

Our lives, our communities

Promoting independence and inclusion for people with learning difficulties

Craig Hart, Chris Shane, Karen Spencer and Angela Still

This research was carried out by people with learning difficulties and explores how they live their daily lives.

The study, from Central England People First, shows how 15 adults with learning difficulties live and what they think about their lives. It compares experiences of living with parents, living independently in the community and living in a 'village community'. Independence, choice and control were important themes in the study. The report gives ten recommendations to promote independence and inclusion for people with learning difficulties.

The ethics and practicalities of user-controlled research are described using activity diaries, network diagrams (showing circles of friends), face-to-face interviews and participant observation. The report also shows how people with learning difficulties can undertake and control real research using their own methods.



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1 Introduction

This research is very special to us. We are members of Fresh Start, the research and training part of Central England People First (CEPF), and this project is built on CEPF's work over many years. It uses our ideas in ways that we want to use them.

CEPF is an organisation of people with learning difficulties, run and controlled by people with learning difficulties. Over the years we have tried to work in ways that allow us to control our activities. There is a lot of research about people with learning difficulties that is done by researchers with learning difficulties and by researchers without learning difficulties. Some of this is very good but, in the end, the ideas that people with learning difficulties put forward are usually taken over by the researchers.

This is our first research project that we have done by ourselves. We have had control over the whole project. It says important things about the lives of people with learning difficulties. This does not mean that we have not had support, but we have been very careful about how and when we have used it.

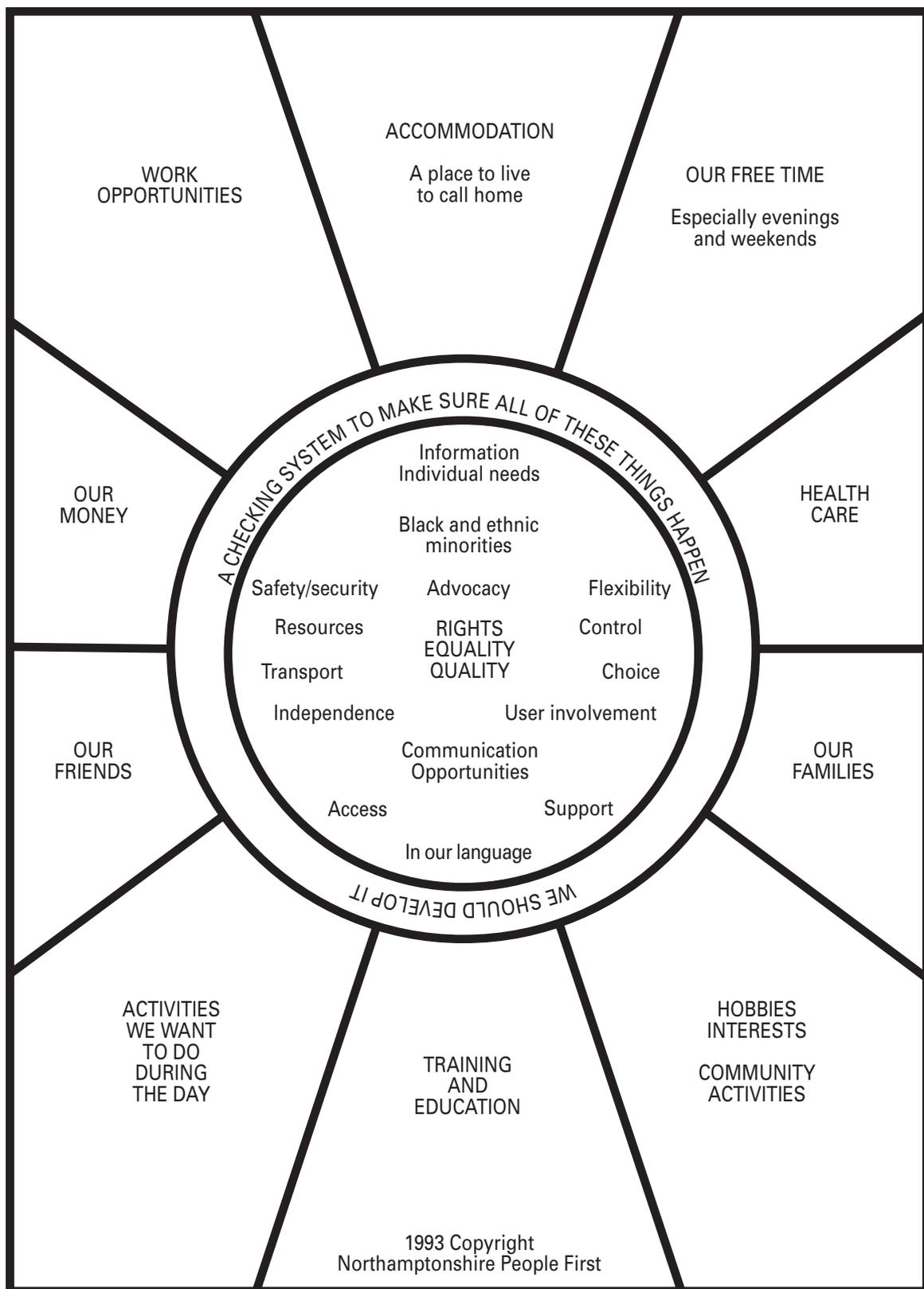
The way we have done the research is just as important as the things that we have found out. The report tells the story of how we went about it, what we have learned from doing it, as well as what we have found out.

It also uses our ideas. We developed a checking system to make sure that all the things that people with learning difficulties say that they need to have a good quality of life were in place as long ago as 1993 (see Figure 1). This still works. We use it to understand what people with learning difficulties need to be in control of their lives.

The aim of the research is to use these ideas, working how we want to work, to find ways of freeing people with learning difficulties from control by others.

The report covers how we did the research and what we found out. At the end we decide what all this means and make recommendations about how things should change.

Figure 1 Circle diagram



2 How we did the research

Using support

We used two types of support. The support people that we work with regularly helped us to work out ways to collect information and to work on what the information means. We also had a research support person, Ian Buchanan, who talked to us about our ideas, gave us advice on how to do research and helped us write up the research.

It was important that we used our regular support people because they understand how we work. It was also important that the research support person worked in the way that we wanted. We chose a research support person that we had worked with many times before. We had to be able to trust everyone in the project and know that they wanted to work in the way that we wanted to.

The project took a lot longer than we thought it would. There were two main reasons for this. We started the project in September 2003, as we had planned, working with one support person.

Our work was held up because the support person had a road accident and was off work for several months. We used some of this time to prepare with the research support person but the delay meant that the project was caught up with our other work and got further behind.

