



WE ARE NOT STUPID

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People First Lambeth



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Contents List of what is in this book

Acknowledgements	page 4
Thanks to everyone who helped to make this book happen	
Series Introduction	page 5
Peter Beresford writes about this series of books	
Preface	page 7
Nicola Smith writes about this book	
Summary	page 8
A short bit of writing explaining what is in this book	
Foreword	page 12
Raymond Johnson talks about self-advocacy and this book	
Introduction	page 15
What this book tells people	
Changing Names	page 18
We thought it was important to change people's names in this book	
1 How we did the research	page 19
Our research	
People we worked with in the Research Group	
2 Starting our research	page 25
We chose to work with each other	
We live in this world too	
We want to be heard	
Why we are doing this research instead of other people	
3 Researching together	page 31
Our research support	
Ground rules	
Being paid: funding	
Our minutes	
Writing this book	
Changing names	
4 Standing up to bullies and rude people	page 37
5 Being called racist names: what we tried to do about it	page 41
6 Rape and sexual abuse	page 45
7 Having relationships	page 53
Not all relationships are good	

8	Choice and Independence	page 61
	Choices	
	“Independence” means taking control of your life	
9	About our staff	page 67
	Telling us what to do	
	It is not the staffs’ job to tell us off, be rude or boss us around	
	We don’t want staff to stop the joking: It’s good when staff can take a joke	
	Staff can sometimes be frightening	
	We don’t like staff wrongly accusing us of not telling the truth	
	Staff can say hurtful things	
	Staff can think they are in control of us	
	At times nothing we say is confidential: staff talking to staff	
10	We want what everyone wants	page 83
	Being where you don’t want to be	
	Getting out and about	
	Transport trouble	
	What the white paper (Valuing People) means to us	
	We want what everyone wants	

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Series Introduction

This book is the first in a new series which *Shaping Our Lives* is publishing. We know that service users often have difficulties sharing their first hand knowledge and experience with each other and ensuring that these are readily available to inform and influence mainstream policy and practice. We know that service users and those who seek to support them frequently find it difficult to get hold of such “service user knowledge” and experience to help them increase effective user involvement and to improve the quality of services and support that people receive. At the same time, we know that they find such first hand evidence and information particularly valuable and helpful.

That is why *Shaping Our Lives* is producing this new series of new publications. They will provide opportunities for service users to publish key findings and share knowledge and experience that can help improve the lives of service users and secure their rights and needs.

As an independent service user controlled national organisation and network, *Shaping Our Lives* works to increase the involvement of service users and to improve the quality of their lives and support services. We are closely linked with local service users and service user organisations, as well as working with government and other organisations to improve the quality of service users’ lives. We carry out research and undertake development work. We are made up of and work with a wide range of service users. This includes people with physical and sensory impairments, Deaf people, older people, mental health service users/survivors, people living with HIV/AIDS, who use palliative care services, with experience of being “looked after” in state care, children and young people, people with learning difficulties and so on. We work hard to be inclusive and address issues of diversity.



**Peter
Beresford**

We are very proud that this book *We Are Not Stupid* is the first in this series. In our view it breaks new ground. It has a special contribution to make, to challenge the exclusion and disempowerment of people with learning difficulties. This is a book by people with learning difficulties, reporting the findings of a research project carried out and controlled by people with learning difficulties, to help change the lives of people with learning difficulties. As the authors make clear, people with learning difficulties are still often treated as less than full citizens, less than adults, less than human. This book provides evidence of this, but also highlights how things can change. It is intended to add to the weight of work now going on to secure people with learning difficulties' rights, equality, opportunities and participation.

This book tells important truths. Some of them may be difficult for some service providers and others to hear. We hope that they will also hear the positives; the praise for good services and good practitioners, for sensitivity, creativity and support. This is a book which we hope everybody who comes to work with people with learning difficulties has an opportunity to read – because it offers the chance for them to become the workers people want for the future, to help transform people's lives, life chances and support.

Peter Beresford

Chair, Shaping Our Lives

Preface

We Are Not Stupid is based on the research work carried out by members of People First, Lambeth and is proof that people with learning difficulties can be researchers into their own lives and issues. This is in contrast to much of the existing research work about people with learning difficulties.

This book looks at the issues which affect people with learning difficulties, such as bullying, racism, relationships, choice and independence and staff. It is told from the point of view of people with learning difficulties and is an honest insight into their experiences, problems and views. It is a book that many people will identify with, including people who do not have learning difficulties because it is about people wanting an ordinary life.

This book also sends out a challenge to *Valuing People* [White Paper]; it says that not enough progress has been made in the past six years. There are still barriers that stop people with learning difficulties from moving on from college into work, or living independently, or from having a social life. Some of these barriers are because of practical things like transport; others are because of people's attitudes towards people with learning difficulties. These are things that the government still needs to address.

Finally, this book send out a clear message that people with learning difficulties are just like everyone else. They want the same opportunities as everyone else. They want to live as part of the community, to work, to have relationships and a social life, and to have choice and control over their lives. They want to be respected as individuals, without discrimination, and they want the right support to lead the kinds of lives they aspire to. I hope that this book will challenge and inspire everyone who reads it, and that policy-makers and professionals will hear the message that "we are not stupid".

Nicola Smith

Co-National Director: Learning Disabilities, NHS

Summary



This summary of *We Are Not Stupid* says in a few words what is in each chapter of this book. The first three chapters say how we worked together and did our research. The rest of the chapters are about what happens to people with learning difficulties. At the end of each chapter we tell you what we think about what happens.



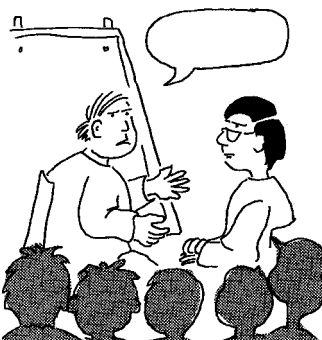
Chapter 1: How we did the research

Our research is about the lives of people with learning difficulties. We also found out what people with learning difficulties want their lives to be like. We interviewed people about what is happening in their life and what changes they would like to see. We say who took part in this research and how we organised our interviews.



Chapter 2: Starting our research

We chose to work together because we trust each other and work well as a group. We started off by talking about how fed up we all were about being put down by people who don't understand us and make us feel stupid and small. We wanted to do something about it and show people how we felt and what we thought. We want to be heard, to put our voices across, to try and help people understand that we are human beings too. We wanted to show people that we can write a book. We are doing this research because we know what it's like to live for your whole life as a person with learning disabilities.



Chapter 3: Researching together

We had someone who supported us to do this research and write this book. We all supported each other as well. We got on well and found we didn't want or need ground rules for our meetings. We were in charge of this research and what went into this book, not our supporter. Getting funding and getting paid for doing this research was difficult but

we did it in the end. We tell you about how, with support, we wrote this book and made it safe for people to say what they wanted.

Chapter 4: Standing up to bullies and rude people

We started talking with other people with learning difficulties and people told us that a lot of people with learning difficulties get bullied and called nasty names. Some people don't think we are human like everyone else. We need to stand up to these bullies. Not all people with learning difficulties stand up for themselves. Some people need support to stand up to bullies and rude people.



Chapter 5: Being called racist names - what we tried to do about it

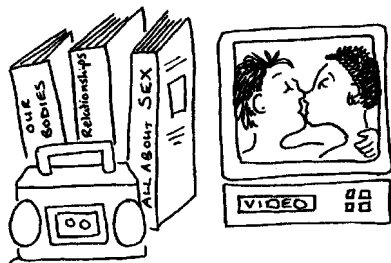
We found that white service users were sometimes calling black service users racist names and decided to try and do something about this. We asked two Social Services managers to meet with us to try and sort out the problem. What we found was they didn't help at all. They said they would but in the end they did nothing. This put us off working with Social Services to try and solve this problem. We felt like our time was wasted.



Chapter 6: Rape and sexual abuse

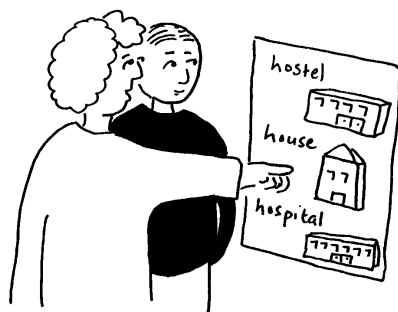
In this chapter we hear that some people with learning difficulties get forced to have sex without their consent. It can be in the family or in the street or in a residential home. We talk about what to do if people are pestering you for sex or following you outside. Some people with learning difficulties must learn how to say no and understand that "no" means "no". People also need to be protected, by staff that support them, from being raped or sexually abused in residential homes.





Chapter 7: Having relationships

People with learning difficulties can find it hard to have a relationship if they want one. Staff or parents can stop them, or not support them, to meet with boyfriends or girlfriends. People with learning difficulties should be able to have sex with their boyfriend or girlfriend or to get married, or live together and make a baby if they want. People need to know about how not to get pregnant though and how to protect themselves from catching a sexual disease. Not all relationships are good. Sometimes people with learning difficulties end up being treated very badly in relationships. People should get support to get out of bad relationships if they need it.



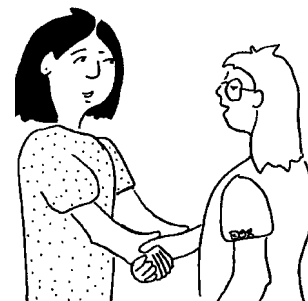
Chapter 8: Choice and Independence

In this chapter we tell you what independence means to us and the people we talked with. People with learning difficulties often don't get any choice about what they are doing in their lives. We kept on hearing about how it was what the staff wanted them to do and how the staff were not asking people with learning difficulties what they want to do in their life. People with learning difficulties want to make their own choices and have a say about what happens in their lives. We don't want people to control us. For us "being independent" is about taking control over your life as an adult and having a say about what you do in your life and what your needs are.

Chapter 9: About our staff

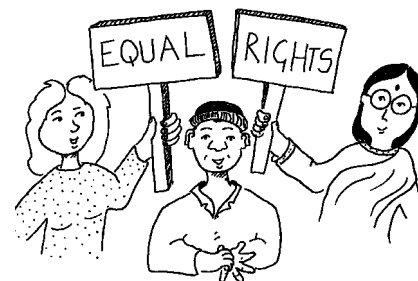
We hear, and we know from our own lives, that service staff can be nasty to people with learning difficulties and give you nasty looks and get away with it. They can talk behind your back as well. It is wrong. Some staff can be nice but not all of them. Some of the staff can be horrible to you but when you say things about them they don't like it at all. Staff can follow you around or boss you about and not let you do what you want to do in your own home. Some staff are scary. We are standing up against this, telling the truth. We don't believe in

letting staff pull people down. In this book we let people know what we want staff to be like. We want friendly, kind, polite, understanding staff, with a good sense of humour and a good personality, who support us to do what we want to do.

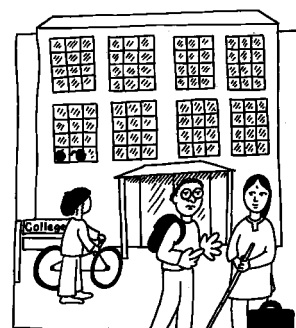


Chapter 10: We want what everyone wants

In the last chapter of our book we look at what stops us living the life we want to live and we look at the White Paper called Valuing People.



The people with learning difficulties we talked to said they are not getting out a lot. They want to mix with people a bit more but they can't. Some people have been going to college years and years and they don't get a good job. They just keep going to college. Some people want to move into their own flats and lead their own life but they can't, because they can't get the support they want. People want to go out in the evenings but they can either get stopped or don't get the support they need to go out. Transport is a big problem. Often people can't use buses much without support or don't feel safe on the bus but they can't afford taxis and don't have a support worker to go with them anywhere.



The white paper Valuing People is supposed to help people with learning difficulties but it's not helping enough. Things are not changing enough. People with learning difficulties are still not living the sort of life they want to live. We want the same as everyone else, just a normal life where we mix in with other people in the community. We want to be safe on the street. We want some respect and to be treated like human beings.



Foreword: Self-advocacy and this book



My name is Raymond Johnson. I've got learning difficulties. Back in the early 1990s I got to know People First as an organization through a sexuality conference. At that time I had problems with my family and Social Services told me I had to share with another person with learning difficulties in Tottenham. I didn't have any choice. I didn't get the respect I get now. I felt I was banging my head against a brick wall most of the time.



I went to Manpower Government schemes. They paid me peanuts. This was in the Thatcher years. At the time People First was only a small organization. The idea about self-advocacy had come over from The States. Little by little I got to know how People First worked and how to stand up for our rights and believe in ourselves.



I'm the National Self-Advocacy Worker for People First National now. I've been doing this job for a few years. I left People First Lambeth in January 2002. What I do is I go up and down the country to look at how self-advocacy groups are getting on and how user led they are. Let me explain about it. When I see the groups, in whatever part of the country I'm going to, I find out if the users run their group instead of the supporters or if it's the other way round.

Some supporters say I don't have the power to represent other people with learning difficulties. These are supporters who think they can get the power to run the group instead of people with learning difficulties. The sort of supporters who say: "We are going to do this today. We are going to do that today". We have to make our voices heard.

This book tells people about how people who haven't got learning difficulties treat us in general, out on the streets and in places like pubs, the theatre, sporting events, public transport and in services that are for

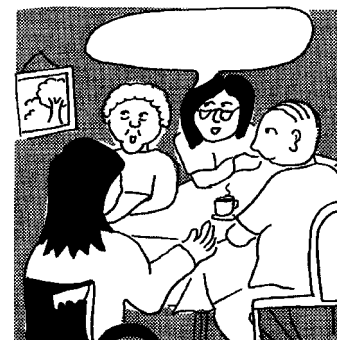
people with learning difficulties and not run by people with learning difficulties.

We are telling the truth, the whole truth and nothing but the truth and putting it down in black and white. This book tells people how we've been treated in the past and shows how we want to be treated in the future.



The things that happen in Lambeth could happen anywhere else. Nowhere is perfect at all really. In my job I travel all over the U.K. Basically I get to hear stories. I get to hear that in some group homes people are treated badly. I get to hear how groups can't get money or people can't get jobs because of how society looks at us, like we're stupid people. They say "you're too stupid, too slow" and all that.

The White Paper [Valuing People] said day centres should be shut down but at the moment they are still there. I feel sorry for people in day centres. If people like to be in there it's sad. They are not getting a good wage like I am. As far as I'm concerned they haven't got anything interesting to do. I went to day centres in Hackney and near Tottenham. My personal experience of day centres was that they were a bad place for me as a black person, and not only just for me, for other black people as well.



I was in Leeds a while ago and people were telling me they don't get their voices heard in the day centre. I've been across the country and I've been hearing that people with learning difficulties don't get their voices heard for some reason.



The reason why we wrote this book is to show people who haven't got learning difficulties for starters (we are talking about professionals, doctors, nurses or any man or woman in the street) that we are not stupid. We can tell people who haven't got learning difficulties what our point of view is. We can write a book and do the things that everyone else does.

This book is written in plain English and is jargon free. It is written in a way that more people with



learning difficulties can understand. We would like other people with learning difficulties to hear what we've got to say, to hear our voices and see how we stand up for ourselves. We shouldn't be ignored anymore and looked upon in the bad way that society sees us at the moment.

Raymond Johnson

Introduction: What this book tells people

We are a research group run by and for people with learning difficulties. Research is finding out things and writing it down. Our research is about finding out about the problems that people with learning difficulties face and finding out what can be done to change things for the better. We make all the decisions about what research we do and what happens in our research group. This book is about us and our work. We are one of the first groups of people with learning difficulties to do this sort of work.

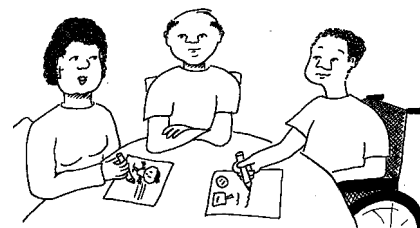
We work in People First Lambeth. People First Lambeth is a charity that supports people with learning difficulties to stand up for themselves and take control of our lives. People First Lambeth also works towards making the lives of people with learning difficulties better by campaigning on their behalf. People First Lambeth has a Management Committee made up of people with learning difficulties. A few years ago we became an independent charity. This has taken a long time and been a lot of hard work for the directors, members and supporters of People First Lambeth.

Our names are Jennifer Taylor, Vanessa Williams, Maggie Brennan and Ian Hiscutt. Jennifer and Vanessa got the Research Group together in June 2001 along with Ray Johnson. Ray Johnson had to leave the group after a couple of years because he got a new full time paid job nearer to where he lives. Ray, Jennifer and Vanessa are black, Ian and Maggie are white. We are all members of People First Lambeth.

In this book we say what we think about life... our life as people with learning disabilities.

