produce accessible information. This included easy read booklets, information on audio tape, using Makaton, role plays and drama, picture maps, CDs, websites and videos. However, easy read booklets – the most popular method were not always very successful at reaching out and including people with learning difficulties. Some researchers struggled to translate complicated and difficult issues into easy read information.

Many researchers we interviewed had only thought about accessible information once the project got going. Projects found that making material accessible takes more time and costs more money than they had allowed for. This shows that accessible information must be thought through properly as the project proposal is being developed.

Leaflets can be boring

There is also the question of whether grant funders are prepared to accept and fairly assess a proposal that may be presented in a different format and in different language to the usual academic style.

In other places, where we were told there was accessible information, we found pictures but still with difficult words. For example, some pictures would be
added to a leaflet but the researchers had not really thought how to explain their project in an easy way or whether a leaflet was the best way to tell people about it.

Our impression was that leaflets were, on the whole, quite serious, with lots of words and sometimes boring. This was a shame because the researchers we interviewed were passionate about their work but this did not come across in their materials.

In other cases, only some information was accessible. In one project, people with learning difficulties had been involved in advising about the project’s website but there were no expectations that the researchers themselves would produce their materials in accessible formats or find ways to explain what they were doing that people could understand.

A typical example was of one research project where there was concern about accessibility but a lack of skill and dedication to the issues. Researchers had developed a presentation with slides and had given this presentation to a number of conferences and groups, However, they hadn’t done any presentations to people
with learning difficulties and did not feel confident about doing so.

These researchers had also prepared some information in larger print but they were unsure about the options available for accessible information. They didn’t have technology to help them (such as a picture bank on computer) and didn’t have a budget for accessible information.

Those projects that had tried to be more accessible had used the following methods to tell people about what they did: easy words, pictures, photos, Makaton signs and symbols, drama, audio tapes, video tapes, local radio, CDs, large print, Braille, different languages, hearing aid loops, role play and picture maps.

They’d also tried to make the following documents accessible: the project’s recruitment letter, interview schedule, agenda, minutes, consent forms, questionnaire, and background information to the project.

In two projects, the accessible information and the very involved way of working, had led to better involvement by advisors and participants. This had led to the researchers re-wording questions and changing materials in response to people’s comments.
Telling people

All the projects had plans to tell people about their findings but not all the projects had thought about letting people with learning difficulties know about them. Some projects were only planning to write articles and give conference presentations aimed at other academics and professionals. They felt this was who their research was aimed at.

Most projects did want to tell people with learning difficulties about their findings but, again, some projects were limited by having little time, money and experience in how to get information out to people.

As well as more accessible reports, projects used other ways of telling people: audio tapes, video tapes, CDs, accessible articles, accessible booklets, interviews on local radio, visits to schools and word of mouth.

A few research projects had chosen interesting ways to tell people about their work. In one project, people with learning difficulties made a play to tell people about the research. The play was taken round lots of local groups and received very good feedback. This play was then videoed so other people could see it.
Another project translated everything into their local community languages. Another produced a resource pack for participants.

Quite a few projects were using websites. In one, the website was developed with advice from people with learning difficulties.

However, in two projects there were no plans to feed back to participants and in several others they wanted to but hadn’t really developed a good plan.

**Making changes next time**

We asked the people we interviewed whether they would like the research to be done differently in the future. The following four points were made by many people.

1. **Involve more people with learning difficulties**

The major change people would make is to involve more people with learning difficulties, at more stages of the project. Two teams said they would want to involve people with learning difficulties from the very
beginning, so they could suggest what research should be done and help to decide how to do it.

Researchers say they want to involve more people with learning difficulties

One team said they would like someone with learning difficulties as a paid researcher. Other teams said they would have used more people with learning difficulties as advisors and consulted people from local self-advocacy groups.

One of the teams said they would try to involve people with high support needs, and also people from black and minority ethnic communities.

2. Allow more time

The second major change people would make is to allow more time so that people with learning difficulties can be properly involved. This means allowing more time for supporting people, and having more time to make sure that people understood the consent process.
Accessibility

Some teams said they would try harder to make their materials more accessible. One team said they would work in a slightly different way, to make sure that people with learning difficulties were properly included and involved.