The second reason why the project took three years to finish, twice as long as we planned, was because the work took longer than we thought it would. The research plan had to be changed much more than we thought. We had to:

- change the way we did the research
- work out how we could do the research and keep in control of the project.

The way that we did the research was very different from the way we planned it, although we stuck to our basic plan.

- First we came up with questions based on our circle diagram (see Figure 1 in Chapter 1). We used these to ask each person who took part in the research and up to five people who they said were important to them (see Appendix 2).

- We also asked each person who took part to fill in a network diagram of people that are important to them (their circle of friends). They could include as many or as few people as they wanted.
- We also spent time on different days of the week and at different times of day with each person to see the kinds of things that they did and who they met.
- Before we started the interviews and observations, we did 'pilots' working with people we knew to check that the questions worked and to sort out how to arrange the research.
- When we finished collecting information we looked at it carefully so that we could write this report.

Doing it our way

We have found that it is not easy for researchers with learning difficulties to get permission to do research from support people and people who manage services. We found it difficult to find places that would work with us. We think that this is because people do not think that we can do it and we do not come from an organisation, like a university, that people look up to. Where we have done research, most staff, support people and relatives do not believe that we can do it. They expect our support person to ask all the questions.

Two members of our research team had problems with their own support people they had at home. These people did not understand what we were doing. It took a long time to get them to understand and be more flexible so we could do our work when we needed to.

We have had similar problems in our partnership working. Some of our past partners have made us feel very small. One partnership wanted only people who could read and write to interview people. They wanted support people to take more control over the interviews. They thought that we did not have the skills to be 'professional' researchers like they were. They wanted to control everything. The best partnerships have been where we have been respected as experienced people. Research is about getting the right information. There is more than one way to do this.

We think we have done our research in a professional way.

We had to sort out how to use our ideas. We did this with our research support person. We decided to do this by finding out about people's networks (that is, the people they know and are important to them). We also looked at how our experience and our ideas help us understand some important ideas (including inclusion, friends, strangers and membership). We also used the circle diagram (see Figure 1 in Chapter 1) to work out all the kinds of questions that we needed to ask. We did this with our research support person and made a questionnaire with our own support people before we tried out our project on a member of the team (we did a pilot).

The pilot was very important. We found out some important things.

- Using a video camera didn't work (we couldn't use it in shops, for example).
- Even when researching a member of our team, it was very difficult to get every friend or relative that he asked to be involved to join in.
- Sometimes when we made an arrangement the research didn't happen (because we just missed each other or transport went wrong).

These were important lessons and they have been issues in the real research. However, we learnt about the person's life from these experiences as well as from asking questions.

This pilot work was also very important because we could make a set of guidelines for researchers to remind us what we had learnt. We were asked to work in an 'ethical way'. The guidelines are how we understood what that means and the rules that we worked to.

Guidelines for researchers

- 1 All information must be kept within the project – confidentiality.
- 2 Respect the person's home, space and life. Do not take over. Keep in the background as much as possible.
- 3 Respect any place you visit. Follow any rules.
- 4 Remember the project is about them and not you.
- 5 If someone asks you to leave because they have changed their mind, then leave.

(Continued)

- 6 Make sure you have your own food and drinks.
- 7 If you smoke, take breaks to smoke away from where you are working.
- 8 Always explain what you are going to do and why. Ask the person if they are happy with what is going on at the same time.
- 9 Listen to the person at all times.
- 10 Work at their pace.
- 11 Do not put words into people's mouths.
- 12 Respect what people say.
- 13 Be patient.
- 14 Make sure you interview people where they are happy to be interviewed.
- 15 Ask the person who the research is about if they want to be at the interviews with people they have asked to talk about them.
- 16 Make sure that anyone you interview has support or a friend with them if they want that.
- 17 If a person is finding an interview difficult, then ask them if they want a break or to stop.

We also had some very good information from a parent about how parents and carers and support people may feel about being asked these questions. The main point was that parents and carers and support people may not feel comfortable telling people with learning difficulties how they saw the needs of their sons, daughters and so on. We made sure that people knew that it was all right not to answer questions that they did not want to answer. We also made sure that people knew that things would be kept confidential (see Appendix 3). This was quite hard for us. But, as researchers, we were being told that some parents and carers thought they had the right to control people with learning difficulties.

While we were getting the questionnaire ready we prepared training material, consent forms (see Appendix 3) and project information for the research. We decided to get people in the first area (First Town) to carry out the survey themselves, trained by us and given support by us. We felt that this would mean that we could get along faster with the research. This approach worked, but not as well as we thought that it would. Some of the pilot problems were still there (especially arranging meetings and

interviewing friends and relatives). Also the researchers did not have the experience that we have had and they did not own it. They found it difficult to make time to arrange interviews. We found that it takes a long time to set up the research. Also the questions they were asking were our questions, not theirs.

Another problem was that people found it difficult to rearrange their lives to do the work, as their parents, carers and support people did not see it as important. Only the network diagrams from First Town and some of the personal information was good information. For the rest of the research we decided to do the interviewing and observations ourselves, even though it takes longer.

It took us a long time collecting information and it was hard work. We worked with 11 people and interviewed them and their friends and relatives, making about 50 interviews. When we could, we recorded interviews but we made notes every time. We also made a network diagram, or circle of friends, for every person and a diary of the things they do in a normal week. Finally, for most people, we hung around with them and observed them doing ordinary things in the day and, when we could, in the evening and at weekends. We talk a bit about each person in the next chapter and talk about what we think the information means in Chapter 4.

Part of doing it our way was keeping control. When we came to making sense of the things that we found out, we went back to the circle diagram and all the things that we have talked about. There are 23 of them and people had said lots of things. We experimented in using a computer program called N6. Our research support person suggested this. It is used to understand what people say when you have ideas like our circle diagram to check everything with. It sounded difficult to understand. But it did make information easier to get at.

We went through some of the interviews and marked them for each idea in the circle diagram. Our research support person did the same. We then compared what we had all done. It was all a bit different and we discussed why this had happened. Most things were the same but one of us had marked the interviews a lot more than everyone else. We decided that the research support person should mark everything in the way this researcher had because it was accurate and marked all the information we needed. Even doing it this way, we did not find it easy to work with but doing the work showed us something very important.

We found out that some of the ideas in the circle diagram were more important in this research than others. Independence (and dependence), choice (and no choice) and control (and controlled) seemed to come up most of the time and to overlap a lot of the time. Other ideas came up less often and usually they were linked

with one or more of these three important ideas. This led us to stop using N6 and discuss the interviews and all the other information that we collected thinking about independence, choice and control. Doing this meant that we talked about a lot of the other ideas. It helped us.