Ian

This book... tells [people] that people with learning difficulties are not stupid and that we



Jennifer



Vanessa



Maggie



Ian



want more power. We have got something to say.
Ian

This book is about our experiences and what we have been through in our lives with a learning disability... I would like you to read it and find out for yourself.

Jennifer



This book tells you how we did this book
Ian

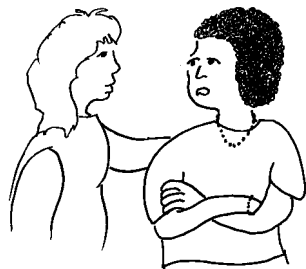
... We tell you how we did the research in the first place so other people can get involved in this type of research. [So that] some people can do it without learning disabilities and some people can do it with learning disabilities.

Jennifer



We explain how we did our research and how we got together... to do it... [and how] it was difficult getting funding at first but we got through it at the end.

Jennifer



[We tell you how] we worked with [other] people with learning difficulties to find out their experiences as well and find out how they feel in their lives, not only us... It was important to get other people with learning difficulties to do the research...

Maggie



We interviewed them and asked them questions about their lives and told them about the research we are doing and they were interested in getting involved in the research because it was important to them.

We tell people about day-centres and what it is like. People have had a lot of bad experiences.
Maggie

We found out about different residential homes. Some people are treated badly in there.
Maggie

Getting bullied and getting called nasty names.

Jennifer

Some of the time... they don't give choices in residential homes, they just tell you what to do all the time...

Maggie

Some staff can be really nasty to you.

Jennifer

We tell you about people being abused by someone and bullied.

Ian

There is a lot [about] abuse in this book we are telling people about people's experience of being raped and sexually assaulted.

Maggie

[This book lets the reader know about] how people with learning disabilities were angry about not getting enough support.

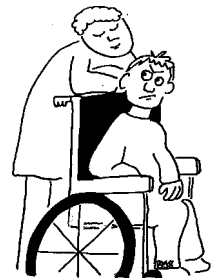
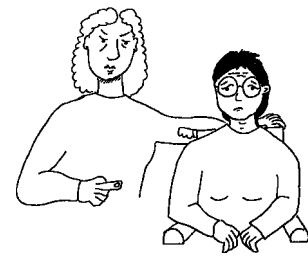
Maggie

We stand our ground and tell people "look, right this is our life, if you don't like people with learning difficulties just don't take the piss out of us, or take liberties because it is just not right. We have got the right to live on this planet like you have and if you don't like it you know what you can do."

Jennifer

We are telling these people what we think.

Jennifer



Changing names

All the names of people we talked to and people we talked about in this book have been changed from Chapter Four onwards, except for Vic Forrest, our support worker. All the names of places that are mentioned like residential homes and colleges have also been changed. In a few places names have been changed more than once.

Chapter 1 How we did the research

Our research

Jennifer said this about what the word “research” means:

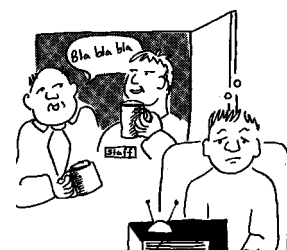
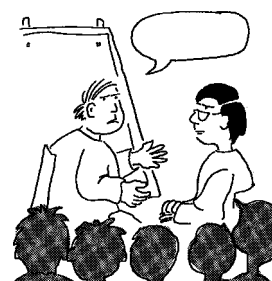
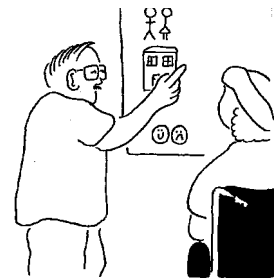
It’s like a piece of information that people want to get, to find out about things.

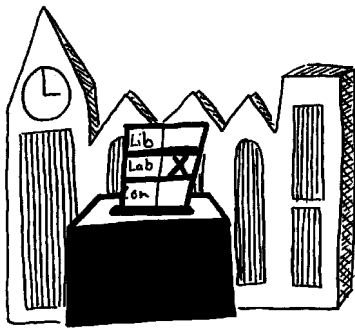
Maggie said this about what our “research” is:

It’s a piece of work that people do, finding out different people’s views about different services. We have the right to find out about different services.

We wanted to look into the things we cared about the most and write about them in our book. What we cared about was what was happening in the lives of people with learning difficulties. We had not been meeting together very long when we put together some ideas for things to start looking into. This is what they were:

- People going to day centres and not getting properly paid jobs.
- People being nasty to people with learning difficulties and making us feel stupid.
- What people with learning difficulties lives are like: What is in their/our lives?
- What do they/we want?
- How can they/we get it?
- People with learning difficulties being controlled or bossed around by people without learning difficulties.
- The names people with learning difficulties get called.
- People with learning difficulties trying to get what they/we want but not always getting somewhere. For example people wanting to move and Social Services saying they will do something for months on end without any changes happening.





- People forcing themselves on people with learning difficulties, making them have sex when they don't want to.
- Racism.

Ray was also interested to find out how many people with learning difficulties in Britain voted in the election. In the end we decided that this would be too difficult to find out.

Ray said that we should try and find a way to do as many of our research ideas as we can and find a way to fit our ideas together.

What we decided to do was talk with each other about the things we wanted to look into. This was not hard to do because between us we have a lot of experience of the things we wanted to look at. We decided that we would speak with other people with learning difficulties to see what they had to say about the things we were looking into. We also worked together to try and put right some of the bad things we have in our lives as people with learning difficulties. We did this for ourselves and for other people with learning difficulties.

Our research is about:

Finding out about daily life
Ian

Our daily life, the people with learning difficulties
Jennifer

We want to know what is going on with people with learning difficulties
Maggie

Jennifer explained what the point of our research is:

We want to let other people around the country know what is going on in people's lives, people with learning difficulties. We want to know what is going on. That is why we want [people] to have copies of the book, so that people will know what is going on, how people with learning difficulties are suffering, because it's us that's going through all the pain, the hurt and the fear and bullying and



all that stuff, not them and we are not putting up with it any longer.

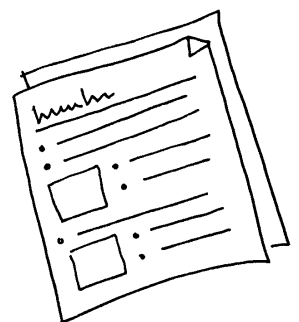
Maggie said this about the point of our research: People should know about us... We have a learning difficulty and people shouldn't treat us really badly. [We want to] let people know where we are coming from, to put them straight so they can understand what we are about.



People we worked with in the Research Group.

We found out a lot from talking to each other and other people with learning difficulties in People First. We also talked with different people with learning difficulties who are not People First members and interviewed them. At the interviews we decided to ask people these questions:

- What do you like in your life?
- What don't you like in your life?
- What do you do in the daytime?
- What do you do at night?
- What do you do at the weekend?
- How do staff treat you?
- Does anyone boss you around or stop you from doing anything?
- If you are being bullied can you say what happens?
- Has anyone forced you to have sex?
- Are you allowed to have a boyfriend or girlfriend? Can you tell us about this?
- How do you want your life to change? What do you want in the future?



We wanted to find out about their experiences and how they live, what their life is like now.

It took us two days to talk through the questions with people.



We asked people if they would like to be interviewed... They said yes... We talked to each other and asked questions. We were finding out different people's views.

Maggie



Twelve people with learning difficulties (including us) took part in the meetings where we talked through the questions together. Six people were black and minority ethnic. Seven were women. The youngest person was in his late twenties and the oldest was in her late fifties. Five people lived in residential homes. Five people lived in their own flats with support and two people lived with their parents. Five people were going to a day centre for people with learning difficulties. Six people were going to college courses for people with learning difficulties. Three people had paid jobs as self-advocacy workers.

We decided to only talk with people we knew and trusted. There were reasons for this. As Jennifer put it:

I didn't know who to trust but I trusted them [the people we interviewed]. I trust Raymond and Vanessa and you Vic but people outside I didn't trust. They might gossip to people from outside. I wanted to keep it in People First because it is confidential. If it's something to do about your life and what happened in the past it has to be private.

Ian said:

They trusted us because we knew them. They wouldn't talk if they don't trust us.

Vanessa said:

We chose people who like to talk about their problems outside of here, [problems they have] maybe on the street, maybe at home.

We got in touch with some people by ringing them up. Other people went to day centres or colleges that some of us went to and we talked to them and asked them if they wanted to take part in the research.

We organized the interviews ourselves.



Vanessa said:

I organized all the meetings for people from Nicholas Road, [day centre] getting them here and making sure they were involved.

We had very little money and couldn't afford to meet with people outside of London anyway. As Jennifer put it:

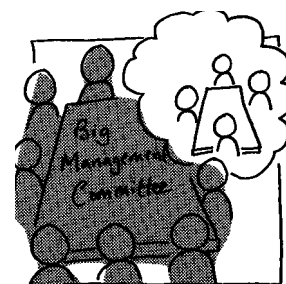
We didn't have the money to stay in a hotel. We would have had to find the money to pay them back.

In our day to day lives we all meet a lot with different people with learning difficulties who talk with us about what is happening in their lives and the problems they have.

We know that other people with learning difficulties can have the same sorts of problems as us and the people we interviewed. Sometimes we talked about the problems that people we knew had. They had told us their problems when we were talking to them outside of Research Group meetings.

Sometimes people with learning difficulties wanted to tell us something that they wanted putting in the book. So we had some extra meetings with them.

We have all been to lots of big and small meetings and conferences where people with learning difficulties say what we want out of life. We live this life with other people with learning difficulties and know what we are talking about.



We want to tell you...

We wanted to show that we are human

We believe all people should be treated with the same respect

We know about what happens in our lives better than anyone

We wanted to get people with learning difficulties' views about how we get treated.

We decided what our research should be about

**It was important that we worked with people we could trust
and that they could trust us**

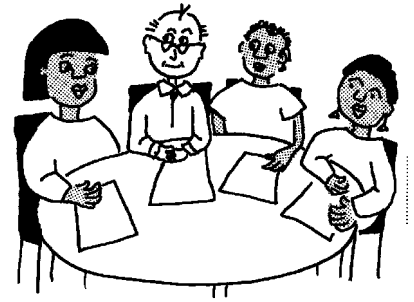
We made up our own research questions

We interviewed other people with learning difficulties

Chapter 2 Starting our research

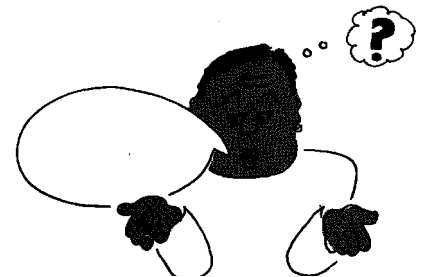
We chose to work with each other

The research group is controlled by us researchers with learning difficulties. The way we started was our supporter, Vic, asked Ray who was working as the Self-advocacy Development worker in People First, if he thought people might like to be supported by him to do whatever research they wanted to do. Ray was interested in getting a research group together. He chose to ask Jennifer if she wanted to be in the group and then Jennifer and Ray chose to ask Vanessa. When Ray left Jennifer and Vanessa chose to ask Ian if he wanted to be in the group. We had decided that we wanted to be in a group of three, and no more but then we changed our mind when Maggie offered to join the group.



We live in this world too

In one of our very first meetings Ray wondered why people and society are against us rather than for us. Maggie has said some people are against us. Jennifer said some people are nice and some people are not nice, there are “nasty people out there”. Ian said “wicked people”.



Jennifer and Ian have talked about being put down by people. This is what they said:

Jennifer said:

It could be anyone like your Aunty, your friend, doctors or psychiatrists who put us down all the time and make us feel stupid and small which we're not. They think that we haven't got a life to lead and that is very sad. They think that we can't do things for ourselves.



Ian said:

Why don't they get a life, we are human after all. We have got to live on this planet to.



Jennifer said:

Just because they are normal and they have a decent life and that, they think they can tell us

what to do and boss us around all the time. They think we haven't got a right to live this life like everybody else. Nobody's perfect. I think it's sad in a way.

Ian said:

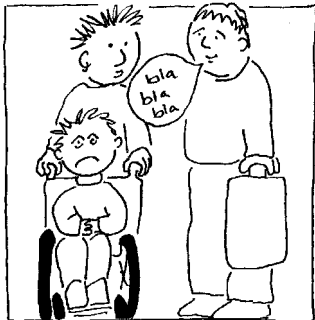
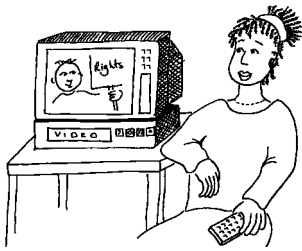
Sad in a way they've only got a small mind.

Ian has talked about how people with learning difficulties don't get on television. One time he said:

People with learning disabilities don't get on game shows; [it's] always normal people. People with learning disabilities don't go on telly at all like... shows like Blind Date and also they don't get on action films. It's disgusting we should be able to get on game shows and made up films not [just] real life [television programmes].

Jennifer has talked about how:

Sometimes people without learning difficulties patronize us. Like being treated like a little teddy bear rather than a person.



We want to be heard

We want to be heard and these are some of the things we have said about this:

Vanessa has said:

We are trying to get our voices heard so that people don't take the piss.

Ray said:

We are trying to help people in the street to understand us a bit better.

Ray also said:

We want to get people to notice what we are trying to do.

Vanessa said:

We are trying to get people to realise that we are human beings the same as they are. Even if we have got learning difficulties we still have a right to be in this world.

Ray said:

We are going to be professionals.



And Jennifer said:

We are going to be our own boss.

Maggie said:

We want to show people that we can write a book and then tape it, some people can't read.

Vanessa said:

You can braille it for some who can't see.

We are hoping that later on we might be able to go on TV or the radio and talk about the work we do. We want people to know about the difficult things that happen in the lives of people with learning difficulties like being bullied or getting called nasty names and people treating us like we are stupid when we are not. This book is also meant to give other people both with and without learning difficulties ideas for making the lives of people with learning difficulties better.

When we first talked about making this book, Ray said:

We can say to people about how we live our lives and what Social Services thought about us. They thought we needed to go to day centres and be paid peanuts.

Jennifer said:

We might want to go to work and get a good wage.

Vic asked us:

Who the book is for?

Vanessa said:

Us.

Ray said:

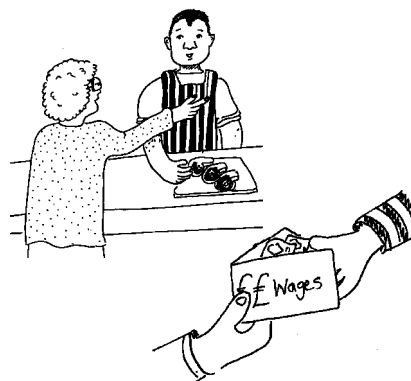
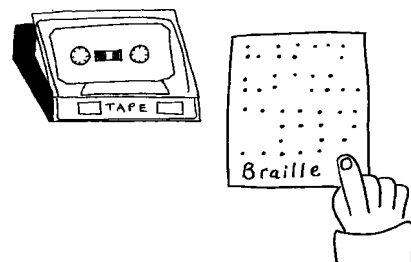
Everyone in society so that they can understand about us.

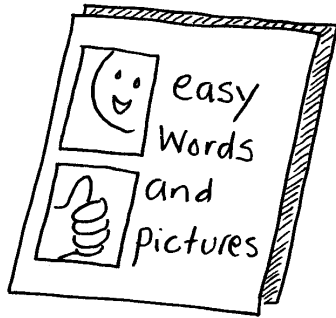
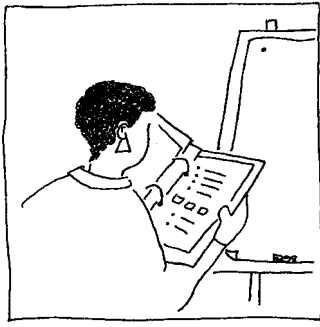
He said:

It would be a good idea if MPs listened to us. All us Research Group members said that social workers do not understand us.

Vanessa said:

It would be good if social workers read it because they take the piss.





And Jennifer said:

It would be good if they stopped bullying us and telling us what to do and let us get on with our own lives.

Vanessa said her social worker was “shocked” when she told him she wanted to live with women.

Vanessa said this about social workers:

Some of them are nice, but not all of them.

Everyone thought that it would be good if this book was as accessible as possible for people with learning difficulties.

Why we are doing this research instead of other people

Apart from, as Ian put it: [Wanting] “... to know what the people [with learning difficulties are] doing in their lives right now”, there is another reason why it is important that we as people with learning difficulties should be doing this research.

Jennifer has explained why we are doing this research:

... People like psychiatrists and doctors and teachers and stuff are writing stuff about us saying that we are stupid and can’t do stuff, but we are not stupid. We’ve got our own minds. We know what’s good for us and we know what we want in our lives, not them telling us what we want in our lives. They’re the ones who are wrong.