Money

Some of the teams said they would ask for more money so they could pay for more accessible materials, like an interactive CD. Some teams also said they would want more money in the budget so they could tell all the participants what they found out.
Chapter 4: Conclusions and Recommendations

80 Let me in – I’m a researcher!

Think outside the box

Be prepared to change

Plan together

Get the right funding

Get better at accessible information

The door to research must be unlocked because we will make a difference if we are there!
Conclusions

All the people we interviewed gave us their time and attention and some people were extremely generous in helping us do this research. Researchers were passionate and dedicated about what they were doing. These research projects were being done because those involved were interested and committed to people with learning difficulties and the issues concerned.

We found some examples of really excellent involvement where researchers had put effort into reaching out to people with learning difficulties, listening to them and changing what they did as a result. We also found some examples of good, imaginative accessible information. Often the two went together: good involvement included attention to good accessible information.

However, despite goodwill and effort, people with learning difficulties were usually being involved in research in limited, traditional and fairly unimaginative ways. In very few cases was real power-sharing
happening. Research is still ‘done to’ people with learning difficulties not ‘done by’ us. Effort to involve people often didn’t work very well because there wasn’t enough time, money, support or outreach. For these reasons, people with learning difficulties had little influence over the topics, processes, conclusions and dissemination of research.

This lack of influence and power for people with learning difficulties in research can also be seen in the fact that most people were unpaid for their involvement or only paid a small amount. Only two researchers out of twelve projects were employed in a research team. Until people with learning difficulties are given real paid jobs as researchers and can influence research questions, design and processes, then we won’t know if research is really useful for us.

With a couple of notable exceptions, this lack of good involvement really surprised us. Especially because these were projects chosen by the Department of Health because they seemed to be good at involving people with learning difficulties.

The academic world and the usual ways in which research is funded do not help the process of change.
To involve people with learning difficulties effectively, research has to be:

- done to a longer timetable;
- with money for more imaginative ways of involvement (for example, face to face outreach can cost more in terms of time and outreach costs than sending out a questionnaire);
- more support and more teamwork.

This may mean that researchers have to learn new skills to do this sort of research. These skills could include things like how to run a focus group, give accessible presentations, and use the technology available to prepare accessible information.

Funding organisations must be prepared to assess applications on how the proposal has been put together and how people with learning difficulties have been involved in that. They must be prepared to fund projects that take more time, contain more costs for transport, support and accessible information, and include higher dissemination costs which cover interactive events and media. Funding organisations also need grant officers who know how to assess these
things and are prepared to offer support and guidance to applicants and grant holders.

One of the projects that employed a person with learning difficulties as a researcher felt that this person had been able to support participants better, contribute new things to the research process and make changes that colleagues without learning difficulties had not be able to.

“Sometimes it helped to be a person with learning difficulties when we were doing the interviews. I feel people found it easier to talk to me than a professional because I have been through similar experiences – they were comfortable talking to me.

The main thing is winning people’s trust. Once you’ve won that, then you’re in. If there are too many doubts, no-one will open up. Sometimes it takes a lot to get people to open up, so we started.”

This is the heart of the matter: when people with learning difficulties are involved they make a difference. Whether researchers and funders are convinced by the ethical reasons for involving people, the fact is that better research data and different research findings are the result of good involvement.

Researchers with learning difficulties have the advantage of knowing what it feels like to have a learning difficulty. This expertise can change research.
An example from our experience is that we were asked to comment on a website at one research project and the comments we made had not been thought about by the researchers and they changed what they did as a result. The people with learning difficulties we interviewed said they felt more comfortable sharing their views and experiences with us. This suggests we were able to gather more information or different information than if we were interviewers without learning difficulties.

**Recommendations**

To sum up, we think this research tells us six things:

1. **Think outside the box**

   There are traditional academic ways of doing research. However, people with learning difficulties are involved better when imaginative and accessible methods are used. This leads to better research, better data and the chance of real change.

2. **Be prepared to change**

   If people with learning difficulties are involved well, then research needs to be flexible because ideas will come up which change how the project is running, what it is finding.
out and how it plans to tell people about it. People with learning difficulties are still the subjects of research, not those in control of it.