We also looked back at our plans and realised how important the place that someone lives in is. For that reason we thought about:

- people at Smith Homes (South Village main site, the West Village house and East Wing)
- people living with their families
- people living on their own.

This gave us lots of things to compare and each researcher looked closely at two people or a single person and a couple who had been part of the research. We could not say a lot about some things, like minority ethnic groups, because there were few people taking part but we could say a lot about others, like how important parents are and living in a town.

We have set out what we think our research means in Chapter 4. We asked our research support person to edit our words into the final report. We did this because we are not experienced writers and our research support person is used to research report writing. Even though he did this using 'our words', we have been over the report three or four times and changed what it says and added new bits. We do not like using jargon words but sometimes we gave our research support person permission to use jargon. An example is 'working in an *ethical way*'. We let him use this because it describes things that are important to us. The way that the report was written was especially important for Chapter 4 because we say what we think about what we found out in that chapter. For earlier chapters we asked him to use the notes that we agreed as we went along. In some places where we needed facts and not what we think, we asked him to look things up and add them. This was quite a difficult way to work. When our research support person got stuck, he did not go ahead in his way but met us and we talked about it. We did this for each draft and in the week before the final report needed to be in.

It was a long process for us. We found the Joseph Rowntree Foundation had a good understanding of our work as people with learning difficulties and what we wanted to do, and were very supportive throughout.

3 What we found out

Our research is about comparing how different people live. We know that everyone is different but we also know that how they live depends on the choices they have – on whether they have been able to make their own choices in the past and whether they can make their own choices now.

Making choices is affected by the place that a person lives in, by their family and by the support that they get to make choices. It is affected by their independence and control.

We have compared people living in different places and with different family relationships and backgrounds.

We have compared people from Smith Homes, which is based around a ‘village community’, with people who live with their parents in the family home and people who live on their own in the community.

There are big differences between the choices people have in living their lives at Smith Homes. The main Smith Homes site that we visited is in the countryside at South Village, four miles from the larger village of West Village and six miles from the nearest town, Small Town. Over 50 people live at the main site in six units for between five and 11 people. Five people at Smith Homes live in a large town house in the village of West Village, and ten people at Smith Homes live in a large old house (called East Wing) in Small Town opposite the town’s main school. At the main site there are workshops and other facilities that are used by people from Smith Homes and some people with learning difficulties who come in from outside.

The people who live with their parents in the family home or on their own in the community live in North Town and First Town, and use services and support from a mixture of different places.

So that we can understand what we have found, we have compared how ten people of the 15 people in the research live in detail. This is because the information that we collected on the four people from First Town was not so good, although we learned a lot about how to do the research when we collected it. We also used one of the Smith Homes people (Sue) less because the way we looked at what all the information meant to us was by each of us thinking about two people or a single person and a couple that they had observed and interviewed. This made it easier for us to talk about what we had found and see what it meant. We do mention things that we

know about the First Town people and Sue to support what we understand from our research.

The 15 people in the research are as follows.

- *Andrew*, who lives at East Wing.
- *Carl*, who lives with his parents in Little Village, a large village near North Town.
- *Sally*, who lives at the Smith Homes main site at South Village.
- *Linda and Peter*, a married couple, who live with support in a flat in North Town.
- *Loretta*, who lives in the Smith Homes group home in West Village.
- *Kurshed*, a woman who lives at home with her parents in North Town.
- *Louise*, who lives at the Smith Homes main site at South Village.
- *Mark and David*, brothers of African-Caribbean origin, who live with their parents in North Town.
- *Sue*, who lives at the Smith Homes main site at South Village.
- *Anthony*, who lives in First Town in one of a number of houses near each other run by Jones Homes.
- *Lisa*, who lives with her mother in the family home in First Town.
- *Tina*, who lives in a residential home in First Town.
- *Tommy*, who lives in First Town in a small group home.

We looked at Linda and Peter as a married couple together, although they have many separate interests and do some things separately. We looked at Mark and David separately because there is no reason to assume that brothers will do things together. But, because of their relationship, we found it easier to talk about them together.

In the rest of this chapter we talk about 11 of the people, and some of the things that we know about them and their life in the community. We talk about each person,

their families and some of the things that we found interesting or important about their lives. We did not get such good information about the four people from First Town so we have included only the information that we could trust. This is their circle of friends, our name for their network diagram (see Figures 2 to 4 in Chapter 4 for examples).

Andrew's life and community

Andrew is a white man in his 40s and lives at East Wing. He has lived there for five years. Andrew used to live at the Smith Homes main site at South Village and is very pleased with his move. Andrew has a brother, Philip, and sees him every month or so. They get on very well. Philip is married with a son.

Andrew goes out a lot on his own, in Small Town. He has friends at Smith Homes and knows a lot of people who live in Small Town who he talks to. He is known locally as Cliff because he is a 'Cliff Richard fan'.

Andrew does not do his own food shopping but goes in turn with other people from East Wing with a staff member. Andrew does some of his own cooking, washing and so on with support. He thinks he has enough money to live on.

Carl's life and community

Carl is a white man in his late 30s and lives with his mum and dad in Little Village, a large village near North Town. Carl has a sister and he sees her and his brother-in-law, his Nan and some cousins. He would like to move out but his parents do not want him to move and he is going to get an advocate.

Carl goes out only occasionally to his local People First group's social events, and to the pictures or club with his mum and dad. He relies on transport from support people, the council or parents. When he is at home he spends a lot of time in his bedroom. He sometimes goes for respite care at the resource centre in North Town.

Carl does not do his own food shopping. He thinks he has enough money to live on. He would like to 'change his job', to one that pays. His parents are very protective and don't like him crossing roads since he was knocked down.

Sally's life and community

Sally is a 35-year-old white woman who lives at the Smith Homes main site at South Village. She sees her mum, dad, sister and brothers. Sally has her own cat, which she talks about a lot. Sally does not want to move but she did not choose to go to South Village in the first place.

Sally gets the Saturday public bus to Small Town and goes shopping by herself. Although she goes shopping on her own, her other social activities are with people with learning difficulties. Everywhere else she goes she goes by minibus (or taxi). In her own time she feeds animals and buys the food for them.

Sally gets support to get up in the morning and to get ready for work. She does not do the food shopping so does not have as much choice foodwise. Shopping is done to a healthy eating plan. Sally thinks she has enough money.

Linda and Peter's life and community

Linda and Peter are a married white couple. He is in his early 50s and she is in her 40s. They live in a flat with support (from a private provider) in North Town. They have lived there for about three years and got married when they moved in. Peter has no family. Linda's family did not approve of her getting married and she sees her Granny Wilson every now and then. She used to get on well with her mother and brother but is disappointed in them. She sometimes sees her mum.