Maggie said the following about why it is good that people with learning difficulties have done this research:

To say our say about what we think... to tell people our views.

We want to tell you...

We chose each other because we get on

We have to work with each other. We wouldn’t be happy if the staff chose anyone to join the group.



The service users are in charge of the Research Group and it would be wrong if the staff chose who they would like in the group. We feel safe here.

We are the ones controlling the Research Group.

Vic is just supporting us.

People with learning difficulties are treated really badly.

They [some people without learning difficulties] treat you like dirt, like you don't exist.

They think we can stand there and take it.

They think they know better.

They think they are clever.

They are no different from you.

We all have needs.

We would like to have our voices heard all over the United Kingdom.

We want our voice to be heard all over the world. We want everyone to have copies of this book.

Because they will walk all over you if your voice is not heard.

If you sit there and don't say anything they will still take the piss out of you. If you stand up for your rights they leave you alone.

[We want our voice to be heard] So that people can understand our feelings and notice us as well. They [some people without learning difficulties] think we haven't got feelings but we have and that's why people take the Mickey out of us and it's got to be stopped.

You have a brain, you have a mind, you have choices. It's your life at the end of the day.

We want staff to understand people with learning disabilities.

To know where they are coming from.

Chapter 3 Researching together

Our research support

We have a supporter called Vic. He is white. He goes to Brunel University to do a Ph.D. He works with Professor Peter Beresford in the Centre for Citizen Participation. Vic helps us to do what we want. He helps with writing things down and is helping us to make this book. We went to Brunel University to meet with Peter and talk about the work we do while we had lunch there.

Vanessa said:

Vic is just here to support us... he is there for us, just to make sure that we are getting the right support that we need.

Vanessa said:

He supports us on the work we are doing. As well as supporting us to do the research and write this book Vic does other support.

As Vanessa put it:

Vic does other support work as and when we need it.

Vanessa said:

Vic supports me to make phone calls to Social Services, to phone where I live, to phone cab companies and he supports me on sorting out things that I need sorting out like if I was going to go somewhere and I needed to get hold of that person to say that I need to be picked up.

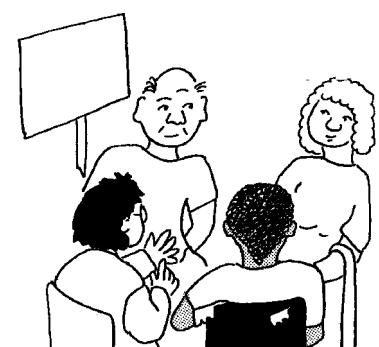
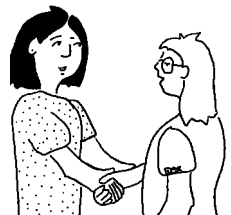
We all support each other as well. This is what we have to say about helping each other:

Ian said:

We all support each other in this group.

Jennifer said:

We look after each other in this group, which we do quite a lot.





Vanessa said:

We are there to help each other out. We listen to each other and don't criticize each other.

In a different People First Group one of the group members called Vanessa a "bitch".

Vanessa said:

So I called her it back... we don't do that in here.

Maggie said:

We work together.

Jennifer said:

This is what this research group is all about, working together.

Vanessa said:

Ray was very supportive and very helpful to me... Ray was a friend to the group.

Ian said:

He was trusting.

Vanessa said:

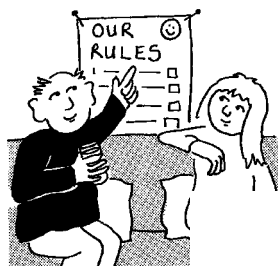
I trusted him because anything I told him didn't go out.

Ian said:

I used to call him Mr. Blobby. He thought it was funny.

Vanessa said:

I miss Ray.



Ground rules

We didn't want rules in this group because as Ian put it:

There are too many rules in this life.

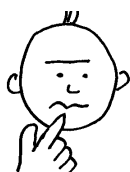
Vanessa said:

But we do listen to each other and we need to.

Jennifer and Maggie don't like people to swear in the group.

Jennifer said:

Swearing sometimes puts you off your work.



Vanessa said:

When I get irritated I do swear because it gets things off my chest and it stops me from lashing out and stops other people getting hurt.

Ian and Vanessa sometimes like to swear to get things off their chest. So they said they would try not to swear unless, as Vanessa puts it:

Something has really wound me up.

We all trust each other not to tell other people what we talk about. We trust each other to keep what we say confidential.



Being paid: Funding

Although we wanted to be in the Research Group even if we didn't get paid Jennifer said right from the beginning that:

It wasn't right that people with learning difficulties only do voluntary work and not get paid.

Vanessa said:

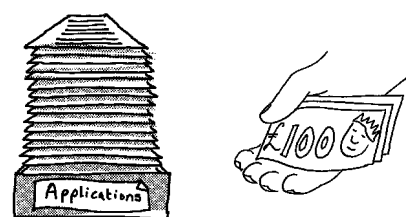
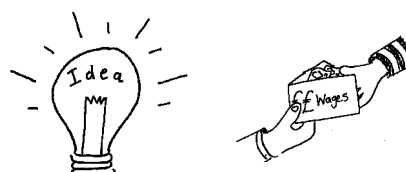
I felt hurt that I wasn't getting money for the job I was doing.

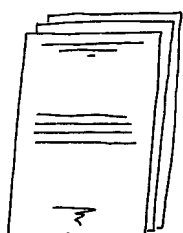
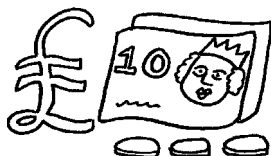
Jennifer said:

It was my idea to get the Research Group members paid, cause they wasn't getting paid at first, but they are getting paid now.

In the beginning we agreed that Vic could ask Peter about how we could get funding. Peter said we could get in touch with Ken Simons at the Norah Fry Centre. So we emailed him and he wrote us a really nice email and gave us a list of organisations we could try and get funding from. Vic tried to help us fill in a National Lottery funding form but it was very difficult to make the form accessible for us. In other words we couldn't really understand the form.

Another problem was that the National Lottery wanted us to be really clear about things that we had not sorted out about our research at that time. We needed time to sort out what we wanted to do in our own way. Also at that time the National Lottery took five months to make up their mind if researchers





could have money or not from them and we wanted the money quicker than this because we were working on our research and we wanted to get paid.

In the end Emma Stone from Joseph Rowntree gave us a list of organizations that might have been able to give us money. Eventually, as Jennifer put it:

We got the funding to get the research on it's feet properly. We had a meeting with Anne Curno from Trust for London.

Trust for London gave us money to pay us as much as we could get a week without risking our benefits being stopped. They also gave us money to pay for taxis, food for meetings, any tapes or paper we needed and to pay Vic to support us; Vic was a volunteer at first.

Ian said:

When I used to go to People First before I didn't get paid... It's good [getting money] you will be able to buy things in the shops and also go to [the] pub and on holidays.

Our minutes

Vic writes up the minutes of our meetings. We all say if we think the minutes are alright. Jennifer reads the minutes at the meetings and supports the Research Group to decide what we are going to do in a meeting and who is going to do what.

Jennifer has said:

You [Vic] don't put jargon words in the minutes so that we can understand what you are writing about.

Vanessa said:

If you [Vic] put in jargon words we wouldn't be able to understand it and you would get into trouble with us because you would have to write it all over again.

Our meetings and our minutes are confidential.

Jennifer said:

Confidential means "private". The only other person who saw our minutes apart from us and Vic

was Peter Beresford. The Research Group agreed to him seeing the minutes after we had met with him.

Writing this book

We started writing this book by going through the minutes of our meetings and what people said at the interviews. We talked about what we had found out and what we think about it so we could put it in our book. We chose words we wanted to use to tell people about what we have been doing and what we found out.

Sometimes when we were talking about things we put them straight in the book. We listened to the tapes of the meetings we set up with other people with learning difficulties and put in some of the things that other people with learning difficulties were saying. We also talked about what they were saying and wrote down some of the things we said after we had listened to the tapes. We spent a long time working on writing this book.

Some times we didn't get much writing of the book done because we had to sort other things out.

These are just a few of the other things we did while we were writing this book.

Vanessa said:

Conferences

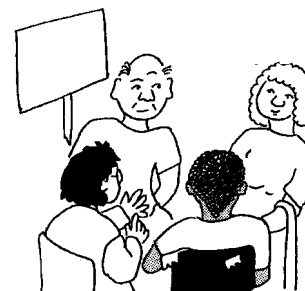
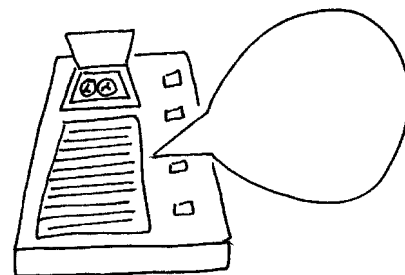
Jennifer said:

Meetings and going out sometimes, taxis for people... and write a letter... about the work we did for the Department of Health.

Changing names

We thought it was important to change people's names in this book. Vanessa said:

So that management and the whole country don't know who we are, cause then they won't say that Ian said this, Maggie said this, Jennifer said this and Vanessa said this.





Maggie said:
It's confidential.

Ian said:
It's private, we don't want people to find out who said what.

We told all the people that we interviewed that we wouldn't use their real names in this book. Ian said if people find out who said what: "You might get into trouble". All the names of people (including staff) and places in this book have been changed from this point on except for Vic's. In a few places names have been changed more than once just to make sure that we have protected people's confidentiality.

We want to tell you...

We make sure things get done. We say what we think and Vic [our supporter] writes it down for us.

Vic supports us to feel more comfortable in meetings. He is here to support us on everything that we would like support for.

Everyone supports everyone here in the Research Group and in People First.

We make sure that Vic is alright as well as the service users.

Vic should have a say, just a bit of a say to find out if we are happy with everything in the Research Group.

It is very important that people with learning difficulties doing work get paid. It's about time that organisations started paying them [people with learning difficulties] good money not just peanuts, like a proper job.

[The Research Group] is a paid job and when you come to a job like this you have to have commitment and stand by that commitment.

It was very difficult at first to get money for doing research but we did get it in the end.

Chapter 4

Standing up to bullies and rude people

The people involved in this research talked a lot about bullying.

Maria said that:

Some people think we are stupid.

Recently someone outside said Eric was sick in the head. Roseanne said:

Even in People First, members can be rude.

Someone [a member of People First] said that the people with learning disabilities are thick... so we [the members of the group she was in at the time] banned her for three meetings... you can't behave like that in meetings.

Stuart said:

I don't like people when they mess about with people all the time. When they bully around, I don't like it... In the centre people follow you round, call you names I don't like it.

Maureen said:

Hit me on the bus. Wesley [centre user] hit me on the bus... Call me names at the centre, [and] Debbie [centre user].

Marlene talked about someone making bad comments about her when she was outside. Marlene told the people how rude they were and not to say what they were saying.

Marlene said:

They should be treating us like human beings not like muck.

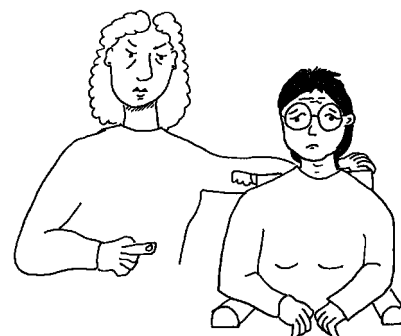
Craig said:

We are not animals we are human beings.

Craig told us that somebody on the street said to him:

You are weird.

And Craig said the following to him:





You are bloody weird mate not me and I'm bigger than you and a lot tougher.

Roseanne said:

That's right you've got to tell people that so they will leave you alone.

Maria said:

Yes get it drummed into their heads so that they will leave you alone.

Roseanne said:

If you don't stand up for yourself people will walk all over you.

Maria said:

They will carry on taking the piss out of you until they come to their senses.

Roseanne said:

They have got to learn they can't just take the Mickey out of you.

The rest of the group agreed with her.

Maria said:

We have got a right to live on this world as well as nasty people.

Maria said once when someone called her a nasty name in the pub she said:

Get a life and grow up, I am not "handicapped".

She felt "proud" when she said that. We all think it's important to stand up for ourselves when people put us down or ask us what Maria calls "stupid questions".

Marlene said:

I was out on the street and someone asked me why I go around on two sticks and I said it's not your business its time enough that you grow up... So they backed off. People do ask stupid questions.

Maria said:

They should mind your [their] own business.



Roseanne said that sometimes when people ask her stupid questions she tells them to “back off”. She also tells them to “wrack off”.

Roseanne said:

If you don’t tell them they are going to keep asking you questions.

Sometimes when strangers try and talk to Marlene: “as if there is something wrong with me”, when she goes to the public toilet or something, Marlene says:

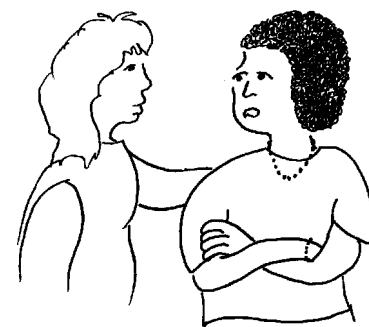
It’s not your business, you shouldn’t be asking me those sort of questions.

When people make comments about Maria on the street or “wherever you go” Maria says:

Have you got a problem with that?

Roseanne said:

When people offer to help me politely by asking if I need any help “I say no thank you”, but people are not always polite.



We want to tell you...

We are bullied a lot and it’s not right.

People don’t like it if you’re different.

We are called rude names like “thick” and it’s not right.

Why should we have to put up with all the bullying and rude names? It should stop.

If you don’t stick up for yourself people out there will keep on bullying you.

It is important to stand up to bullies.

People who have got learning difficulties should be supported to stand up against bullies and rude people.

Chapter 5

Being called racist names: what we tried to do about it

Eric [a black man with learning difficulties involved in this research] wanted to talk about racism and being called racist names. Maria [a black woman with learning difficulties involved in this research] said that she wants:

All the bullying and racism to be completely stopped... It is not fair on us that people call us [black people with learning difficulties] names and take the piss... we were not put on this earth for nothing.

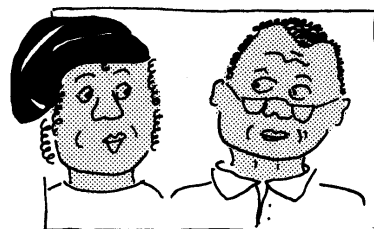
People get called bad names Ola told us that he gets called "chocolate face" by some of the other people who live in the same residential home as him. Eric told us that when he used to go to a day centre, service users used to call him racist names. He said that staff did nothing to stop the problem. In the end he got angry and lost his temper with the people who called him names. He said then the staff blamed him for losing his temper.

Roseanne [a black woman with learning difficulties involved in this research] heard a service user calling a member of staff a "black bitch" on the mini bus. She said:

I tried to hit her [the service user]. All I was doing was trying to stick up for black people. It wasn't just for myself it was for the escort and the driver and the other black people on there.

Roseanne said:

Derek [a white manager of a service] doesn't do anything about racism and I know he doesn't because when it does happen it is like it has been brushed under the carpet and I know for a fact that the black staff say the same things as I am because it is all brushed under the carpet and not dealt with.





As Roseanne puts it:

We organised a meeting with Derek and James [one of the managers in Social Services for people with learning difficulties]... We wanted to know what they could do to help stop racist name calling... We were trying to get things changed so the black people don't get bullied anymore.

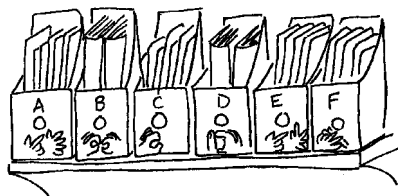
We went on the internet to see if anyone could help us to work out what to do about racist name calling. We got some ideas from people on the internet.



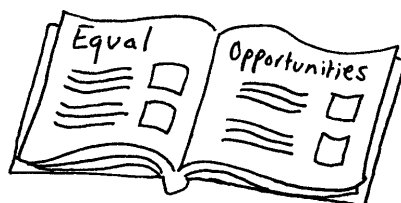
We had a few meetings with James and Derek. At one of these meetings James told us that a black social worker and care manager in the borough had written about racism and how to support black people with learning difficulties.

Roseanne said:

It's been in the office and no one has took it out and read it. It's been shoved in the corner on the shelf.

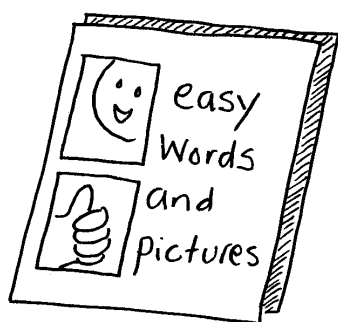


James said we could use this writing as a starting point to make a change for black people with learning difficulties in the borough. He said that this writing could be sent out to the staff and service users in the borough. This writing had not been copied and sent to people before. James said the writing could be made accessible for people with learning difficulties. First of all he said People First could make it accessible. After People First put in a bid for money to make the writing accessible he told People First it would save time if Social Services worked on making it more accessible first. We have not heard anything more about this for a long time.