3. Plan

To work well you have to plan ahead to involve people with learning difficulties, not do it as an afterthought. People need to be involved from the start of an idea.

4. Get the right funding

Getting the best from people with learning difficulties costs time and money and these things need to be built into research budgets. Paid researchers with learning difficulties may require a paid supporter. Timetables need to be longer. Information needs to be presented in different ways. This is difficult without the right funding and almost impossible to change once a project starts and funding is set. Researchers need to start involving people before ideas and proposals are developed to get this right.
5. Get better at accessible information

Researchers need to get training and experience in producing more accessible information. People with learning difficulties should be involved in the production of information.

6. People with learning difficulties make a difference

This research shows that, when people with learning difficulties are involved at the heart of research in effective ways, then they make a huge difference. The research covers different questions and gets different information.

People with learning difficulties can do proper research.

The door to research must be unlocked because we will make a difference if we are there.

We did it!
Chapter 5: Our final thoughts

Once on a visit to London my wheelchair broke down.

I couldn’t find anyone in London who could fix it.

I felt like a beached whale. I felt very vulnerable.

I got someone to put me on a train back to Norwich.

I hoped that the assistance I booked would be there to meet me off the train when I arrived.

Sometimes we were made to feel like a nuisance but we still did the research. So can you!

Hotels, restaurants and taxis were also a problem.
The Project: A poem by Brian White

When I first heard about it, I thought it’s a good way to earn a few bob, never realising what it entailed.

So like a “big daft Geordie” I signed on, always knowing there was my good friend Joan at hand to give me help when I needed it.

Anyway, it started – introductions, socialising, sharing hotels, meals, drinks, good times, bad times.

I soon realised I was completely out of my depth. This was nothing like the National Forum.

But Catherine explained the plan – taught us, showed us techniques on how to do the basics, interviewing, questioning, what to ask, when to ask and we had lessons on types of research.

We did role plays, worked out the grant money, costed accommodation, travelling, materials and how much to keep for the report launch as well as our own fees.

It wasn’t too bad, as I felt I was part of a team.

But still everyone seemed more experienced, so when the research sites were allocated, I held back – what could I offer?

But I learnt even a clown like me can break the ice with a joke and a smile.
I was given two sites, mainly because everyone else had plenty.

I was so lucky my sites were with Gordon (who is now my good Irish friend) who is experienced at research and his supporter Dee.

I humped the bags and Dee had the money.

Our researchers were great, helped us no end – food, tea, coffee, and even went on tours.

But honestly, they couldn't have been more helpful or friendly.

Then with all the sites researched we came back and told Catherine all about it, thinking “make sense of that lot”.

But she wasn't fazed.

She took everything we gave her and set it out piece by piece.

Like a jigsaw, it started to make sense.

A picture was beginning to form, even to me – it was wonderful!

And here it is, all our own work, with a little help from our friends.
What we learned from doing the research

I'm glad that I kept a personal diary about the experience of doing research because it helped me to look back on what we had done and to note down the mistakes we made and to get it better the next time. It's good to learn from your mistakes.

This was not an easy project to work on. When we all first met in early summer 2003, we were interested in the work but we also had lots of questions. What was it all about? How would the support work? Would we get paid?

If this project worked, then it was because of team work. By the end of the project we were friends. We'd gone through a long, sometimes difficult journey together.

What we learnt about team work was:

• use people's strengths and talents;

• stand together when there are problems and try to work it out;

• find good ways to have honest discussions;

• have social time together;
• share feelings and personal experiences in meetings as well as practical things;
• stand by each other when we're going through rough times;
• work as equals.

It worked for us that everyone did a bit of everything, so we all experienced the whole project. We had to be involved in all the decisions and all the work. This helped us feel involved and committed to the project.

We teamed up in pairs or in threes to do the interviews and the fieldwork and I'm glad we did it this way. I liked having the chance to bounce ideas off other people, share our skills and support each other and work in a team.

How support worked was very important. We needed support. Doing research can be difficult and travelling around the country can be
complicated. It worked for us that supporters didn’t just stick to supporting the person they originally came with but got to know everyone too.