Linda and Peter walk or use public transport. They go out a lot and travel about. Linda has a marked limp following a stroke but gets around well.

Peter works in the mornings. Linda once did and would like to again. They are happy. They buy their food, with support, and have choice in what they cook. They do not think they have enough money.

Loretta's life and community

Loretta is a white woman who lives at Smith Homes West Village Group Home. She sometimes sees her parents and aunty. Loretta needs a lot of support to keep her independent. She takes medication but can be alone for up to two hours.

Loretta has lots of friends. Most of her friends are from Smith Homes. She listens to CDs in her free time and watches TV. She also goes to the pub sometimes for a drink. Loretta helps around the house with the people she lives with.

Loretta does her own food shopping with staff, not on her own. She gets to choose her own food sometimes but she doesn't cook. Loretta thinks she had enough money to live on.

Kurshed's life and community

Kurshed is an Asian woman in her mid 20s who lives at home with her mum and dad in North Town. She has an older sister and brother. She also sees her cousins, sister-in-law, nieces and nephews. She visits India with her parents from time to time.

Kurshed does not go out unless it is to shop with her parents at weekends. All her friends are from her day centre. At the weekends she listens to music and watches TV. Kurshed was asked about going on holiday but says that she can't go.

Kurshed works at a charity shop on one day and would like to go full time. During the research she did not get the job, which really upset her. She doesn't get support with money because she doesn't have her own money. She says she is given enough money.

Louise's life and community

Louise is a white woman in her 50s who lives at the Smith Homes main site at South Village. She has lived there for 32 years. She did not choose to live there or choose the people she lives with. She has a sister, Charlotte, who visits her every two weeks and she goes to stay with her and her niece. Charlotte is going to move further away but has told Louise that this won't change things.

Louise reads, tidies, paints and does her washing in her free time. She likes to spend money on getting her hair done. She uses the Smith Homes bus or a taxi to travel but the ordinary bus wasn't good for her. Louise goes on holiday, sometimes with Smith Homes and sometimes with her sister and niece.

She goes shopping on a Saturday. She sometimes goes with staff to get food shopping. She has enough money to live on.

Mark's and David's life and community

Mark and David are African-Caribbean brothers in their 20s who live with their parents in North Town. They have a sister who does not live at home. Mark talks more than David and sometimes speaks for him. They go into respite when their parents want a break. David and Mark do not want to move but have not been given information.

They don't go out with their parents much. Mark listens to his music and David watches DVDs. They go out more when they are using respite care. They do art at college and Mark, in particular, is a pretty good artist.

Mark and David do not have their own money but have some money to spend. They do not get their own shopping.

Sue's life and community

Sue is a white woman who lives at Smith Homes main site at South Village. She had her 50th birthday during the research. She went to Smith Homes when she was 18. She says that she chose to live there and the people she lives with. Sue does not have any family.

Sue goes to events just for people with learning difficulties, like the discos at Smith Homes. She used to go to a nightclub in Big City (Endings). Sometimes she goes swimming at Small Town on a Monday. Sue travels by minibus or car because she sometimes has fits. Sue has a boyfriend Jim and can be alone with him.

Sue gets support when she does food shopping and she gets to choose food for special occasions, like birthdays. She wasn't sure if she had a bank account but said that she had enough money.

4 What this means

The importance of money to people making choices

Money is very important to people making choices. Only Linda and Peter pay their own bills and are in control of their own bank account, although they do get support in handling money. They also do their own shopping. They get support to do that but, after two years, they do shop on their own for food some of the time. They seem to have the most choice, independence and control. They enjoy travelling about on their own and Linda, in particular, is very sociable. They said that they didn't have enough money to live on – most other people said that they had enough.

We discussed the importance of having control over money. We all felt that it is very important for people if they are to have control over their lives, have choice and be independent. However, some of us thought that it was sometimes better for people with learning difficulties to have money controlled so that they don't get into debt and end up in court. Some of us thought that people should have the choice to overspend unless they are worried about getting into debt.

The people who seem to have the least independence are Carl, Kurshed, and David and Mark who live with their parents. Kurshed did not want her parents to be involved in the research and kept the interviews to her friends at the day centre. Carl asked his mum if she would be interviewed but she did not want to be involved. She did send a letter to say that Carl, who is in his late 30s, could take part. Most of Carl's and Kurshed's friends go to the same day centre as them. They do less social things in their spare time than the others. A lot of their social activity is with their parents. Carl, Kurshed, David and Mark have their own bank accounts but their parents keep their bank books. When they talk about having their own money they mean spending money, really pocket money that they are given by their parents.

At Smith Homes it is the money person who looks after the bank accounts for everybody who lives at the main site at South Village. Everybody knows how to get money. They fill in a form once a week to say how much money they want for the week. The money person gets this money out of the bank and gives it to people on a Friday afternoon. The money person will tell people if they can't afford to spend that much or if they need to spend money to keep under the savings threshold to keep their benefits. The manager is the authorised signatory for the benefits. They have looked at a mobile bank visiting the site, but no one would do it.

People at West Village and East Wing have their own bank accounts. No one has a card because this could be open to abuse by staff. Everyone had to set up a direct debit to Smith Homes for their services and utilities. Everyone puts some money in the tin for food shopping and the food shopping is done all together. It is Smith Homes who pay Sally's local People First group costs, not Sally.

Parents also seem to control more parts of people's lives when they live at home. Carl wants to live on his own but his mum is against it. She is worried that he is not able to live on his own. Some time ago he was run over by a car and broke his arm. His mum feels that he is not safe to be on his own. He is protected from going out because of this. However, when he is at his local People First, he goes out in North Town to the shops with friends. He also goes on his own to collect one of our researchers, Angela, from the bus stop when she visits North Town. To get from the local People First office to the bus stop and back he has to cross main roads.

We know less about Kurshed and David and Mark. They said less about their parents because they aren't discussing an important change, like living alone, and Kurshed, in particular, did not want to talk about her home life. Being private may be part of being in a Hindu family but she said nothing to suggest that the control that her family takes over parts of her life was different from Carl's. Carl, Kurshed, and David and Mark don't have as much choice as they could but they all love their parents.

Things people do

We learned a lot about the things that people do and their choices, independence and control, especially the things that they do in the evenings and at the weekends. We asked people what they do and we made a diary for a normal week. But we also went along with them, when we could, to see for ourselves some of the things that people do.

What people do in the daytime

During the daytime people were busy. Most people do things in the day as part of organised day services. Most of the things that people at Smith Homes do were at the main site at South Village. There was quite a lot of choice.