Roseanne explained what happened in the end:

Janice [the social worker who had written about racism] had made a book about racism and bullying and name calling... They [Social Services] said that they would make Janice's book accessible... They just haven't done nothing about it. They should make a book public about racism but they haven't.



We stopped working with Social Services on racism and people with learning difficulties. In the end People First fundraised and got money for a group for minority ethnic and black people. The group members will be supported to stand up against racism in whatever way they choose.

We want to tell you...

There is a lot of racism from the white service users and it always comes against the black people.

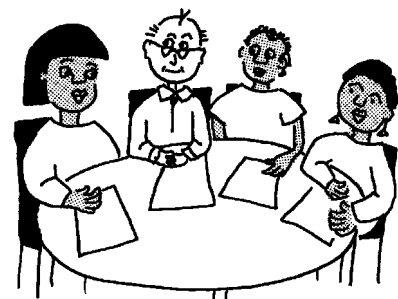
The service users should be getting on with one another not going against each other.

We are all human beings anyway it doesn't matter what colour you are.

Managers should be supporting the black service users but sometimes they are not supporting the black service users. Sometimes they just brush racism under the carpet.

If Social Services say that they are going to do something they should stick to their word... We don't want to work with people who don't stick to their word.

If Social Services are not going to help us we might as well organise our own group.



Chapter 6

Rape and sexual abuse

Several people with learning difficulties involved in this research had been raped or sexually abused. Two women, Alice and Christina, who were raped when they were children wanted to talk about this. We thought it was important to talk together about this because, as Alice put it:

... It helps us to get our lives together again and also I found it easier because Christina understood me. That's how I saw it.

Christina said:

It's hard to come off your chest, hard to explain what happened to a counsellor. It was hard for me to talk about it to my counsellor. I was about twelve and it was part of my family that did that to me. When I talked about it with the Research Group it gave me more confidence and put my life back on track.

Alice and Christina talked a lot about how they worry about what clothes they wear. They said it helped them to talk together about this and how they still can feel uncomfortable when they are not fully covered up. We talked about how as Alice put it:

Not all men are the same and how it's not that women are asking for it by wearing things.

It's the, as Christina says:

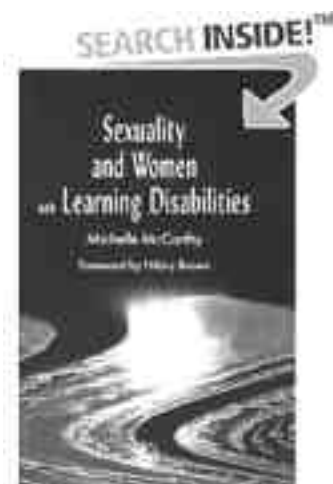
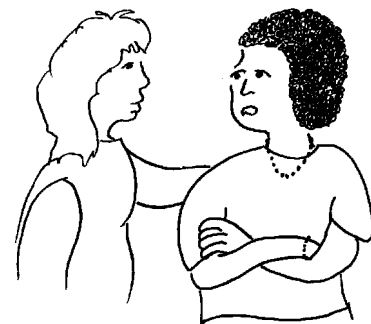
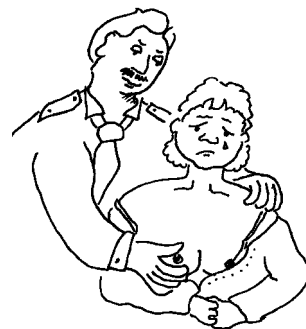
One track mind of some men.

Maria said:

It's the magazines they read.

We talked together about how we can tell men to leave us alone. One person in the group had to swear at a man recently and tell him to "**** off" when he asked her for sex.

Vic asked us if we wanted to see a book by Michelle McCarthy [McCarthy, M. (1999) *Sexuality and Women with Learning Disabilities*, London: Jessica Kingsley] about sex and women with learning





difficulties. We did. We realised a lot of women with learning difficulties get raped or sexually abused.

Christina said that the bit of Michelle McCarthy's book we had read brought up memories about what had happened to her in the past. We talked about how women with learning difficulties should as Christina put it:

Be treated nicely and the men shouldn't be forcing themselves on you.

Alice said:

It's our body and the men should leave the women's body alone.

We talked about, as Christina put it: "women taking care of themselves." Christina brought up how "... difficult it is for a woman who has been raped to have a relationship with a man".

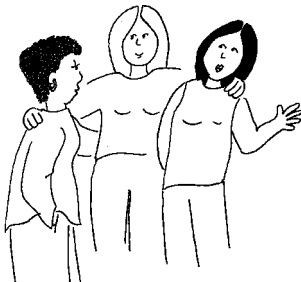
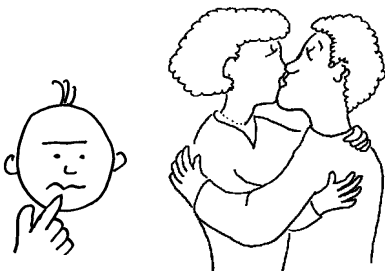
Alice said:

Sometimes after a woman has been raped, you might want to wait a bit before you start having a relationship with a man... because not all men are rapists. I don't like hearing that word "rapist" it turns my stomach a bit... I don't want a relationship with a man anyway. I feel comfortable with women because it's much better for me... I am not a lesbian and I prefer women's company ... Last night, before dinner, a man in Grassacre [a residential home] wanted to find out why I was so quiet and upset. He touched me on the shoulder to find out why I was a bit upset. He is not like all the other rude men. He is different. He is alright I can talk to him. I've known him since before I came to Grassacre.

Roseanne talked about the time when a minibus driver tried to have sex with her and she said:

I don't take that kind of crap.

Roseanne told us that the driver said "Fine, how come you can stick up for yourself?" Roseanne said she was sixteen years old when this happened and that she couldn't talk to anyone else about what happened. Roseanne said no woman or man should have to put up with violence or abuse.



Eric explained how a woman pestered him asking for sex and took his money on the street after taking his trousers down without his permission. Eric went to the police to report the crime but the police didn't do anything. The woman has done this twice to Eric. The woman had asked Eric if he wanted any business. Maria pointed out that this, "is what prostitutes say when they want money for sex". Eric said someone said he should get a personal alarm to make her go away if she comes up to him again. Eric said this woman is very difficult to get away from.



Eric suggested that Alice went to see a counsellor so she could talk more about being raped in her childhood, because he thought this would help her. Eric was having counselling and Vic and Christina have had it in the past so they talked to Alice about what it was like. We supported Alice to apply for free counselling which she eventually got.



While we were doing this research Marlene, a service user, was raped at Heath Road [a residential home,] by a resident. She wanted to tell people about it in this book and arranged a special meeting to tell her story. This is what she chose to say:

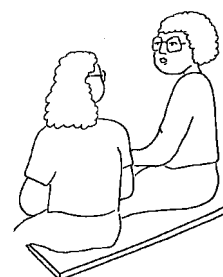
Tuesday the 26th of March 2002, the time was half past nine at night, this guy Andy [another service user] he raped me on that day [in the residential home where Marlene lived]. I couldn't tell anyone because it was very difficult to.

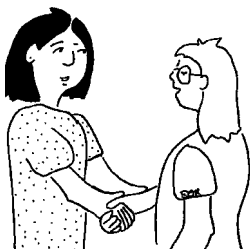
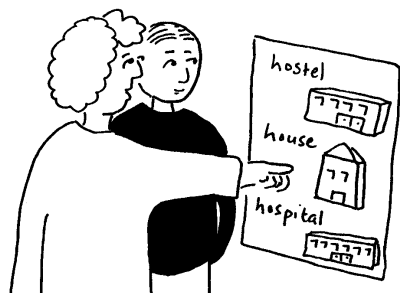
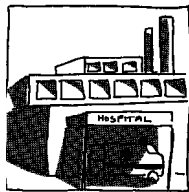


I managed to tell them one day later because it was frightening because I didn't know what was happening to my body. Before that happened he was trying to get me to move in with him and I told him "no". He asked me to move in with him and that's when he did it afterwards. So in other words he was being a bully.



I managed to tell someone at Nicholas Road [the day-centre Marlene attended]. They called the Care Manager [from the Social Work Team] that was Audrey at the time. Then they phoned Heath Road as well. They rang and told Rick [a worker in the





residential unit]. The police was called as well, after Heath Road was called.

They had to check me over to see if anything was broken and the ambulance was called as well. They took me to hospital, the nearest one. They checked me over. They said that nothing was broken and then I went to the Retreat I think it's called, that's the other side of the hospital. They took blood and swabs and the pregnancy test as well.

Oh and the Police took him [Andy] away. I was offered to go to a Hostel but I didn't know what they were like. I didn't want to go. I didn't want to leave Heath Road. I was under a lot of pressure.

I was moved from upstairs to downstairs [in Heath Road]. I spent one night in a hospital bed. Then I was moved into room 4 [in Heath Road] on the 28th of March. I've been there ever since. Then I had counselling as well. Then they said I was coping quite well, I didn't need counselling again and if I do in the near future I can always ring up for another one... Basically some of the staff were very supportive including the Manager, Olive and Troy as well and Rick [staff in Heath Road].

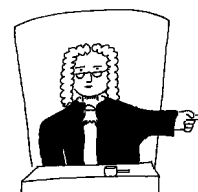
I think sometimes I do remember it but not as often now. I don't remember it all the time, only if I'm not doing anything I remember it; if I am sitting down in the lounge or in the mini bus. That's why I go on the exercise bike to keep myself busy. But I've got a present now, because I spend most of my time on the exercise bike the owner said I can have it

...I found that some of the staff weren't supportive. One of them I just found that they didn't believe me. They thought I was lying. She asked what happened. I just said to her whose side are you on mine or Andy's and she said she can't take sides. She said either I would be lying or Andy would be lying; that's all she said. Eve [the manager of the residential home] said if some

things happened you can't question the person because it's already in the police's hands. But to sum it all up one of the night staff knew he [the man who raped Marlene] was up to something. I didn't like him anyway, [the man who raped Marlene] you know sometimes you have to be nice to people but it still doesn't give him the right.



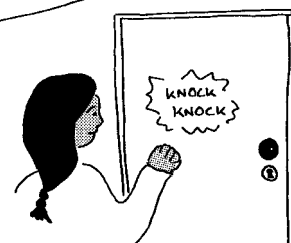
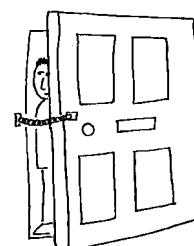
It didn't go to court because there wasn't enough evidence. He didn't get away with it anyway because I reported him. The court people said I would make a good witness.



I'm helping out all the other women who have been raped. I'm telling everybody to look out for yourselves, so that it doesn't happen to the other women besides myself.



On the 17th February 2003 I spoke to the inspectors [of Heath Road]. We had an inspection and I told them that the doors in the bedrooms can't lock so could we have the lock changed and he said yes. [Before then] I asked the Deputy Manager if we could have, if I could have another lock on my door and he said "no" because of safety reasons in case there is a fire and you couldn't get out. It's wrong not having a lock inside the bedroom because people can just walk in and it's your room. Staff say "you are not to go in other people's rooms" but Patricia goes in and I say "get out". We need a lock so that people can't just barge in when they feel like it.



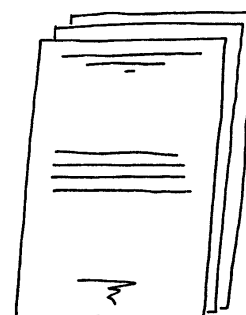
Six months after Marlene was raped at Heath Road she said she heard one member of staff tell another staff member what was in the minutes of the staff meeting. This included information about the rape. The staff were talking in the lounge in front of other residents.



Marlene said:

They were looking back in the staff meeting.

Marlene was very upset by this because as she put it: I thought it was confidential. I thought it was not supposed to be said about what happened to me upstairs. I didn't want all the staff to know about it





not everybody. Now they all know, even the agency staff and even the handyman and that's not fair.

Maria said:

That's not fair it should be confidential and it's bringing it all back to you again.

Marlene said:

When I told people I thought it was going to be a secret. I swear because now everyone knows.

We want to tell you...

It should be spread around the world how things like this happen. People need to know about these things [sexual abuse of people with learning difficulties]. There should be leaflets about it in organisations like Mencap and Social Services departments. All over the place in different organisations so they [people with learning difficulties] can be safe.

If a man asks you for sex and you say no, if he continues to keep on, if he keeps coming to pester you, you can report it. If you are out on the street you could go to the nearest shop and ask if you can use the phone, but tell them I am being pestered before you use the phone. You could phone the police or your home [if there are support staff there] and ask them to come and help you.

If somebody is pestering you in a residential home for sex and you don't want to know you can tell the staff and tell the Manager as well.

If it was your own family that was raping you like your Granddad or your Uncle, go to the police straight away and report it to whoever is on the desk at the police station.

Women can go to a safe home. A women's refuge.

If anyone is hassling you outside you can phone the police on a mobile phone.

[Women with learning difficulties could learn how to defend themselves], take up kick boxing to feel safer walking down the road.

[Sometimes when you tell staff about being pestered they don't take any notice] and they should listen... when

something is going wrong and speak to the person and say “stop pestering”.

If staff of residential homes don't help you can speak to someone higher in Social Services.

We want the staff to be supportive when people with learning difficulties tell them they are being sexually harassed or abused and make sure we are alright.

It's annoying that staff can say “forget it” [sexual abuse] when it's all still in your head.

Some women don't want to live with men because they are frightened because you don't know what could happen in your own room. Women don't have to put up with living with men if they don't want to. We can say no to living with men.

Two people in the Research Group know men with learning difficulties who have been raped. It's not just women it's men as well that gets sexual abuse. Men should be supported as well as women.

Chapter 7

Having relationships

While we were doing this research it became more and more clear that, as Craig put it:

It is hard for people with learning difficulties to have relationships or a girlfriend. Sometimes people can't find a place to be alone with a partner. Some of the people who took part in this research told us that they are not allowed to kiss or cuddle a partner in the day centre they go to and that they are not allowed to invite people like boyfriends or girlfriends to their home.

Roseanne said:

We think that this is not right.

Maria said:

It is out of order.

During one interview Roseanne asked Mihesh [a day centre user]:

What would you do as a hobby?

And he said:

Go date... music, sport, Burger King... drink lager.

Roseanne said:

Mihesh has a girlfriend but he doesn't go out with her. I don't think he gets the opportunity to do it.

Vic said:

Where is his girlfriend?

Roseanne said:

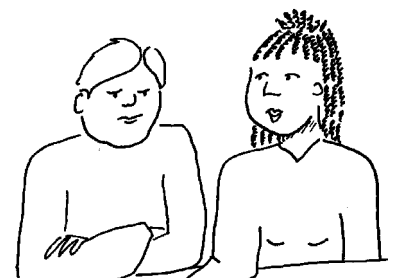
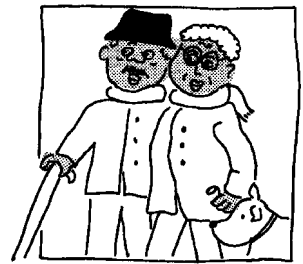
Nicholas Road [day centre]... Mihesh's girlfriend is one of my friends. I know her. I know that they don't go out with each other.

Maria said:

What about the daytime do they get the chance to go out together in the day time?

Roseanne said:

No they don't.





Maria said:

Do they get the chance to cuddle and kiss and everything?

Roseanne said:

No; because the staff are there all the time. They keep watching you.

Vic said:

What happens if you do kiss and cuddle?

Roseanne said:

You get caught.

Maria said:

That's not nice is someone keeping watch over them 24 hours every single minute.

Roseanne said:

Yes.

Maria said:

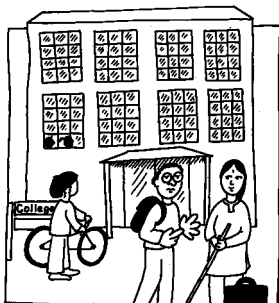
Can't they go down the park together or go shopping together like normal people do?

Roseanne said:

No... his girlfriend is a wheelchair user too.

Maria said:

I think it's out of order, number one that they are not allowed to kiss and cuddle, and number two the staff is getting too strict in there. They are human beings and they should cuddle and kiss if they want. It's not harming anybody. Its only a kiss and a cuddle.

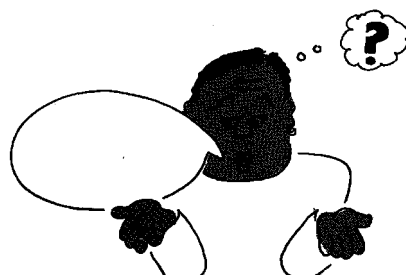


Craig said he doesn't get a chance to kiss and cuddle his girlfriend. He said:

There should be a place where you can kiss and cuddle... It's disgusting I want somewhere to kiss and cuddle... she lives in a "girls" home full of nuns, a convent, and she is not allowed to come back to my home and I'm not allowed to go to her home. I only see her at college when I can.