It was also important that support was something we all gave. It wasn’t just supporters helping out researchers with learning difficulties. We all helped each other. It was a two-way thing.

We couldn’t have managed without the support of the group. We felt well supported by everyone. It’s great to have people to talk to, share experiences with, get advice from and have a laugh with

was reflected in our decision to pay everyone the same daily rate. However, it was always clear that we were the decision-makers and in charge of the money.

It was useful to have someone who had the job of supporting the whole group and guiding us through the detailed research things. It helped to have someone central to organise
I liked working in pairs. If I got stuck on a question you jumped in. If you got stuck, I jumped in

some of the practical things, like minutes and meetings. This person could also be a sounding board for us individually in the meetings or at other times.

Travelling on the railways is an experience in itself, often not a positive one. We have had the company of drunks, punks and various life stories. Having booked assistance it is sometimes not in the right place at the right time, leaving you wondering is it was worth the effort

We feel we learnt a lot. It was really tough at times. It was very tiring (we had to do eight interviews in a day at one project). There was a lot of travelling and a lot of organisation involved.

There were also challenges in learning about research, like how to do analysis. There were also challenges as a team. Sometimes we had to sort out disagreements.

One of the hardest things was dealing with the research sites and the interviews. It was not always easy for team members to set limits on what the research participants wanted to talk about.
There were sometimes distressing interviews, which we had to deal with afterwards. This would have been impossible without our supporters and the help of the group as a whole.

But it was satisfying to get through to the end of the project and see all the hard work come together. We enjoyed doing presentations and finding new and fun ways to share information.

Getting to talk with some of the researchers was worse than getting an audience to see the Pope!

I wish I’d said “I’m sorry I can’t get into that” and put my foot down when people started talking about upsetting things. We should have come over stronger.
We also enjoyed meeting all the researchers and people with learning difficulties around the country and hearing their views. It surprised us that most researchers we met were really down-to-earth. They welcomed us and answered all our questions.

We learnt about the practical things of doing research, like how to position your tape recorder and how to make notes. Another time it wasn't switched on and we missed the whole interview, a costly lesson to learn. It was good to tape the interviews but it is a lot of hard work to get it off the tape and onto paper so that we could take information back to the group for analysis.

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What will change as a result of our work?

At the start of this research we said we weren’t interested in doing something that ended up in a boring report, sitting on a shelf.

We are interested in changing things. We want more people with learning difficulties to get the chance to do research. This means more than being an advisor or occasional worker, although those things are important too. But it also means designing research, doing fieldwork and analysis, and managing projects and budgets.

For this to happen, research funding needs to be given, or involve, a wider group of people than is common up to now. It is very important that researchers think about how they can involve more people with learning difficulties in more powerful positions in research. It also means funders thinking about where they give their money and what for.

This group of people have actually done the work and done the report. It could change researchers’ minds about involving people with learning difficulties, with more people involved as paid researchers.

The research shouldn’t be put into a cupboard and forgotten about.
2005

Can I be one of the researchers?
I thought you’d never ask!

I wonder if I will be able to do a good job?

Can I come and interview you?

Yes!

I hope I don’t mess it up!

These are the things that I found out.

How interesting, you’ve done a great job!

We must pay you!
Learning Difficulties Research Initiative

Gordon Grant, Paul Ramcharan

University of Sheffield
Contact: g.grant@sheffield.ac.uk or p.ramcharan@sheffield.ac.uk

The twelve research projects are supported by the Learning Difficulties Research Initiative. The LDRI has a reference group of people from academic and policy organisations and government departments. It includes people with learning difficulties.

The reference group meets every six months and its jobs are to:

• check how the research projects are doing
• give help and support to the projects
• read final reports from the projects
• tell the Department of Health how the projects are going
• work out the overall lessons from the research projects and tell the Department of Health about how to get information this out to people.
**Symptoms of abuse in people with severe learning difficulties**

Ali O’Callaghan, Glynis Murphy and Isabel Clare

Tizard Centre, University of Kent, Canterbury CT2 7LZ
Contact: a.c.o’callaghan@kent.ac.uk

The aim of this research was to find out how abuse affects people with severe or profound learning difficulties. Many of the people who took part in the research don’t use spoken words, and so found it hard to communicate what had happened to them.