- Andrew works in the gardens, uses computers and does craft and woodwork in the Smith Homes workshops.

- On most days Loretta cooks in the kitchen at the café, Top Kitchens, at the West Village nursery. She also goes to cooking classes at a local college.
- Sally mixes up her week, doing craft on two days, working in the office for two days and going to a local People First group on another day.
- Louise goes to a workshop for semi-retired people on one-and-a-half days (they were doing card packing for six months so that it would run), she goes to the Woodland workshop for retired people for a day-and-a-half, and goes to college on two half days to do a maths course ('Number Count') and an English course ('Make Words').
- Sue works in the craft workshop because she enjoys working there. She said, 'I work in craft making rugs and things'. Sometimes she does her project on her father who is dead.

People in the North Town area had the same sort of choices during the day but they were organised through one of the day centres instead of Smith Homes.

- Kurshed went to a day centre on three days, she did an outdoor pursuit course on another and also did a work placement.
- Carl worked in the gardens at a day centre on two days, went to his local People First group on two days and was at home on one day.
- David and Mark did the same things. They went to college to do an art course on two days and went to a day centre on the other days.
- Peter worked for a couple of hours every morning, then did housework and watched TV most afternoons.
- Linda went to a day/resource centre on three days, to her local People First group on another day and sometimes went shopping on her free day. At the day centre she does rock climbing but is not there all of the three days.

The big difference between people who live at one of the Smith Homes places and people who live in North Town is that some of the people who live in North Town have days or time in the day to themselves. Also people who did activities or worked at the main Smith Homes site could not leave their work to pop out to the shops or just have a break. The same is true of the main day centre in North Town because it is on an industrial estate. Sally, like Linda and Carl who also go to a local People First group, can go out and about in the day if she wants.

It is different for Linda, Peter and Carl. They have times in the day when nothing special is organised. Peter does housework and he watches the television. Linda does shopping. Linda also uses a day/resource centre that is in the middle of the town and she does not have to be there. Carl usually stays in on the day when he does not go to a day centre.

What people do in the evening and at weekends

We found that people did different things in the evenings and at the weekends, and that a lot of the people that we worked with went out and did things regularly. It was the people who lived with their parents that didn't.

Kurshed and Carl both said that they spend their spare time at home. So did David and Mark. Even though David and Mark are brothers, we wanted to find out about them as separate people, but their diaries were exactly the same. David and Mark's diaries showed them both watching TV most nights, but we found out that David likes to play games. The diaries might be the same because David is quiet and Mark sometimes speaks for him.

Peter and Linda seem to have the most choice of what they do in the evenings and at weekends because they live independently.

At Smith Homes Andrew has most choice. He lives at East Wing in Small Town and goes out when he likes and there are things to do. He has the most independence.

We have already talked about some of the things that give people choices. Having control over money is important. Being independent (living independently) is important and living with parents seems to give people least independence. The place that people live in is also important. We discussed this and think that Linda, and Peter and Andrew have more choice because they live in the middle of large towns. They can do things on their own easily.

David and Mark, and Kurshed live in the same large town. Carl lives in a small town. They do not have the same choice. This seems to be because their parents have a lot of control.

People at Smith Homes who do not live at East Wing also have limited choice because they have to travel to the town. When they do, some people make more choices than others. On Saturdays in Small Town they can go around the shops or wherever they want to go on their own or with a group. Loretta and Sue stay with a group but Sally and Louise don't. Andrew, from East Wing, does not join the group.

We discussed what we found out about what people do.

Carl said that he is labelled. We agree and think his mum and dad label him a lot. We think Carl is even more controlled because of the label – other people do not let him make his own decisions (there is no respect). We have already mentioned that his mum would not take part in the research and that she gave Carl her permission to do the research.

When Sally goes out it is in a minibus with a group of people. She goes shopping on her own but other social activities are with people with learning difficulties. We think that Sally has limited choice in going out on her own, which is a bad thing, although she goes a lot but she cannot decide to just go out. Sally can see her friends on site when she wants. We think if Sally has no money staff will not take her out.

We think Loretta goes out more than Kurshed because she has more choices to get out. She can tell the staff where she wants to go. Kurshed isn't allowed to go out alone and Loretta can never go out alone. Someone is always with her because she has fits. Loretta seems happy as she has less to complain about life in general.

We think Linda and Peter have most choice because they are independent and they live in a town so they can go out when they want. If Linda and Peter have no money they can still go out.

Even people who have a lot of choice because of where they live and the kind of place they live in could have more choice. Andrew gets support to get to his day services, but there is no public transport. We think that this support is forced on him. Andrew would be more independent if he worked in Small Town or somewhere he could get a bus to. Also he goes to football in the nearest city with people from Smith Homes when it is his turn and he would like to go more. A member of staff goes with them in his own time.

What people thought about their choices

People that we worked with talked about things like being happy and whether they are labelled. We also saw how they got on in different places when we went round with them. In that way we learned about how their choices made them feel.

Andrew uses services just for people with learning difficulties but does not think he is labelled. We think he is labelled because of the way some people treat him in the pub

(sometimes people can say things that are rude because they do not know him), but we think Andrew does not see this. He is known locally as Cliff because he is a fan of Cliff Richard and looks like him. People who know him use the nickname as friends but some people are rude. Andrew sees it as people not having respect for him.

Andrew sees his brother, Philip, every six weeks. They go out for lunch. They seem to get on well. This is the only family Andrew has. Philip labelled him 'mental handicapped' (this made our researcher angry but he did not challenge it because he was researching and the place to challenge it is in this report). Using the old term shows that Philip does not understand what labels can do to people. He does not understand that they show that some people don't believe that others can make choices and be independent.

We have already talked about how Carl would like to move out and that his mum is worried about this. We think that moving out might help change a lot of things for Carl by giving him independence. David and Mark also live with their parents and do not want to move but have not been given the opportunity. We don't think that they get enough information about their options.

Deciding to be independent is not easy. Peter does not have any family. Although Peter and Linda are the most independent people we worked with, Linda's family, her mum and her brother, were not happy when she decided to marry Peter. They decided to marry at about the time that Linda decided to move to independent living. Linda does not see her mum much and one of the people she chose to be interviewed, a worker from Solar (a private care provider), said that she thinks that Linda feels let down. Linda appears to be happy with her choice and so does Peter. After the interviews, before we finished the research, they had their third wedding anniversary.

Sally, on the other hand, does not want to move even though she did not choose to go to South Village in the first place. She does not want to move to East Wing even though this has been discussed with her. We think she is happy where she is as she has got people she knows there, relationships. Sally likes to be in charge of some things but does not want to be responsible for the big things. We think that Sally has more confidence when she is at South Village, or in a group of people she knows, than at other places.