Maria said:

I think that's wrong.



Craig said:

I love her and she loves me so what's wrong with them.

Maria said:

I used to live in a convent and they've got rules in there, strict rules. I didn't like it but I had to go by their rules and what they said and that. I had to have supper on time and mass and prayers before supper. I had to go by their rules and what they say, but I wasn't there for long.

Craig said:

I have never ever been alone with a girlfriend before and I want to. We are human. I know I am human.

Maria wondered if:

... There was a law about that, kissing and cuddling; that people with learning difficulties are not allowed to kiss their boyfriend or girlfriend. I can't work out why the staff don't let people do what they want.

Roseanne said there is a rule in Nicholas Road that you are not allowed to kiss and cuddle in the centre. She said:

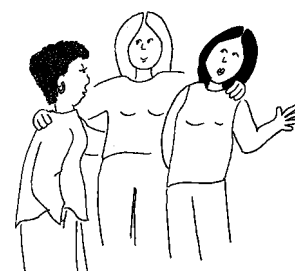
The staff keep watching you every time you want to do something and if you do something you get caught. They are worried that if you go too far women will go and complain. You have to be very careful of the women being taken advantage of. ... You have to be very careful of the women's point of view and the man's point of view.

Roseanne said:

Staff they watch you; cause Jerry gives me a hug sometimes because he is my friend, nothing more than that. They keep opening doors to see what you are doing in there... They say it is not appropriate to do that there.

Craig said:

I am going to cuddle people if I like in the canteen [at college] if I like. I know it's a bit of a risk... I like to live risk.



Maria said:

It's not against the law to cuddle your girlfriend. If you want to cuddle your girlfriend, cuddle.



Carrie said:

Lucy [Carrie's carer] said I'm not allowed to have any boyfriends at home... boyfriends to stay overnight.

Roseanne said:

Because it's her house [the carer's] you're not allowed. It's her house.

Roseanne said she was not allowed to have her boyfriend come to visit her in the house she used to live in with a carer.

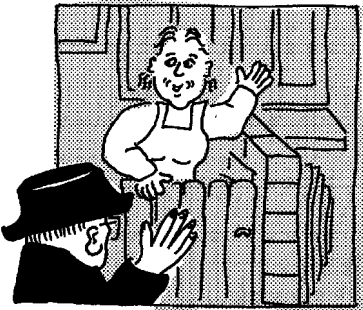
Maria said:

Say if he came for dinner or something and then went home instead, are you allowed to do that?

Roseanne said:

No you're not allowed to do that. That's a rule.

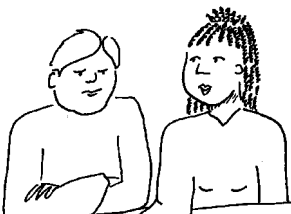
Carrie said she was only allowed to see her boyfriend: "at the centre". Both Carrie and Maureen who live in the same house said none of their friends come to the house they live in. Their only visitors are family.



Roseanne talked about something that happened in the residential home where she lives:

On the 17th September 1998 I got caught hugging someone. My feelings was very bad that day. You know when women's feelings get very bad you can't help it. The Friday before Christmas, Olive [the Manager of the residential home] and my key worker came to speak to me and I was very angry and was shouting "what have I done?" I don't normally shout but when someone pulls me up about something I shout sometimes because it shows that something's wrong and it's a lot of anger.

They found out I had a crush on Cyril... He is a member of staff. It wasn't just my fault though. It makes me feel bad just me getting the blame for



it... It's nobody's fault really it's just the way people feel sometimes. I didn't mean to, it's just he's a nice person and when people are nice to you sometimes you get a crush on people that is nice to you...

One of the staff said men are only after one thing. That's why they asked me not to give him a hug... I tell you why that's ridiculous. I was really upset not long ago and Donald (one of the staff) gave me a hug and he's a man anyway.

Vic asked:

What do you mean by having a crush?

Roseanne said:

I don't know what it means, that's the word they used... it's just he was kind to me and he knew my mother.

Maria said:

Did you fancy him?

Roseanne said:

Certainly not.

Roseanne said:

Marlon [a service user] keeps asking me to go out with me... but I'm not interested... Marlon should take note of what I'm saying.

Maria said:

No means no.

Craig said:

I want a girlfriend.

Roseanne said:

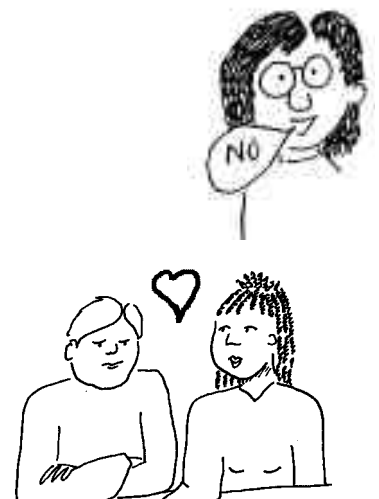
Talk to the woman and chat her up and see what happens.

Not all relationships are good

Some people have relationships but they are not always good ones.

Maria said:

It's important to come out of a relationship if the man starts drinking and taking drugs, like crack





cocaine. I've seen my ex partner taking it. He takes it all the time. I told him if you don't stop smoking that stuff I'm going to leave you and I did. I put all my stuff in a black bag and left. I couldn't live a horrible life with him. He's got all people up there now smoking the stuff.

I was with him for seven months. I came out of the relationship because I couldn't stick it no more with him. I said to myself get yourself a decent life Maria and I did. There were so many people coming up there during the night and in the evening and he is probably doing it right now. He is saying I should go back to him, my friends tell me, but I've got a decent life now and I don't want to go back to him. I don't want to see him after what he's put me through.

Maria came out of this relationship during the time she was taking part in this research. The social workers found Maria somewhere to stay for a little while. As she puts it:

They found me a foster home... I stayed there for a little bit but I left there fairly soon because I couldn't get on there with the husband's wife because she was too bossy for me telling me to do this and that and I must eat their food not my food.

Sometimes people have good relationships. Maria moved in with a new boyfriend who she was happy with and during the time we were working on this book she got engaged and then married to him.

We want to tell you...

More people with learning difficulties should get married and have their own home together if they want to. If people want to live with their boyfriend or girlfriend, and see how it goes, they should. No one should stop them.

It is not easy for people with learning difficulties to have a girlfriend or boyfriend relationship. They should have places to go when they are in relationships to kiss and cuddle.

They should have more support about how to have safe relationships and how to use condoms and all that, to be safe. They should be more done in clinics, like doctors and nurses should listen to us and give us more information about how to cope with relationships.

People with learning difficulties, should put on their own dating services. They don't care about people with learning difficulties having relationships anyway. We are human beings too and we should be having people getting married and kissing and cuddling.

We just want people with learning difficulties to have a relationship together. Don't care what anyone else says. If you want a girlfriend have a girlfriend. If you want a boyfriend have a boyfriend. They can't stop us. Go out shopping, go to the cinema. Just be caring. That's what life is all about, doing things together. Some people want to settle down. Some people want to get married. People need to be supported to get on with relationships.

People with learning difficulties should have support if their partner is treating them badly or calling them names or shouting at them. They [staff and carers] should give them advice, tell them what to do, because some relationships can be really nasty specially if they are drinking heavily and taking drugs. That's where people like us have to be careful.

Chapter 8 Choices and independence

Choices

The people with learning difficulties we talked to often didn't have many choices about what they did in their lives. Roseanne said:

I don't think people with learning difficulties always do have a choice, because people won't let them. I am speaking on their behalf because I know people are like that. They don't let people have their choices and make their own decisions.

This part of our book shows how Roseanne and Maria supported Craig to understand how some choices were his to make and not other people's.

Craig said that the teacher at college wanted him to do woodwork but he didn't want to do it. He said the teacher "put him down" for woodwork still, even though he didn't want to do it. Craig said the teacher wanted him to come to college on Mondays but Craig wanted to keep coming to the Research Group. Craig said his mother was behind him and wanted him to do what he wants to do.

Roseanne said:

It's his decision at the end of the day. If I am going to make a decision I've got to think it through and make sure it is the right decision.

Maria and Roseanne explained to Craig that he doesn't have to do what he doesn't want to do in college.

Craig said:

But the teachers are the boss in college.

Roseanne said:

I don't think so. That is wrong.

Maria said:

If that was me I would go to college and if they said to me do you want to do that course or this course I would stick to one course, computer skills, because I like doing computer courses.





Roseanne said:

Because that's the one you chose.

Maria said:

If they ask me why I am doing a computer course I will say that's my decision and if they say to me "why don't you do a better course?" I will say "no I won't do it". They can't force you to do another course if you don't want to do it.



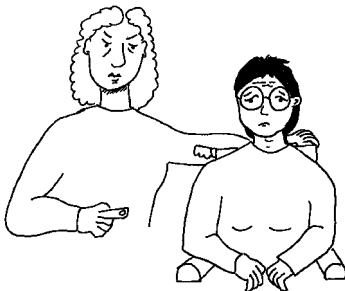
Craig got Vic to phone the college to tell the teacher he didn't want to do woodwork and wanted to come to People First all day Monday and Tuesday afternoons.

Craig said

It looks like I'm going to get tougher on them.

Independence means taking control of your life

Roseanne told us how some staff try to make people with learning difficulties do things for themselves when they can't or find it very hard. She said:



I went out on the Grassacre [day centre] bus. My friend came with me. He wanted to help me with my seatbelt and then the escort reported me to my key worker when I got back home. She said I could do my seatbelt myself... Cab drivers help me with my seat belt. I think it's all right for people to help me with my seat belt. If I can't see the hole they would have to help me anyway.



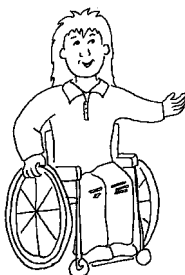
We talked about what the word "independence" means. Some staff think it means as Roseanne put it: "Doing everything for yourself and that's not right at all."

Maria said:

Independence means taking control of your life.

Roseanne said:

So independence does not mean doing everything for yourself.



Maria said:

You need someone to support you especially if you are living in a flat on your own, like Julie.

Roseanne said:

Someone should be there if you need help.

We all agree that “independence” means as Roseanne put it:

Taking control of your life, but that doesn’t mean doing everything.

Roseanne told us that a member of staff said she must use the phone on her own. For reasons we cannot explain here Roseanne cannot use an ordinary phone without support. Roseanne told us that the member of staff said he was “going to get hard on her”. Roseanne didn’t want to go home because she was afraid of him being hard on her. Craig said he thought “hard on you” meant being “a bit more tougher”. Maria said it could mean “getting nastier and more strict”.

Roseanne said:

It is not right for staff to be strict with us they should be supporting us and being nice.

Roseanne said:

If he carries on the way he is there will not be any clients using that service. If it wasn’t for us they wouldn’t have a job and I am going to remind him of that. He had better think about it.

Maria said the following about the way this staff behaved:

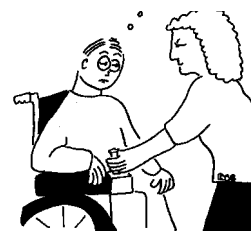
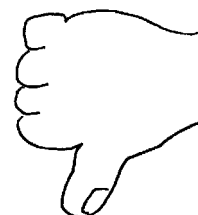
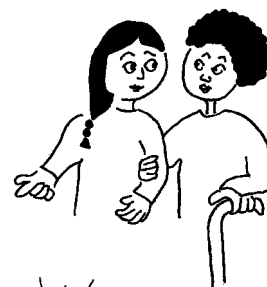
I don’t call that support. He should have more decency than that. He is staff and he should act like a staff.

Roseanne said this about the Manager of the day centre she used to go to:

[He] wasn’t hard unless he needed to be, like when someone was being racist.

Roseanne talked about the time she was beaten up in a home by a member of staff and said this about where she lives now:

It doesn’t feel [good] it feels like a “home”. It just reminds me of when I got beaten up, that’s how it feels to me so he had better think again before he says he is going to be hard on me.



Craig said:

We should turn the tables and start being hard on the staff.

Roseanne said:

I can turn nasty and when I do he has had it mate. So he had better be warned.



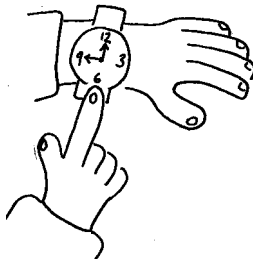
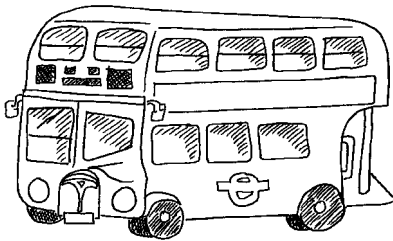
Maria said:

We have enough with bullying and racism and rape going on without putting up with staff getting strict on the clients.

Transport trouble

It can be very difficult if you don't travel on public transport on your own or drive. You can be dependent on "transport". This is usually a minibus. Sometimes "transport" can be, as Roseanne puts it:

A pain in the arse.



Not so long ago Roseanne told the driver for her residential home that she was going out with the day centre and would be back a little bit late. The driver told Roseanne he would pick her up a bit later than usual.

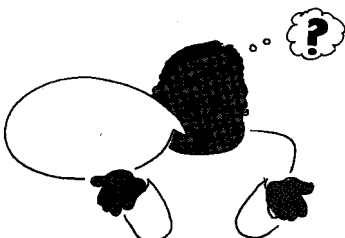
When Roseanne got back to the centre the driver had been and gone. Roseanne was very angry. She felt she had done everything she could to sort out her transport and still (because of other people) it had gone wrong. Roseanne had to wait a long time for the bus to come back to take her home. She was angry about this as well. So angry she didn't want to get on the mini bus.



Then to "top it all off", as Roseanne put it, she "got told off" (about her behaviour) – by Liz [one of the staff at the residential home] when she arrived home. Roseanne was worried about being told off by the manager of the residential home all the next day. This is because Liz had said if the manager had been there she would have "told me off" as well.

As Roseanne put it:

What a wind up!



Roseanne decided she didn't want to go out with the day centre any more.

Roseanne said:

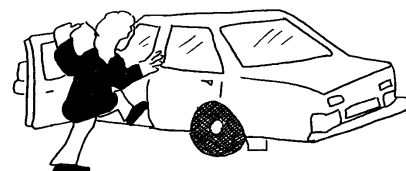
I try not to get angry but when there are other people involved they get late home too.

Maria who travels on her own said if it had happened to her she would have: "done her nut".

Towards the end of this research project Roseanne decided that she would like to travel back to where she lives in a taxi on her own rather than in a mini bus. The taxi fare was paid for out of the Research Group's money that we got from Trust for London.

Roseanne said:

It's because I want to be like everybody else and get around and go home when I want to go home like Maria. I just want to be independent more. I don't have to rely on the mini bus to take me home when they want to take me home. I can go home when I want.



We want to tell you...

Staff don't always let you be in charge of your own life.

We make decisions about where we go and what we do because it's our life at the end of the day.

You can't just assume that somebody wants to do something. You've got to ask them first.

It's not down to the social workers, not down to the teachers, we make the decisions and we are sticking to them.

Staff try to change your mind but we can stick to our own decisions.

It's very hard to stand up to staff when they are not listening to you and doing what they want. It's hard to stand up for yourself when they are trying to change your mind. Sometimes it upsets me.

Staff should be kind to people with learning difficulties.

Sometimes when staff don't listen to you it works if you get another member of staff who supports you to talk to them.

Some staff say you have got to do everything yourself.

Independence means taking control of your life.

Independence does not mean doing everything for yourself.

Sometimes staff say people can cope on their own when they can't.

Sometimes staff force you to do everything on your own and it's not that easy.

We want to be independent but we still need someone there to be supportive.

Staff can tell you to do things that you can't cope with on your own. Like fill in forms. You can't do things on your own you can't cope with.

Sometimes staff tell you to do things that are dangerous.

It should be your decision how you get to A to B [as a person with learning difficulties who cannot use public transport without support].

People should be able to get cabs if they want rather than get the mini bus.

With a cab some people have got more control and can go home when they want to and to get to a place on time.

Chapter 9 About our staff

Telling us what to do

The people with learning difficulties involved in this research talked about how staff can tell us what to do, or order us about.

Roseanne told us that last week a member of staff told her to: "... go out with another member of staff to get some drinks for a client".

Roseanne said:

If he'd come up to me nicely and asked me if you wouldn't mind going out with a member of staff I would have said yes.

Roseanne said:

He just assumed he could tell me to go out, and I told him I don't want to go because that is not the way I'm supposed to be spoken to.