**Effectiveness of group cognitive behavioural treatment for men with learning disabilities at risk of offending**

Glynis Murphy, Neil Sinclair

Tizard Centre, University of Kent, Canterbury CT2 7LZ
Contact: g.h.murphy@lancaster.ac.uk

This research aimed to find out if a particular kind of treatment helps men with learning difficulties who sexually offend. This treatment gets the men in the study to think about their behaviour and come up with a plan for their behaviour which can help them not to offend or not to offend again. This kind of treatment has not been used with people with learning difficulties before.

**Health facilitation and learning disability: evaluating the role of health facilitators**

Ghazala Mir, Karl Atkins

Centre for Research in Primary Care, University of Leeds
Contact: medgm@leeds.ac.uk

This research looks at how people can be supported by workers called health facilitators to think about their own health needs. People with learning difficulties should be able to get good healthcare. There should be more easy to understand information and support. It will look at barriers to people being involved in health plans. And it will look at examples of good practice.
Information for all: evidence based guidance on producing accessible information for people with learning disabilities

Jackie Rodgers
Norah Fry Research Centre, University of Bristol, 3 Priory Road, Bristol BS8 1TX
Contact: j.rodgers@bristol.ac.uk or m.baker@bristol.ac.uk

This research looked at making information easier for people to use. The research has done a guide with different sections to help people make information accessible. It suggests that researchers think carefully about the people they are working with and adjust the information they use to suit each individual group.

The impact of the Human Rights Act 1998 on people with learning disabilities

Pat Finnegan, Stephen Clarke
Contact: p.finnegan@btinternet.com or s.clarke@btinternet.com

This looked at the potential impact of the Human Rights Act on the lives of people with a learning disability. The researchers interviewed people in services, lawyers and people with learning difficulties and their supporters to find out what people know about the Human Rights Act and whether people’s human rights are being respected.

Exercising choice and control: women with learning disabilities and their reproductive health care needs

Michelle McCarthy
University of Kent at Canterbury
Contact: m.mccarthy@ukc.ac.uk

This looked at women’s health issues such as contraception, periods and the menopause. It aimed to find out how much choice and control women with learning difficulties have in relation to these areas of their health. The researcher interviewed people from services and worked with a focus group of women with learning difficulties.
An evaluation of the impact of person centred planning on the lives of people with learning difficulties

Janet Robertson, Eric Emerson, Barbara McIntosh

Institute for Health Research, University of Lancaster, Lancaster LA1 4YT
Contact: j.m.robertson@lancaster.ac.uk

This research looked at whether person centred plans really made a difference to people’s lives. It also looked at the costs of person centred plans. The researchers worked in four areas supporting PCPs in each area, then evaluated how they worked and what difference they made to people's lives.

Will Valuing People make a difference?

 Eric Emerson, Carolyne Lobb

Institute for Health Research, University of Lancaster, Lancaster LA1 4YT
Contact: c.lobb@lancaster.ac.uk

This research looked at the information that is collected about people with learning difficulties, and what this information tells the government about people’s lives. Should other information be collected? Or should information be collected in different ways?

A profile of employment officers for people with learning disabilities

 Justine Schneider

University of Durham
Contact: Justine.Schneider@durham.ac.uk

This research asked questions about supported employment, like who helps people with learning difficulties to get jobs? How do they do it and what works for different people? What needs to change to help more people get good jobs? The researchers used questionnaires to gather the views of a large number of supporters, family members, employment officers and people with learning difficulties.
Strategies for change in services for people with learning disabilities

Rachel Fyson
Norah Fry Research Centre, University of Bristol, 3 Priory Road, Bristol BS8 1TX
Contact: rachel.fyson@bristol.ac.uk

The researchers on this project looked at how Valuing People was being applied and how services were being planned. The research looked at the work done by Partnership Boards and people who plan services.