Louise reads, tidies, paints and does her washing in her free time. She goes shopping on a Saturday. She used to go to church, but she has stopped going because she did not get on with someone else who lives at Smith Homes who goes to church. We think that Louise is happy doing her own thing. Where she lives is

restricted because there is nothing around and no buses. But she seems to do what she wants to and could go out more if she wanted to by asking staff if she could join arranged trips.

When we went round with people, we saw some things that we did not like happen at services. The people using the services sometimes did not mind.

When we went to the workshop to meet Sally she was a bit late getting up. A worker who came in just after her sent her back home to wash and change her clothes. We did not like this. Sally likes being at Smith Homes and it gives her confidence but she did not like being sent to do things like a child. We think that there was no respect and it would not happen if she lived away from the services she uses.

Other people were not worried by things that we saw. Louise works in the workshops at South Village and goes to college – just for people with learning difficulties. We think that if we went there we would jump out of the window because the teacher was patronising. We met a lot of staff at South Village and they did not seem to be patronising. But Louise did not seem bothered. This could be that Louise has always been patronised and thinks it is normal. We don't think that Louise sees herself as a person with learning difficulties. On the other hand we don't think she should be in residential care but, when she was given the option of moving to East Wing, she did not want to move. We found it scary that she is set in her ways, but she has been there for a long time and is happy.

Mark and David go to a day centre and we found it patronising because of the things they do and the way the staff talk. They were putting plastic rings into containers for £1 a day. It was just the same as work for people that we have seen on an old video. We thought day centres had stopped doing that sort of thing. We wonder how people are supposed to learn things to get a job. We think if they aren't going to get a job there are better things they could do. We were surprised that people seem happy at the day centre but we wonder if they have been offered anything else.

Getting real choices and having to decide what to do is difficult. We think that it is fine to decide not to do something but we have found that, in a lot of cases, people don't have the information to decide. A lot of the time they don't know that there might be a choice.

Meeting people

When we went round with people, we also saw how they got on with other people, where they were welcomed and where people were unfriendly or just ignored them.

When we were starting the research we talked about friendship. We talked about family, friends, acquaintances and strangers with our research support. We don't use all of these words and we talk about good friends, friends and people who are friendly or nice. We understand family and strangers.

We found that family and friends can overlap. Andrew is a good example. He sees his brother, Philip, regularly. They are good friends and, as well as going out for lunch, when they meet they often have a drink together. When we interviewed Philip, he and Andrew were off for a drink after the interview and Philip told a funny story about how Andrew once managed to avoid buying a round, although he usually pays his way.

We have said a lot about the families of people who live with them and families are important to many people in our research. You can see this from the network diagrams or circle of friends that they drew up. Figures 2 to 4 show three good examples.