Maria said this about the staff who told Roseanne to go out:

I think he has got a bad attitude on him. It is the way he talked to Roseanne telling Roseanne what to do and Roseanne don't want to do it.

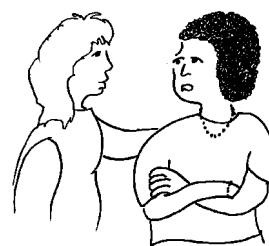
Roseanne said all the other staff say:

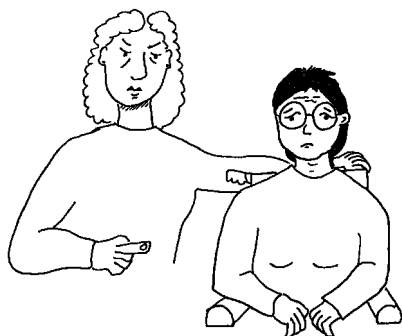
Would you like to go out? And if I don't want to they say "fine", that is a better way of talking to people.

Roseanne said:

It is good if people ask me if I want to go, and they do that with the mini bus, and if I say no that's fine because it is not their role to force somebody to go out. That is a good way of talking to people because it is finding out what you want and what you don't want.

The other day staff said "we are going out to lunch" and I said "I don't want to go" and they said "but you are at home all day" and I said "so what" whose day off is it; theirs or mine?



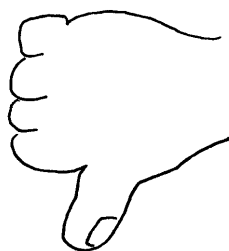


Julie said:

I don't like being pushed around. I get very nervous if someone tells me what to do and [have] panic attacks.

Carrie talked about a problem she has with her carer. She said:

If I fall asleep, I get told off you see... [by] my carer...sometimes at home... in church or something... [they tell me to] "Wake up Carrie".



Vic asked:

Does she say it in a nice way or not a nice way?

Carrie said:

Not a nice way.

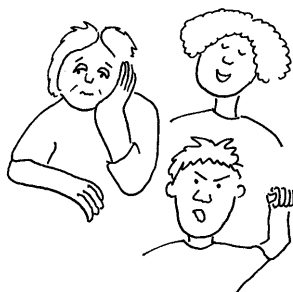
Maureen said staff who support her shout this:

Get up and go to work [to the day centre], [I]don't like it. [They say]Get up and have your breakfast.



Maria said:

It's the way they say it as well. I hate when people start on me. I'm an adult I'm a woman. I don't want people telling me to do this and do that. I know what I'm doing you see, not telling me to get up and go to work and that.



Maureen and Carrie said staff are sometimes ok and sometimes they are not ok.

Maureen said:

My carer boss me about... and the centre boss me around.

It is not the staff's job to tell us off, be rude or boss us around.

Roseanne told us how staff can go against what each other say and how the person with learning difficulties can end up being told off:

I get instructions off the manager [of the residential home]. She tells the senior the things that I'm supposed to do myself. The manager has told me that these are the things that I'm going to be learning, because she is talking about... like when I get my flat.



They are teaching me just small things that I can do myself and the small things I'm supposed to do are: change my bed when it's needed, clean my room when it's needed with the domestic staff (make sure the domestic staff is there as well), my washing when that is supposed to be done (every day that is supposed to be done), washing dishes, having a bath when it's needed (twice a day I'm in there), asking for help when it's needed like asking the domestic staff to carry the Hoover for me. My responsibility is to look after myself, that's what I was told, my key worker told me that.

Staff sometimes stop me from doing the things I've been told by the manager to do. They just keep asking me what I'm doing and it pisses me off when they ask questions like that. They tell me off like I'm doing something wrong. It just feels like I don't want to live there anymore when the staff have a go.

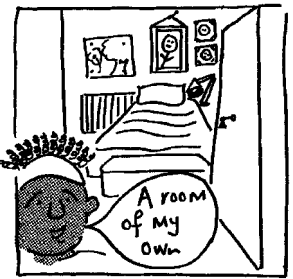
Maria said:

It seems to me that the manager has told Roseanne to do her chores and that the other staff are trying to put her down by telling her not to do them in a kind of way. It seems like they are stopping her from doing what she is supposed to do like changing her bed linen and all that and doing the washing up and looking after herself.

Roseanne said:

I hate being accused. Yesterday I was waiting outside the bed linen cupboard because I needed the domestic staff to support me to carry the Hoover because if I did it myself and carried it and fell over then I would have hurt myself with the Hoover. It was one of the agency staff said I could do it myself. He said I was waiting so that I could listen to the domestic staff's conversation and I wasn't, I was waiting to speak to the domestic lady.

One of the seniors had told me that I must ask for help with the Hoover and get someone to carry it for me. It made me cry because it was hurting me because of the way I was spoken to, not very nice and not very pleasant really.





Sometimes the staff are not rude to me but sometimes they are when they have a bad day and staff shouldn't bring their problems to work.

Maria said:

They shouldn't take it out on the clients if they have got a bad day or they are not feeling too good coming into work. They should keep it to themselves... The manager should sort her staff out because the staff is too out of order that's how I see it. I've had that when staff were getting on my back and on my case. It's not right its making the clients unwelcome and not want to live there... You should complain about that Roseanne because your feelings are being hurt. You have got a right to complain Roseanne.

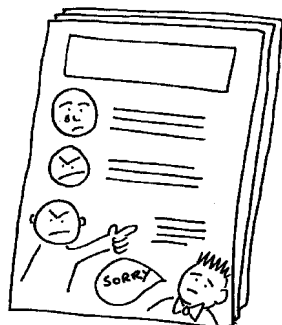


Roseanne said:

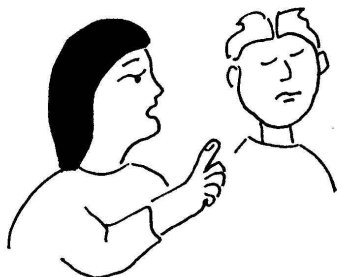
If the clients had spoke to the staff like that they would be straight into the Manager's office and we would get spoken to about it by the manager. But when the staff speak to the clients like that, why isn't the manager sorting them out?



I filled in a complaint form once when a staff was rude to me. I was called into the Manager's office and I told her I'm not the sort of person that does make a complaint for no reason. The manager apologised to me, and the manager told me that no staff should speak to me like that.



I filled in a complaint form because I'm not having staff speaking to me like that. I don't want to make a complaint again though because if I make a complaint I will be had up in the office again. I've had it up to here with managers and that because it really drives me up the wall clients shouldn't be treated like shit in there.



If a client does something wrong they are told off straight away. If a staff does something wrong they are not. I am only living there because I haven't got anywhere else to live. There is nowhere else to go. If I do something wrong I should be spoken to about it, but if staff do something wrong they should be spoken to as well

... When I move will the staff have to tell us what to do all the time or is the word “advising” not “telling”? It is just that a staff where I live (the same person that was rude to me) has told me that when I move the staff will be still telling me what to do. So I need to know is that right or wrong? It should be advising and listening [to] what the other person has got to say to them.



The manager of where I live doesn't boss me around she listens to what I have got to say. Staff are there to listen to you and advise you on the things that you need to do. Jenny [a service user Roseanne was going to be living with] and myself will be the ones who will be doing the interviewing (of the staff or the support workers) with support. If we don't like their rudeness [the staff] and their behaviour then we can tell them to go but we will ring the office and tell them that we are not happy with that support worker because she is being rude and not polite to Jenny and me so we can sack her.



Craig said:

Staff should be nice to people with learning difficulties, kind, talk to you in a nice way.

Maria said:

Staff can't tell you what to do all the time.

Roseanne said:

You have to make mistakes.

Maria asked Maureen this:

How do staff treat you at Nicholas Road?

Maureen said:

Angry.

Maria said:

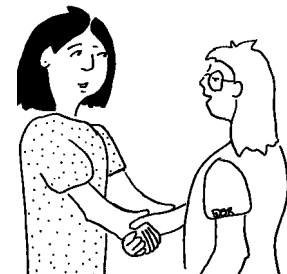
Are some of them strict or bad to you or towards you, can you tell me how?

Maureen said:

Yeah [they] tell me off.

Maria said:

Why, Can you tell us why?





Maureen said:

I was angry.

Maria said:

About what?

Maureen said:

Doing the job, doing plants.

Maria said:

Doing plants, doing gardening.

Roseanne said:

I was there that day when they did, they did have a go at her...I was standing there and I heard every word they said to her... What are the staff's names Maureen, who are they?

Maureen said:

Arthur, Cerys... tell me off.

Maria asked if Maureen shouted back and said:

You should shout back.

Roseanne said:

That's what you should do. You should fight back.

Maureen said:

I am gonna fight back.

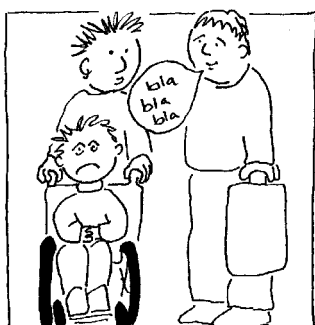
Roseanne said:

Fight back, just tell them you're not gonna put up with it. You see if we sit there and let them do that to us we're [more] stupid than I thought we were. So if we do fight back it will show we are being responsible to do something.

Roseanne said:

Staff shouldn't make you do things that you don't want to do. Like in the evenings staff ask me if I want to go out and they say I should go out, but I tell them that they can't say that, that is not in their role and I say "no" especially when the weather is cold. I like to be in my nightclothes I feel more comfortable without a bra on. When I get free time I like to take it off.

Staff say that I go to bed too early but I think It's down to the individual. When I have been out all



day I don't want to be going out I want to go to bed cause I get tired. The other member of staff, that I like, she don't make me go out. She said you can't force the individual to go out. When staff push me to go out I say "no" and I say in my mind "arse holes I'm not moving."



Craig said:

Staff should be patient.

Roseanne said:

They should have a lot of patience but they don't. They shove us under the carpet when they feel like it.



Craig said:

We have to get tough on them.

Maria said:

Talk to them the same way they speak to us.



Roseanne said:

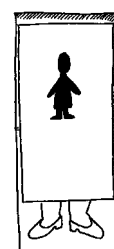
Staff don't like it when the people can stick up for themselves... There are some nice staff. They don't question you all the time. They don't make you do what you don't want to do. They ask you if you are all right when you are doing things like my bed for instance. They ask me if I am ok. It's not just the good staff that ask me if I'm alright clients do as well and some of the people that support us at People First and the staff at college. They [staff at college] told me because I'm new I mustn't do too much and I can sit down when I want to because I get tired easily because I am anaemic.



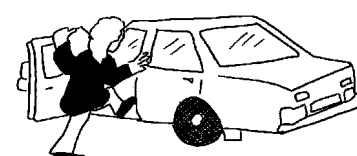
Alice told us about a difficult situation she had been in where she got told off and it was not fair. She said: I was on my monthlies and I wet myself at college and had to get a cab home because the driver wouldn't come back and get me...

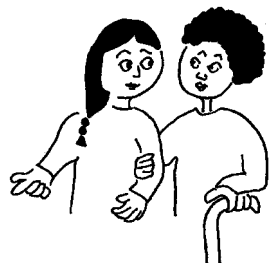
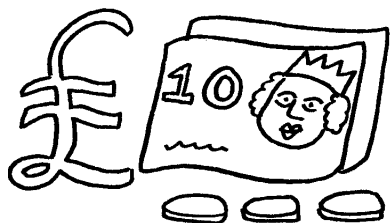


I have a weak bladder and I'd been on the bus for a long time getting to the college. I didn't know where the toilet was, (I've only just started going to college) and it was full [the toilet] when I got there.



It cost me £13.00 to get home. They took it out of my money to pay for it. When I got home I was





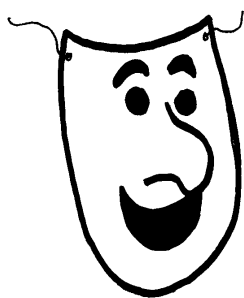
told off by the deputy manager for paying £13.00 and I was told off because I'd wet myself as well and because I'd come home in a cab. I think this is bollocks and arse holes and the research team think this is out of order.

All the women staff know I have problems with my monthlies but he doesn't know [the deputy manager] because he is a man. They should understand these things. Later on other staff told the deputy manager not to tell me off. I got support from the women members of staff.

...Men staff who are dealing with people with learning difficulties should understand that when women are on their monthlies they can have accidents.

I [had] two options I could go home or bring spare clothes of my own but I didn't have any that day. I am not going to put up with being told off for something I haven't done wrong. That place [her residential home] really pisses me off. No wonder I have mood swings. I don't think it's right. That's all I know. But when he [the deputy manager] had a go I had a go back. I said bollocks to you and I went and sat in the bath for hours.

We don't want staff to stop the joking: It's good when staff can take a joke



We think staff should see the funny side of things and they should not try and stop us from joking around.

A man with learning difficulties we interviewed called Mihesh liked to make jokes and staff used to try and stop him from doing this.

Roseanne said:

Mihesh was joking saying something about "condom day" and another word

When Roseanne was interviewing Mihesh she said:
What do you like doing?

Mihesh said:
Drugs.

Roseanne told us:

With that you have to joke along with him [Mihihesh], because if you don't he will go in a mood. You can't be nasty to Mihihesh because he is only joking.

Craig said:

It's a joke he is trying to be funny.

Vic asked:

Do people try and stop him saying "condom day" and what do you think of that?

Roseanne said:

Yeah they do. It's not right. You are allowed to joke about if you want to joke about. You mustn't take it too seriously because if you take it too seriously people will think you are miserable all the time. It's fine for Mihihesh to say that because I say to Mihihesh "Go and ask Derek West [the manager of a service] for the money". He does go and ask Derek and then Derek West jokes around with him. It's good when staff joke around.

Maria said:

I think it's alright at least he doesn't go serious about it but some staff could go serious they don't take it for a joke they just get upset about it some of them but not all of them.

Roseanne said:

I just think it's silly that people just can't take a joke so we just leave the people who can't take a joke alone.

Craig said:

Staff should try to be friendly and joke along with him [Mihihesh].

Maria said:

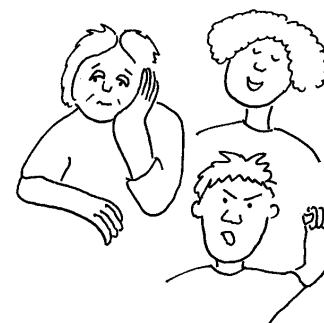
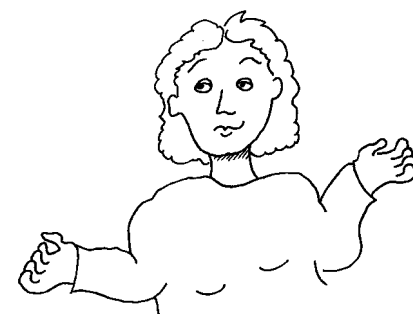
And get on with him as well.

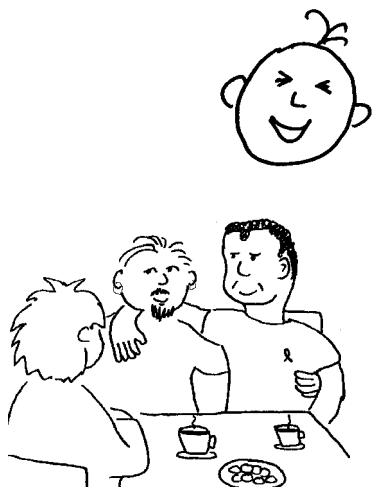
Craig said:

I joke around with the staff.

Roseanne said:

I joke around with people who can take a joke. It's nice to joke around. It's nice to be more jolly and happy.





Craig said:

I always see the funny life. I'm always giggling me.

Vic said:

What about that some people might think saying "condom day" is rude, what do you think about that?

Roseanne said:

It might be to them but Mihesh likes to joke around and you can't take that too seriously can you.

Staff can sometimes be frightening

People told us that staff can sometimes be frightening.

Roseanne said:

Sometimes staff shout at us. Last week a staff [member] shouted at me because he didn't get a message I left with another member of staff for him about me coming home in a cab. He didn't believe I left the message. It's not my fault that the message wasn't passed on. He was very angry. He came close to me and I thought he was going to hit me. I shouted back at him and now I'm scared of him.



I've been upset and scared for over a week now at home. I don't know what he is going to do next. I was very close to him like he was my step father, like a good working relationship. Now I won't be on my own with him. I try and make sure another member of staff is around before I go anywhere he is. I daren't tell my key worker or the manager of where I live about what happened because I am worried that it is going to go back to the driver and he will be angry again.

Maria said:

Staff can hit clients. When I was in the hostel a man staff tried to hit me. I moved away to protect myself as a woman from being hit.