Evaluating support services for school leavers with learning disabilities with special reference to ethnicity

Raghu Raghavan, Nicole Pawson, Neil Small
University of Bradford
Contact: n.p.pawson@Bradford.ac.uk

This research wanted to find out about the support available to people who are leaving school and becoming adults. The research was particularly interested in the experience of people from black and minority ethnic communities. Using a variety of methods, the researchers worked with people with higher support needs and their families from local minority ethnic communities.

Developing measures of core competencies and job performance in residential support staff working with people with learning disabilities

Chris Hatton, Janet Robertson, Eric Emerson
University of Lancaster
Contact: c.hatton@lancaster.ac.uk

This research gathered the views of a care home managers, workers and people with learning difficulties to find out what skills care workers need.
### Number of people interviewed at each research site

<table>
<thead>
<tr>
<th>Research Site</th>
<th>Paid researchers</th>
<th>Advisors</th>
<th>Participants</th>
<th>Total</th>
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<td></td>
<td>Pwld</td>
<td>Pw/o</td>
<td>Pwld</td>
<td>Pw/o</td>
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<td>Residential support staff, Lancaster University</td>
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<td><strong>Total</strong></td>
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</tbody>
</table>

Pwld = people with learning difficulties    Pw/o = people without learning difficulties
Part 1: General Questions

About you and the research
1. What is your full name?
2. What do you do for the research? (Job title if they have one)
3. Who are you employed by?
4. What is the name of your research project?
5. When did it start?
6. When will it end?
7. Where are you up to with the project?
8. Why did you get involved?

About the research team
9. How many people are on the research team?
10. Do any of them have learning difficulties?

If yes:
   a) How were those people recruited?
   b) How are they supported to do their job?
   c) Are they paid?
   d) What have you learnt about working with people with learning difficulties as researchers? (good and bad)
e) What’s been difficult and what have you done about it?
f) Have the people with learning difficulties had any influence on how the research has run or what it’s found out?

*If not, why not?*

**About advisors for the research**

11. Have people with learning difficulties been involved in running the research in other ways? (e.g. as advisors, trainers or consultants)

*If yes:*

a) How many people are involved in this way?
b) What do they do?
c) How were they recruited?
d) Have people been paid?
e) How are they supported?
f) What influence have they had on the research?
g) What lessons have you learnt about involving people in this way?

**About research participants**

12. Have people with learning difficulties been involved in the research as participants?

*If yes:*

a) How do they take part?
b) How were those people recruited?
c) Are they paid?
d) Are they supported to take part?
e) What have you learnt about working with people with learning difficulties as research participants? (good and bad)
f) What's been difficult and what have you done about it?
g) Has involving people influenced the research in any way?

If not, why not?

About accessible information

13. Have you made any information accessible?

If yes:

a) How did you do it?
b) Have you had any feedback about it?
c) What have you learnt?
d) Can we see a copy?

14. Do you want to get your findings out to people with learning difficulties?

If yes:

a) How are you going to do this?
b) Will people with learning difficulties help?
c) What methods work best?
d) What needs to happen to make good dissemination happen?

If not, why not?

Part 2: Questions about this research

Specific questions here related to each research site and interviewee.
Part 3: Other questions
15. Have you involved people from black and ethnic minority communities in your research?

If yes:
   a) How did you do it?
   b) Have you had any feedback about it?
   c) What have you learnt?

16. Have you involved people with learning difficulties in your research in any other way?

If yes:
   a) How?
   b) What have you learnt?
   c) If you did the research again, would you do anything differently about involving people with learning difficulties?

Part 4: Ending
18. Is there anything else you want to say about involving people with learning difficulties in research?

19. Who else should we be interviewing?
   Can you help us contact them?

20. Any more comments?
   Thank you very much.

What will happen next
Our Project Information Leaflet

*Learning Difficulties Research Team*

“getting involved in our research!”

We are a group of people with learning difficulties called the Learning Difficulties Research Team.

Our names are:

Kevin Preen
Brian White
Michael Ratcliffe
Joan Scott
Jackie Downer
Gordon McBride
Amanda Platts

We are doing research about how people with learning difficulties get involved in research.

*See overleaf to find out more!*
What is our research about?

The Department of Health asked us to find out all about good ways to involve people with learning difficulties in research.