Figure 2 Sally circle

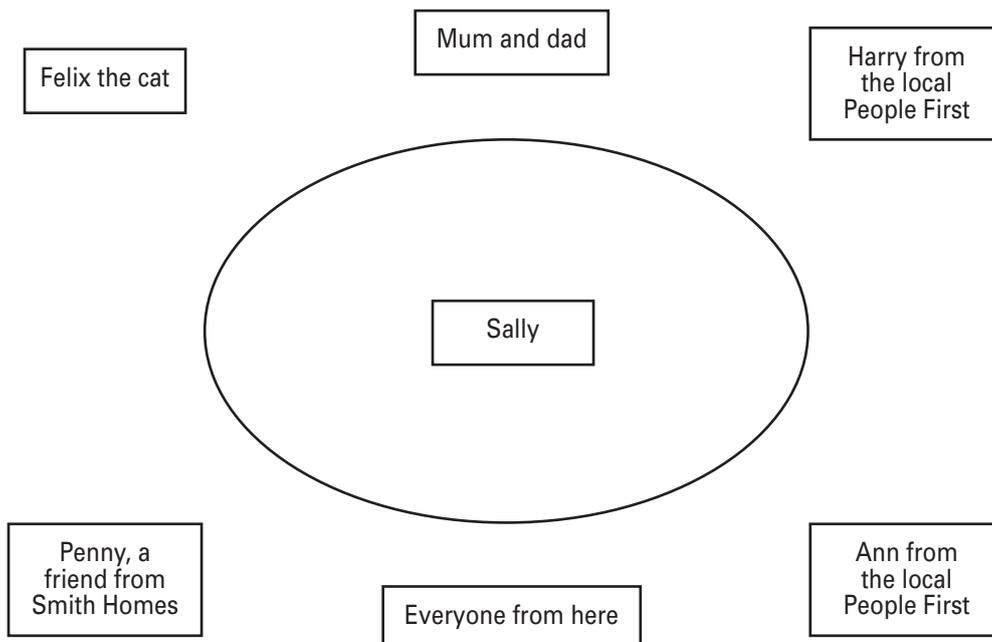


Figure 3 Kurshed circle

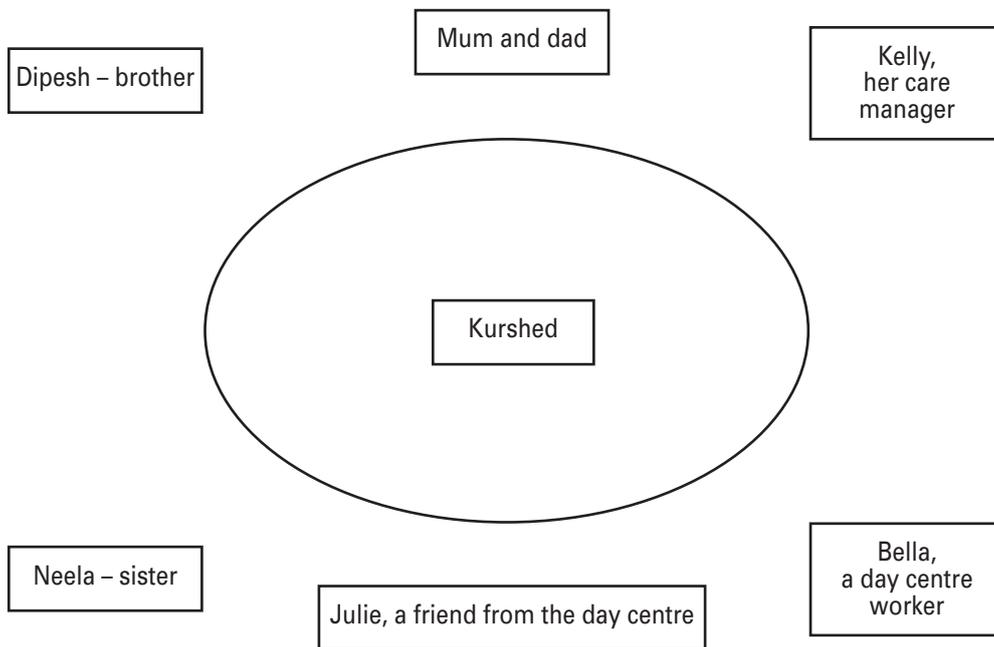
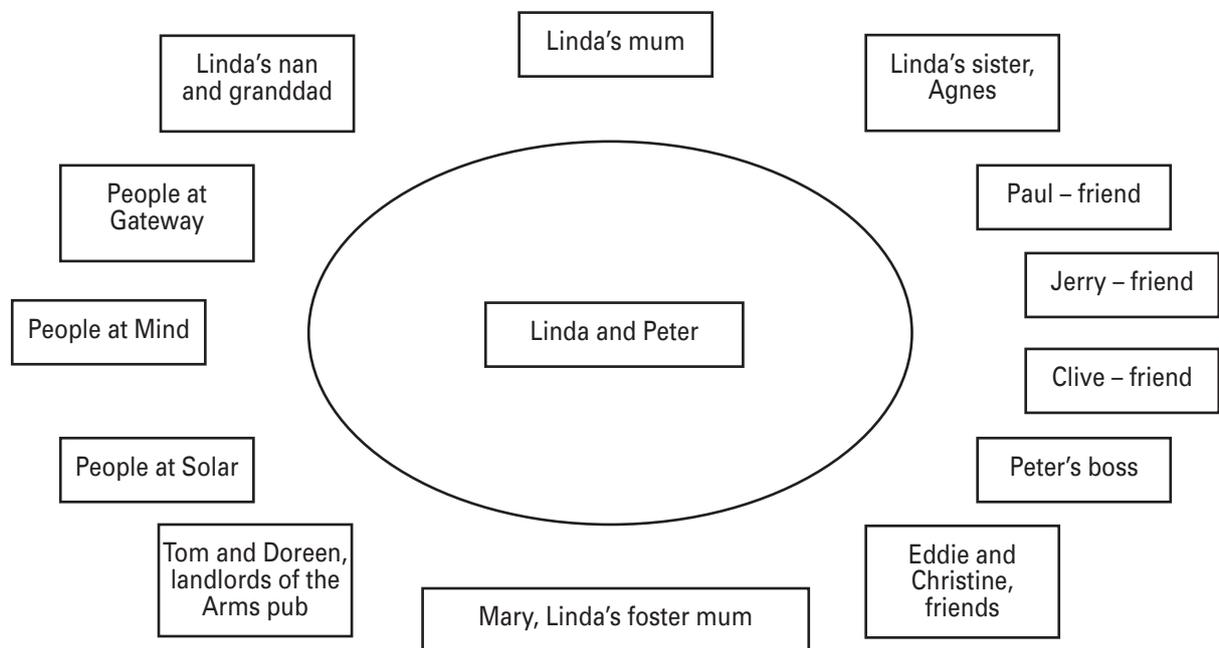


Figure 4 Linda and Peter circle



It is very interesting that, like Sally and Kurshed, there were not many people who named friends who they knew outside their services. Most people listed friends who they lived with or who used or had used the same services. Most people also listed very few friends. Sally was not the only person from Smith Homes to say that everyone there was her friend. This is a way of describing her community. Also, for those people that we went round with outside services, we noticed how few people they knew. Most of the people that they knew also knew each other because they used services or worked in them.

Some people were different and these were the people who lived in town and had the most independence. Linda and Peter were the only people who had friends who had nothing at all to do with the service system – Paul, Jerry, Clive, and Eddie and Christine. They also had more people in their circle than the others and they did not all know each other. They invited another couple, Eddie and Christine, to be interviewed. They knew them around town for years and through church. Eddie and Christine did not know much about their services or support, which is what we would have expected because that is not how they came to know them.

Sue chose her hairdresser, Denise, but she had moved away and she had met her through Smith Homes. Sue also chose Clare, a cleaner from Smith Homes. These were the only workers chosen to be interviewed who were not paid care staff.

We were especially interested to see what friends people met when we went around with them away from services.

Here are accounts of what happened when we were out and about with people. There are no accounts for Carl, Kurshed or for Mark and David. Most of their time was spent with their families and we couldn't arrange to be with them. Families like to be private and, unlike people at Smith Homes, we couldn't arrange to go along on regular shopping trips or to the pub. We think this shows how choices are made for them.

We went shopping with *Sue* on a Saturday. Sue stayed in a group of people. She walked towards the back and waved and said hello to a lot of people. Most smiled and responded when they saw her. They walked into the market and Sue didn't go to the café with the others but walked round talking to stallholders and some of the shoppers. They all knew Sue and stopped to talk to her, one or two for about five minutes. At church on Sunday Sue chatted to different people in the congregation, not from Smith Homes. She went to the Sunday School for a cup of tea after the service. Only Smith Homes people went. Her friend Joan wasn't at church.

We went shopping with *Loretta* on a Saturday morning. She went around in a group of five people from Smith Homes including a member of staff. The group stuck very closely together in and out of the shops. They talked a lot to each other and Loretta said hello to quite a few other people on her way round. On Sunday she went to church in West Village with Marie and a man. She sat next to a lady and talked to another lady who came to sit next to her. She seemed interested that Loretta was going horse riding.

Louise's shopping trip started when she arrived at the bus stop on the weekly bus and went into the market. She was greeted by several people and stallholders. She bought a poncho for a fête that was coming up soon and was chatty to the stallholder. She went off to the café in the market. Her toasted teacake was taking some time so Louise went to buck them up and it arrived a few seconds later. She was treated with respect and people said hello to her as she walked through the town.

When we went shopping with *Sally* on a Saturday morning she went into the pub (the Greyhound) when she had done some bits of shopping. She sat on her own for a long time before making her way to the bus stop. She had to wait for the bus and from time to time said hello to people from Smith Homes.

One Sunday afternoon we went out with *Linda*. Peter stayed at home while Linda went off to walk to the Mind café to bring them some lunch. On the way she spoke to an Asian man and his mother before popping into a shop to buy cigarettes. As she went on her way to Mind she bumped into two African-Caribbean women that she knew and said hello and had a quick chat. At Mind Linda paid for dinners to take away for herself and Peter. She gave her small change to Mind funds. A friend, Ricky, said that he would carry her dinners home for her, as he wanted to see Peter anyway. She said hello and had a short conversation to a young man, Rob, who passed on the other side of the street on her way home. She waved to the landlord of the pub through the window.