Roseanne said:

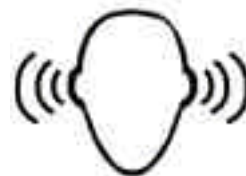
It's very scary for me if staff shout at me because I have been beaten up by staff in the past. When I



got angry about something a woman staff started to hit me. When I went home to my Mum for Christmas my Mum saw bruises all over me when she was helping me in the bath.

Maria said:

It's wrong for staff to shout at clients they should treat the clients nicely and give them some respect as a client.



Roseanne said:

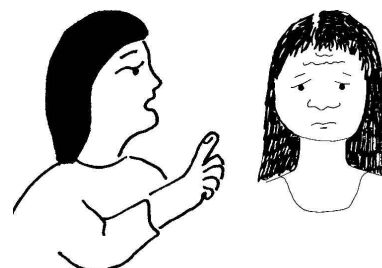
If the client says something then you should listen to the client. It is not right to say you don't believe the client when they are telling the truth. It made me feel even worse than I have been recently when he [the member of staff who shouted at Roseanne after she got a cab] said he didn't believe I had phoned to say I was getting a cab, and he said he didn't believe me in front of four other staff. He made me feel like I was a liar.



We don't like staff wrongly accusing us of not telling the truth

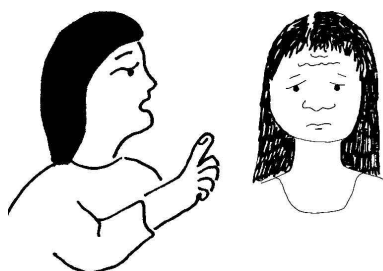
Roseanne told us about another time when a member of staff accused her of not telling the truth. She explained how a member of staff who was trying to make her go out said she hadn't gone out on Saturday. Roseanne had gone out on Saturday to buy hair cream. The member of staff said Roseanne wasn't telling the truth when she told her she had gone out on Saturday. So Roseanne, as she put it:

Got nasty to her because you mustn't pressurise people like that... I don't like being accused; somebody saying I didn't do something when I did do something. They have accused me of stuff before... They don't listen to me. I just got nasty and I don't want to be nasty but I don't like people accusing me of not telling the truth.



Staff can say hurtful things

Staff can say hurtful things. Roseanne told us about one. She said:



I told everyone on the mini bus that I wanted to come off the bus because there was a lot of racism going on, on the mini bus and in the day-centre. The mini bus driver said that if I come off his bus he will leave. I thought that was blackmail. I think it's wrong. It is not right for staff to say that... The same driver that said if I came off the mini bus he would leave. He [the above driver] called me a "spoilt brat" on a different day. I told Derek West [the manager of a service]. Derek told Sheila [a member of staff]. Sheila called me into the office. I was scared. Sheila told me "I am pleased that you can come and tell us what is upsetting you and why". All I can say is that it is wrong for any member of staff to call you names.

Staff can think they are in control of us

Craig told us how staff can think they are in control of us. He said:

You know the Oakden [Further Education College], "sit down do painting" the teacher says to me. I was going to the toilet. I got my own back on them. "You are babies" I said "I am not going to stand it no more. If you want painting done do it yourself I am not going to do it".

Roseanne told us about a time when a member of staff tried to control her in a hurtful way: She said:

Well I was in bed lying down on the pillow as usual and I got woken up by a member of staff who said "are you going to church?" and I said "no". Then he said if I didn't go to church "God won't forgive" me. I think that's spiteful and hurtful saying that. I think it's wrong because that's blackmail. One of the staff said "the bus is waiting for you" and I said "no I'm not going".

At times nothing we say is confidential: Staff talking to staff

Sometimes people with learning difficulties want to say something confidential to staff and not have

them talk about it to other people but it is not always safe to do that. Marlene explained why she did not feel safe to say what was bothering her in her residential home:

I don't trust any of the staff at Heath Road because if I tell them what isn't right I feel that they would go to another member of staff and then they will discuss it and then it will go to the Manager and then I will be spoken to about it.

It just feels like the staff don't trust me because they think I make things up. Like I see Susan [a service user] going into my room and they say she doesn't go in there. So they are liars not me. It's not safe for me to be in that place because they don't believe me. Also I've been attacked in my bed there before; Susan done it. I am going to say to Sandra [the Manager of the social workers] it's not safe for me to be at Heath Road because it aint. It's come to that stage where it is not safe for me to be there. But if I speak to Sandra it will go back to Olive [the Manager of the residential home] won't it?

Vic asked:

Could you ask Sandra if she would be confidential about it?

Roseanne said:

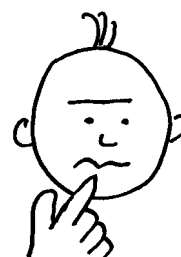
It's come to that stage where it is not safe for me to be there. But if I speak to Sandra it will go back to Olive won't it?... The Social Workers, anything that I tell them, they would tell Olive [the Manager of Heath Road] and then what? You know the rest.

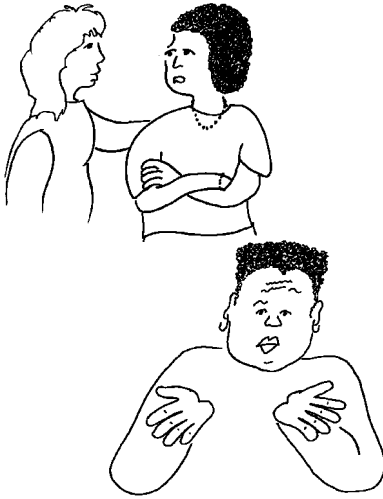
Vic said:

I think you could insist that they were confidential.

Marlene said:

I just hope they would be because anything you say should be confidential and shouldn't be going out unless your consent [is given]... I just feel that I don't trust nobody at Heath Road nobody. The only thing I can do now is ring up and talk to the people [where Social Workers are based] and tell them if I tell you something I don't want it going





back to Heath Road. I want it confidential, private. I have been pulled into the office when I did ring the Rape Crisis Centre and I still can't figure out how she [the Manager of Heath Road] knew about it. When she said to me do you know the people at the Rape Crisis Centre I nearly shit myself. I want to know who told her. I think it was my care manager who told her. I did ask for her not to tell Olive what I discussed and why, but I told something confidential and it was broken and Olive got to find out and I was called in.

We want to tell you...

Sometimes staff tell you what to do.

The person who told Roseanne to go out had no manners. He had a very bad attitude.

Sometimes staff assume that you want to do something when you don't.

Staff should give us some respect and dignity and talk to us nicely, not like we are nothing.

They can't go round speaking to service users in a rude manner.

People with learning difficulties are not children, they are adults. They [some staff] still talk to us like we are kids.

We are people.

People should make their own decisions, the staff shouldn't tell them what to do; it's their own choice.

Their [staff] role is to be there to support you to do what you want. Not to do what they [staff] want.

If staff boss you around tell them you don't take it and that you are not going to do what they tell you to do. It's your right to do what you choose to do. You can make choices.

People try to tell people with learning difficulties what to do all the time. Don't let them boss you around now. You don't have to listen to them.

If it wasn't for the service users they [staff] wouldn't have a job right now. They need to be told that again and again.

Staff need to be told they can't keep on bossing us around.

Staff should be looking at the White Paper [Valuing People].

If a member of staff tells a person with learning difficulties what to do. You can tell someone who is in charge of that member of staff, like their manager.

If someone tells you what to do, you can tell them to do it themselves.

Some people get frightened when they say "do it yourself". People have been told off for saying it. They shouldn't be told off If they weren't spoken to in a proper manner in the first place. If people speak to people in a proper manner they will be polite back.

Some staff tell you what to do, to do this and to do that and don't give you a choice.

Staff should give the service users advice and not be rude to them and tell them how they should live their lives. They should not criticise the service users, which some of them do.

Staff who criticise service users and boss them around should be out of a job, because they are not doing their jobs properly because they are just being awkward. They think they know it all but they don't. They are telling people [with learning difficulties] how to do their jobs but they are not doing their own job right. They think they own you but they don't.

Staff can boss you around too many times. Staff can be frightening.

Staff should not hit you or call you names.

Staff ought to be patient with us.

Staff should not talk down to us. They should be nice and polite, nice and kindly, not like a bunch of idiots [the staff].

We should stand up to the staff and tell them where we are coming from.

Staff should have a sense of humour. Not all of them do.

Some staff should give you more space.

We often get told off but staff get away with telling us what to do.

They shouldn't be telling us what to do. We should be telling them what to do.

Chapter 10 We want what everyone wants

Being where you don't want to be

The people who took part in this research talked about how people with learning difficulties can end up going to college or day centres for a very long time, even if they want to do something else.

In one of the interviews Kelly said:

I'm lucky I do a job that I like... I'm lucky but a lot of my friends they either go to college for six years or go to a day centre for twenty years. O.K. that can be good and that can be bad but some people do want money and want to go out a lot more.

Roseanne wanted to leave the day centre she had been going to for the last 20 years. She said it was:

A load of crap. Nobody likes Nicholas Road because they are supposed to treat people equally but they don't. It's like they have favourites there and that's wrong. People sit on their arses and do nothing all day in there.

Vic asked if Roseanne was sure that "nobody" liked Nicholas Road, if that was what Roseanne really wanted to say. Roseanne said:

Basically the people that I used to mix with didn't like it and the people I didn't mix with I don't know if they liked it or not because I didn't talk to them, did I.

Roseanne said that social workers said she had to go somewhere during the day.

Roseanne said:

Social workers are another people who take the piss. It's like they're taking over your lives.

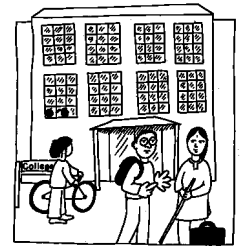
Maria agreed.

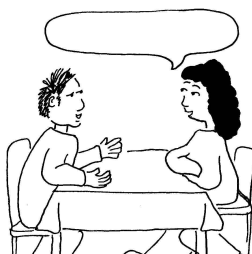
Roseanne asked Mihesh [a day centre user]:

What do you think about Nicholas Road?

And Mihesh said:

Stupid.





Roseanne said:

I interviewed Mihesh because he has a lot of views... I think it's good what Mihesh said about Nicholas Road because it's rubbish anyway and a lot of people say it's rubbish... It's not the same. We used to get paid £1.75 or £2.75 for the job but now you don't.



Vic said:

That's not much.

Roseanne said:

It was a bit of pocket money. They make you work for nothing [now]. It's a waste of time. Being there is like slave labour.



Roseanne asked Mihesh what he would "rather do than come here [Nicholas Road]" Mihesh said "Club".

Roseanne said:

There is more to do in clubs than at Nicholas Road. They take you out on outings. They keep you busy. Mind you they keep you busy at college but you've got more freedom in clubs.



Craig had recently stopped going to a different centre. He used to go every Friday. He said:

I just want to get out of it. You want to get out of it... Look like [a] nick [prison]... I got out as soon as possible... As soon as my Dad was at that door whmmm [I rushed out]... Someone put a bone in my dinner and my Mum said you are never going back there again.



Vic asked:

Was there anything good about that day centre?

Craig said:

No, I liked tea time most. I wanted to get out of there from the minute I saw it. I said to Mum I don't like this place I get a feeling I don't. I never did... No one talk to me anyway, only [one] girl.



Getting out and about

People told us that they often have to stay in a lot.

Craig said:

I have to look after the house. When my Dads in I go out walking round [the] corner. I'm [all] right

for now I'm here Mondays now [at People First]. Weekend I'm out walking. Sometimes I go to the pub... with my friend.

Craig went on to say that at night he:

Listens to tapes, story tapes. Sometimes if I want to, at night now if I want to, go for a walk, thinking while I'm walking.

Maria said:

What else do you do at night?

Craig said:

Normally relaxing.

Maureen said what she does at night is:

Lay in bed. Watch a bit of television. Go out to drive along in the car... My carer drives the car.

Shirley said what she does at night is this:

Relax and then after watch the telly, and then after go to bed.

Stuart said at night:

I do exercise. I do keep fit and video and reading writing, sports, do cooking, chill out and watch the telly.

Carrie said at night:

I watch TV at night. I watch TV, bit of TV till about at nine then I switch it off... I have a bath and I go to bed then.

Kelly said at night:

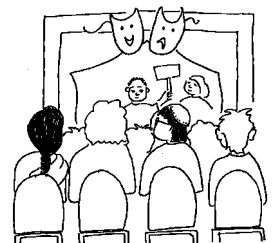
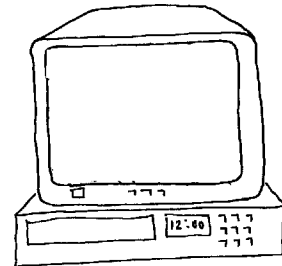
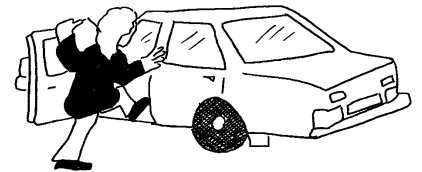
Mostly I watch TV and just go straight to bed afterwards.

Julie said what she does at night is:

Relax.

Kelly said:

I do [relax] but I think a lot of people with disability would like to go out a lot of places with the right support and do things like Vic [like a person without learning difficulties]. All my friends who's got learning disability you can talk to them about any soaps like Coronation Street, Brookside, Emmerdale and it's sad, no it is sad that all of us knows about so many soaps you know. There's





nothing wrong about knowing about the soaps but all of us knows about soaps, but any of us want to go out in the evening and do things like Vic.

Julie said she gets out in the evening when she can because she can go out by herself. She said:

But I would like to do more things and meet more friends... like go swimming.

Maria said:

Cinema.

Kelly said:

If you haven't got the money what can you do. If they are all on benefits, not all of us are but some of us are, what can you do? And if we don't like going out in the night time because this country is not like it used to be years ago, what can you do? Cause nobody don't like going out in the night time.

Roseanne said:

We're afraid because we don't know what's going to happen.

Julie said:

People follow you around and anything like that.

Kelly said:

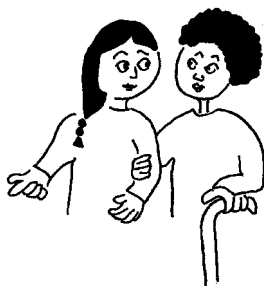
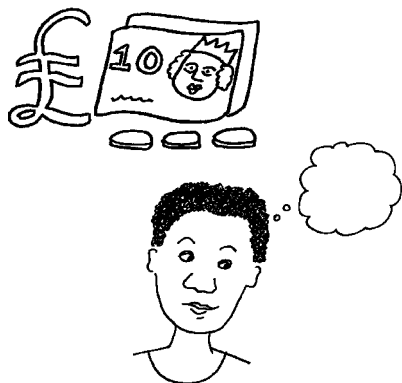
I like going out in the evenings if I get the right support... If I didn't have certain money and certain people in my life I wouldn't do anything in the evening. I would just have my dinner and go straight to bed and that would be from Monday to Sunday.

What the white paper (Valuing People) means to us

We talked about the White Paper called Valuing People that is supposed to be making things better for people with learning difficulties. People said nothing much had changed in their lives.

Roseanne said:

Excuse me which part of us has a say in what happens in either residential [residential homes] and day-centres. I don't call that "Heath Road" [the residential home Roseanne lives in] I call it The



Cubby Hole, like a prison place because you are still locked in, because as far as my bedroom is, that place used to be for naughty school girls and that place we are in it still looks like a prison to me. Good job Grassacre is looking for somewhere else to be.

They are small rooms and not big enough for wheelchairs. I'm speaking on the wheelchair users' behalf. I'm not a wheelchair user but I've got friends who do. The manager has the say but if I'm not happy with something I tell her loud and clear in a polite way because Olive [the manager] knows when I get angry she's had it.

Craig said he didn't have a say in what happened in the further education college he goes to. He said:
... I just shut my mouth, loads of us do.

Roseanne said:

Craig you should have a say because you are using the service.

Craig said:

I'm sure that place used to be a bloody cell; bars up the wall, fences outside. I have minimum say, just a bit...

I don't know why I keep my mouth shut it's like that in all day centres. Put it this way I'm frightened of teachers and teachers are frightened of me. When I go in there Thursdays I think Oh God not this place again.

At one point Craig said:

I feel safe here [at People First] no one can get me. You treat me as humans.

Vic said:

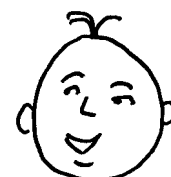
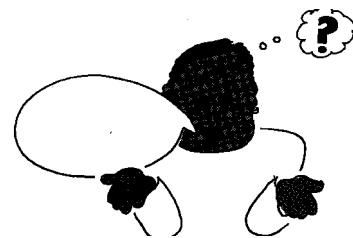
Are you not treated as human sometimes and how?

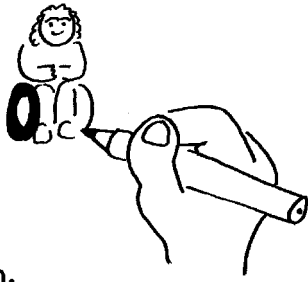
Craig said:

Sit down there don't be naughty be a good boy do work at the [name of further education college].