We are doing this by looking at what’s happened in 12 research projects funded by the government through the Valuing People white paper. These projects are based in universities and research organisations across England.

We want to find out:

- How people with learning difficulties got involved in these research projects
- What works and what doesn’t work about involving people with learning difficulties in research
- What everyone thinks about it

We started our project in May 2003. We are doing lots of travelling around the country to meet people and ask them questions about their views and experiences.

What happens next?

After we finish interviewing people we will put all our information together. We will work out what we’ve found out about good ways to involve people with learning difficulties in research. In 2005 we will publish a report, run a conference and do other things to tell people what we’ve found out.
We can give you a copy of the report.
We can tell you about the conference.

What about my privacy?
There are some things about confidentiality that we want to tell you:

1. We will not use your name in our reports.
2. We will make sure other people cannot guess who you are and what you have said.
3. It’s Ok if you don’t want to take part or you don’t want to answer a question. Just tell us.
4. We will keep our notes and tapes very safely. We won’t show them to anyone outside our project and we will destroy them after the project ends.

This is an exciting project because we are the researchers and we are also running the project ourselves. We manage the money, make all the decisions and do the research.
We get support for all of this from Catherine Bewley at Values Into Action and our supporters. Their names are:

Jane Ellis Morgan
Linette Farquarson
Dee Harrad
Katherine Dobbs
Marie O’Sullivan
Pam Dale

If you want to ask questions, please do!

If you want to contact us, please call:

or call Catherine Bewley on 020 7733 9408

Our contact address is care of: Values Into Action,
Oxford House, Derbyshire Street, London E2 6HG

THANK YOU!
Glossary – Some words explained

**Academic**: research that happens in universities and the people who work in universities doing this work.

**Advisory group**: a group of people with experience and skills who offer advice and support to a research project. People are not usually paid to do this.

**Analysis**: looking at the information gathered through research and deciding what it means.

**Conclusions**: what you say about your research topic, once you work out what the data is telling you.

**Confidentiality**: being careful about using information, and not sharing people’s private information.

**Consent**: agreeing to take part in the research. Before they agree, people should understand what the research is about, what their part in it will be, and what will happen to the information about them at the end of the research.

**Data**: The information you gather in the research.

**Dissemination**: telling people what the research has found out. This can be done in different ways, including reports, conferences, presentations, newsletters, websites etc.

**Fieldwork**: collecting information through interviews, talking to groups, asking questions, making visits etc.

**Findings**: what the researchers found out.

**Focus group**: a group of people brought together to give their opinions or answer questions on an issue.

**Interview schedule**: the list of questions asked at a research interview. Usually the same questions are asked of everyone, so that their answers can be counted and compared.

**Methodology**: the way you do research.
Outreach: going out to find and meet people where they live, work or get together.

Peer supporters: people with learning difficulties who support others in research interviews.

People who don’t use speech: people with higher support needs who don’t use words (but do use lots of other ways to communicate).

Piloting: trying something out as if you are doing it for real.

Process: the order of things that happen so that you achieve what you are aiming for.

Qualitative: research methods that focus on what people think, say, feel and do, often using people’s stories and words.

Questionnaire: a list of questions on paper which you are asked in a set way or which you answer on paper.

Recommendations: suggestions for change which are made because of what research is telling us.

Reflexive: a research method that finds ways to record what the researchers are thinking, feeling and doing and uses this material as research data, sometimes to change the process as it goes along.

Research participants: the people who are asked questions or who test things out to provide the information for the researchers.

Research proposal: the paper that says what your research is about when you are trying to get money for it.

Semi-structured interviews: interviews that are guided by a list of questions but which are also flexible to suit the person being interviewed.

Subjects: a traditional research word that means participants, the people who take part in research.

Timescales: the length of time available for a task.

Triangulation: way of analysing research data that looks at it from lots of angles to see what themes are the same and what are different.

Visual impairment: people who don’t see or don’t see very well.
Useful References and Contacts

References


Contacts
Research at the Department of Health
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Illustrations
Penny Mendonca
Email: pennymendonca@btinternet.com

CHANGE Picture Bank
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Tel: 0113 243 0202
www.changepeople.co.uk