Vic asked:

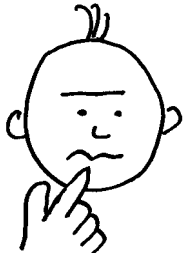
Anything to say about the work?





Craig said:
Paint and paper.

Vic asked:
What do you think about doing paint on paper, this situation?



Craig said:
I am not happy with it, too many rules there.

Vic asked:
What are the rules?

Craig said:
Don't know.



Vic asked:
How do they make you feel?

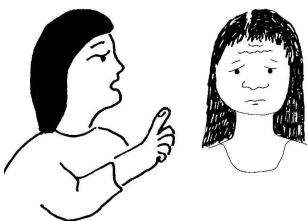
Craig said:
A bit hurried, a bit nervous.

Vic asked:
Can you do what you want while you're there?

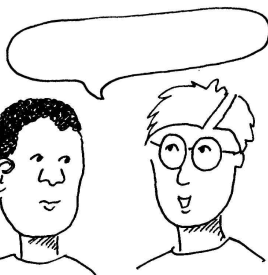


Craig said:
Within reason as long as you sit down, do work, drink your tea and don't misbehave. One thing I sum it up, its crap there I want to get out of it.

Roseanne said:
Every time I say something I can see a glimpse of Olive. Yes I did have a say because I was a Clients Committee member [in a day centre] but I wanted to get out of the Centre because they had all these staff that thought they knew it all. It should be the clients that have a say in there. It's our services. I made rules in that centre.



Vic asked:
Did they listen to you and do it?



Roseanne said:
No, like when I wanted to interview Mihesh I went to Joe [Roseanne's Key Worker in the day centre she used to go to] and Joe said no. I went to Derek [the Manager of the day centre] and he said yes. I went to Joe again and he said no. I went to Derek and he agreed with me all the way along he

said yes it was Joe who was making it difficult by saying no. Derek said it would be good if Mihesh participates in the meeting. In the end Joe couldn't do anything about it because Derek agreed it.

I do have a bit of a say because if I don't want to do something I just won't do it... I do have a say because like if I don't want to get on the bus I can say no. The nice staff are helping me to make a pattern of the things that I am supposed to do. Not pushing me to do it just supporting me. They are just trying to help me. I put it together with myself and my key worker so I can work out where I am supposed to be so that it helps the driver as well. The weekend is free time.

Vic said:

You are saying you do have a say and earlier on you are saying you don't and the place is like a prison, which one is the true one.

Roseanne and Craig said:

Both.

Roseanne said:

The only time I do get a say is when my key worker is on and when Olive is on because those are the only two people I have a say with and Caroline as well because Caroline supports me on the things I'm supposed to do as well... You have a say when they don't disagree with you. When they disagree with you, you don't have a say.

Maria said:

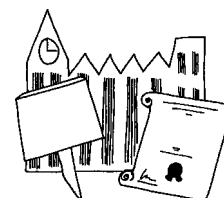
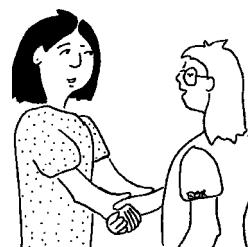
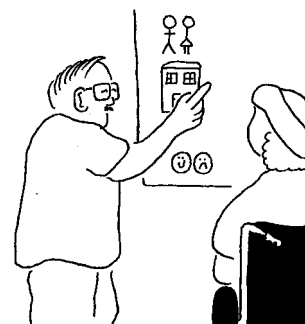
I feel like the Social Services and the Government are stopping us from doing what we want to do. They are stopping us from leading our own lives and I think that's wrong, that's why they are pushing us underneath the carpet.

Vic asked:

What do you think of the White Paper?

Maria said:

I think they are just taking the mickey out of people with learning difficulties. They think they can just





take the piss and get away with it, because they've got the money and the power. They think they know what's best for us, but they don't. We know what's best for us. They are taking money off us. That's why they are getting all these posh cars and jewellery and that out of our money and going on these expensive holidays and that [the Government and Social Services]. If it wasn't for us they wouldn't be in a job right now. We train them and they are not doing the job properly.



In one of the interviews Kelly said:

I don't like when organisations say they are going to involve people with learning difficulties and they don't involve us in things about us. I don't like when people get big money and don't give people with learning difficulties any of the money to work with them. I don't like the way people don't ask us. They say they ask us here but they done it before. I don't like when they get funding bids, and this is big money, big money, and they don't ask us if we want to be part of the training. They do the training themselves, but they don't ask people with learning difficulties to do the training and get paid for the training and involve our families in it. I don't like when people say they know best.



Maria said:

Cause they don't.

Kelly said:

But they think they do.

Roseanne said:

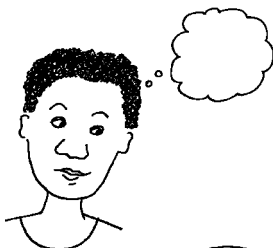
But they don't.

Kelly said:

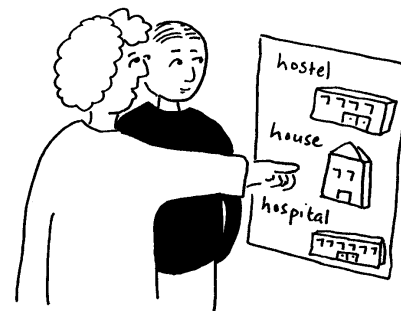
Yeah but they do think they do and they get the money and if it wasn't for all of us in this room today a lot of them people wouldn't be in their jobs and that's what I don't like, they've got all these bits and pieces but they don't tell us.

Maria said:

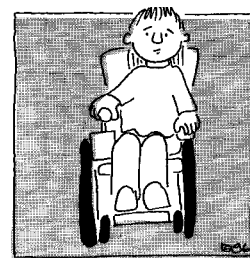
The White Paper is all talk but no action. The Government and Social Services say one thing and



don't do it. Some people who have been in day centres all their lives might want to move on to new things, some people might want their own flat or their own independence but they can't do it because, put it from my point of view, I know what its like to be in a hostel I was in one when I was a teenager; telling you to do this and do that, what time to be in and what time to be out, because you are not allowed to stay in the hostel in the day time without the staff being there. People stay in one place and they don't move on at all a lot of the time I find. Like Roseanne is in Grassacre and she is waiting to get her own flat but she can't move on until they find her a place because Roseanne needs some support.



I feel sorry for them people stuck in day centres because they are not like me going out and coming back when I want, being independent, doing a job. They can't do that some of them are in wheelchairs, some of them can't dress themselves. They can't get away from everything. They have to stay in one place. These people like Mabel Owen [woman with learning difficulties] on the radio said people don't have their own things. They get bossed around and some people with learning difficulties don't like being bossed around or being called names. Some of the staff, but not all of them, tell you to get up make your bed or whatever; they say to you, they just tell you what to do.



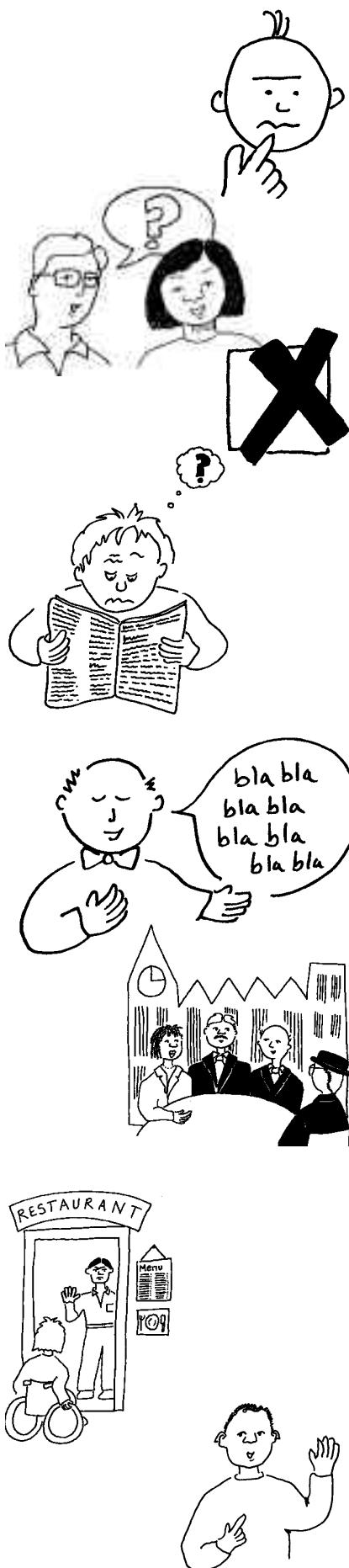
Vic asked:

Do you think the White Paper is going to make any difference?

Maria said:

I don't know, I don't know if they are going to do it or not do it to make the lives better for people with learning difficulties. They say they are going to do it, change this, change that, do this, do that, but I don't know if they are going to do it. I bet it's all talk and no action. It is taking a long time to do it. They can't make up their minds if they





are going to do it or not and it is making me confused and other people confused.

Vic asked:

Has the White Paper made any difference so far?

Craig said:

No, to my life no. My life is still the same.

Maria said:

No. They are saying the same thing over and over and over like a tape recorder until it does your head in. It hasn't changed my life, I know that.

Josh said:

They say a thing and don't do it. They say a thing and they don't carry it out. Look at the meetings they have. Perhaps a little bit changes but not that much. I have not noticed anything change.

Maria said:

It's our lives but the Government and Social Services are trying to control our lives. It's always been like that. I just want to control my own life. I don't want Social Services telling me what to do and that I can't go out to a night club. I like to socialize with other people and meet new friends. I just want to enjoy my freedom. I don't want people to control my life for me I want to control it myself. That's what my Mum brought me up for to control my own life.

Josh said:

Some people in the wheelchairs can only get out when people take them out places. That's what gets me. Sometimes they can't get in places cause there is no ramp.

Maria said:

I've been to some good conferences about the White Paper.

Craig said:

The Council are all liars. They say this they say that but they don't do any of it. They say they will make this city a better place. They say they will make it a safer place but they never do.

Julie said things have changed a bit for the better, she said:

I wouldn't have got my own flat without a bit of support. I would still be in hostels.

Maria said:

It has made my life a bit better but not all of it because it is still the same, nothing is not going anywhere.

Maria talked about one thing that she thought was good. She said this:

I live in a Key Ring flat and I've got a good supporter, cause she comes in now and again to see how we are. She comes in and gives us advice and tells us what's going on in Key Ring. She is a nice person. She is not rude she is a very friendly person. She makes you feel relaxed. You can talk to her about bills any time. She makes you feel comfortable she does. Sometimes she comes to a Boogie Night with me and Josh.

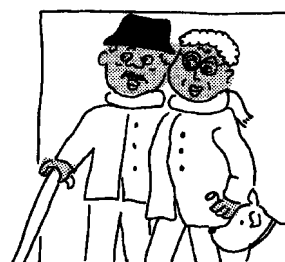
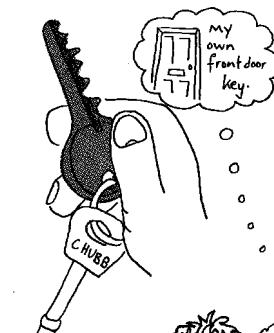
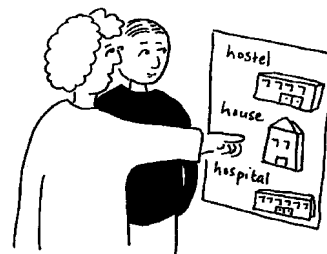
We want what everyone wants

The people we talked to just want ordinary things. Kelly explained what people with learning difficulties want. She said:

I like what so called normal people have. I would like to get a job. I would like to have a relationship. I would like to get money and to do things like so called normal people. Like when you've got a learning difficulty we always have a triple double whammy. We are always the last one to get anything; and the thing I like is just like anybody else. Like I said before, a relationship, speaking out and not being scared, standing up for yourself, having a choice, not being pushed around and getting the right support, learning about my culture, being proud of being a woman, being proud of being black and being proud of being a person with learning difficulties, having children and having choices.

Roseanne said:

You don't get them though.



Kelly said:

You don't; you get it [you understand what I mean].
That's what I would like in my life but it's hard
sometimes.



Shirley said:

I'd like to work with people and help them. I used
to work with the old people.

Maureen said:

I'd like to get a job [as] a nurse.



Kelly went on to say:

I just want to be treated like any so called normal
person, people listening to me, making mistakes
you know, just like so called normal people. I might
need support with what I'm doing but just being
treated like anybody else and that's what I would
like. I would like all the things that Vic has... If you
have got learning disability and if you're a woman
and if you're black it's always a double whammy.
And if you communicate in a different way, like if
you don't speak, it's triple whammy. So yes it's
harder. It's really hard if you rely on people to let
you have a normal life. It's hard and if they don't
believe in the rights of the people with learning
difficulties that they is supporting, it's so hard.

It's like, what life have we got? What life have we
got?

Julie said:

Not a lot.

Craig said:

Not a lot.

Julie said:

People treat you badly.

Kelly said:

If they don't believe in the rights of people with
learning disability what's the point. They can
speak to us nicely but if they don't believe in our
rights what's the point.



We want to tell you...

There should be more people with learning difficulties doing paid work.

There are not a lot of people with learning difficulties getting paid and they should be getting paid if they are doing a good job.

Colleges and day centres are boring. People with learning difficulties should get some paid work.

People with learning difficulties that go to day centres are doing nothing with their lives. You can't call it work. Staff start telling them what to do in there. The service users start bullying each other. There is not enough staff to keep an eye on them.

We know people who have been at the day centre for twenty five years. We feel sorry for them sitting around in the day centre all that time.

People with learning difficulties don't get a choice. They go to college or day centres and they might want to do more interesting things. Like go out and meet their friends, or go a drop in centre where they can meet new friends, or go out to a disco or something, or meet their family, or go on holiday... People with learning disabilities are not going out a lot or doing anything.

A lot of people with learning disabilities are indoors all the time at night.

A lot of people we know are afraid to go out at night on their own. There is a lot of people with learning disabilities getting bullied on the streets or on the buses at night. There should have some more support at night, not late at night, but support to go to clubs. There should be more activities in the evening.

For some people support stops at five o'clock.

Some people who need a lot of support don't get a chance to get out and about.

There should be a lot of supporters supporting people with learning disabilities to get out and about... supporting people to be safe. So they don't feel left out. So they can go and see their family and their friends.

There are clubs but a lot of people have to be on the waiting list for them. I know some people who would go to clubs but they don't like getting there and back on their own.

Our lives are still same as before the White Paper came into action.

At Social Services meetings they don't give us chance to talk about what we want to say. The meetings are hard to understand. They talk jargon words. They are boring. Social services take over the meeting and don't give us a chance to talk. Sometimes they don't even thank us for what we do at the meetings. They just think about themselves and their money and they don't think about people with learning difficulties and what we want.

People with learning difficulties don't have a choice about what they want to do with their lives and all. They want to do things but people are trying to stop us doing what we want to do. We want to go out and mix with people and have a drop in centre and meet other people but they are not giving us that power to do that. I think it's about time that people like us had the power to do what we want to do. People out there need to understand what we want to do with our lives. We have a life to lead as well as other people have. It is not all about people without learning difficulties having a life. It's our life as well. People think we haven't got a life to live on this planet. It has always got to be them, people without learning difficulties and it's not fair.

People should be treated the same, the same way as a person without learning disabilities. We don't get the same choices as people who haven't got learning difficulties.

People should understand our rights. Some people think we are stupid and that we haven't got a right to do things that normal people do. We are not stupid and we are not thick and we are not ignorant. People without learning difficulties should learn to understand that.

We want things people without learning difficulties want like houses, money and cars and clubs and to be on telly.

People with learning disabilities want more choices in life. We want to get involved in more socialising.

People with learning disabilities want the power and the control over their own lives.

This unique book is about the experiences of people with learning difficulties, how they are treated and what needs to change. It is based on research controlled by people with learning difficulties. It tells us how they did the research, what they found out and what needs to be done. It shows how oppressed many people with learning difficulties still are in society, how much they can do and what they want for the future. As one person said:

I like what so called 'normal' people have. I would like to get a job. I would like to have a relationship. I would like to get money and to do things like so called 'normal' people. Like when you've got a learning difficulty we always have a triple whammy. We are always the last one to get anything; and the thing I like is just like anybody else. Like I said before, a relationship, speaking out and not being scared, standing up for yourself, having a choice, not being pushed around and getting the right support, learning about my culture, being proud of being a woman, being proud of being black and being proud of being a person with learning difficulties, having children and having choices.

As the authors say: 'This book is for everyone and we hope other people with learning difficulties will read it, or have support to read it, because it could help them to be more powerful'.



Jennifer
Taylor



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Williams



Raymond
Johnson



Ian
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