Andrew was out and about a lot. One Friday evening we met Andrew at home and went along with him to the pub, the Oak Tree, which isn't the pub that most Smith Homes people use on a Saturday. On the way Andrew spoke to a lady getting out of her car. He didn't know her but admired her car. At the pub Andrew talked to the bar staff and asked after a particular woman member of staff. She had just popped out for a minute and he ordered a pint of beer. The man behind the bar said, 'there you are Cliff, £2.55'. Andrew did not mind. As he wandered around the pub some people spoke to him and we felt that some of those that didn't know him were not treating him with respect. It is a large pub. As one of the women staff left she said, 'see you later, Cliff'. Andrew asked if she was coming back and she said she was. He stayed about 30 minutes.

We also went shopping with *Andrew* on a Saturday. Our researcher arrived early before the support person and went off with Andrew who went into a café where his is well known and people were friendly. Around the shopping centre he went into Boots and got help to find what he wanted. When he found what he wanted and bought it he chatted to the assistant who was friendly. He then bought some sweets. He returned to Boots and had a chat with a different assistant who is a friend and showed her what he had bought. When she had to get on with her work he had another look around and later said hello to a group of people that he knows in the High Street. Finally, he went to the pub (the Greyhound, the one used by people from Smith Homes on Saturdays) and bumped into his support person and had a chat with him.

For most people we saw examples of people who are friendly. Although we didn't go out with Carl, Kurshed, Mark and David we can't think why it should be different for them. We also saw some examples of people who might be called friends (some people that knew Andrew in the pub, the second assistant in Boots or the people that talked to Loretta for a long time). If they weren't friends they were friendly people that they knew well enough to talk to for a while. There was a lot of evidence of respect. In the interviews we found the same. We were most interested in what people said about themselves but most other people who were interviewed thought that the person they were talking about got respect. However, some workers only talked about respect in their services and not about in the community in general.

No one at Smith Homes thought they were labelled but most people in North Town thought that they were – everyone except Kurshed. We don't know why this was. It might be that the people at Smith Homes were not used to the idea of being labelled.

Some people said that sometimes they did not get respect or people that said that they get respect talked about times when they don't. Andrew said, 'Sometimes when I am out people are rude to me' and, later in the interview, 'I get treated with respect'. According to Linda, 'some yobbos call me names and copy [my] limping' and she also said, 'I get treated with respect'. At one point Carl said, 'I get labelled and don't [always] get treated with respect but I am treated the same as other people' but later said, 'I get treated with respect'.

Some family and people who work in services said the same things. Stan, Linda's support worker, said about her and Peter, 'they are mostly treated with respect. They don't get labelled but it is a cruel world out there'. Louise's sister, Charlotte, thought that Louise does get labelled: 'she must do, it must be a huge problem for every person with a learning difficulty'. Charlotte also talked about Louise getting left out of the conversation when she stays with her. She lives in a small village and we thought that she may be more excluded there than at Smith Homes. Andrew's brother, Philip, thought that 'he has loads [of friends] in the town' and later he said, 'I don't think that he is always treated with respect'. Our researcher thought the same.

Some of the same things happen to us, we get respect but not all the time.

5 Recommendations/conclusions

Before we write these we think it is important to say what we think independence and inclusion mean.

Independence is about being able to make your own choices, deciding to take your own risks and having the support to take those choices (all things in the circle). It is not about being able to do everything yourself.

Inclusion is about having the choice to join in activities that people without learning difficulties do. Again, to be included, all the things in the circle need to be in place.

We have made our conclusions and recommendations as ten points.

- 1 We have found that we are still not taken seriously as researchers by a lot of people. Hopefully, this report will make people see that we can do research and help them understand how we can be independent and included.
 - We need to get this report out to as many people as possible.
- 2 Doing the research showed that, as people with learning difficulties, we need to be given a lot more time to do things. Because we gave ourselves more time our research was a lot better. This happened because we had time to learn in our own way.
 - People must understand that we can work well if we are given the time and are allowed to learn from our mistakes with good support.
- 3 We found that the more choices people have, the more included they are in their local community. The people that were involved that had most choice knew more people and were known by more people in different places. Parents were the most important people in the lives of most people who took part and they loved each other. But parents were not always best at giving people choices.
 - Parents and carers need independent support and training from independent people with learning difficulties in how to allow people more choice and how to take risks.
- 4 We think that the Smith Homes community and other communities of this type are communities by themselves. People have a lot of support. People could move if they wanted to but we found that most people did not want to. This is because they feel safe and at home. They can visit friends who live in that community, when they want. People can take ownership of things that they do. Sally is a

good example. She likes working in the office, has control of the post. She goes shopping on her own but likes doing other things with friends. She goes to a local People First group. We did find that Sally was ordered about once at Smith Homes when we were with her. We think that Sally is happy.

- We think people should still have the choice to live in communities like Smith Homes. But staff in these places need better training to respect people by treating them like equal adults and not children. It is also important that people can do some things on their own and some things with people who do not live with them.

- 5 On the whole we found that it is easier for independent people who live and know other people in the local community to choose which social events they go to and when. It is easier for them than for most groups of people with learning difficulties from residential places and for most people who live with their parents. Staffing, support and transport are very important issues.

It is hard to make a recommendation especially about transport because it is not a new issue. Although it is well known, not much has been done about it. More money for staff and for transport of all kinds is very important. As well as understanding about choice and how important it is to take risks, it is also important for staff, parents and carers to listen to what people want if they are to have more choice and control.

- 6 We found that people from the Smith Homes community did go out a lot more than people who lived at home with their parents. But they did not have as much choice as they might have. They can only choose when staff and transport are available.

We have not been able to make a recommendation.

We wonder if, by choosing to live in a safer community, people choose to have less choice?

- 7 We had three people from a black or minority ethnic background. This is not enough to have any real conclusions. Though we think their lack of inclusion and choice is possibly due to their culture we could not talk to any relatives about this. However, it is due to parents having control. But this was also the case with Carl who is not from a black or minority ethnic background and who also lived with his parents.

- We think that it is important that people with learning difficulties from black or minority ethnic backgrounds do research like we have. We would like to

include people from black or minority ethnic backgrounds in our research team.

- 8 A lot of people do not see themselves as labelled. But all people seem to be treated in similar ways whether they think they are labelled or not. There is a lot of discrimination against us and a lot of people think they know better than us. Even Linda and Peter, the very independent married couple, faced this problem.
 - People with learning difficulties should be given more information on their rights. Staff, parents and carers need to be challenged, especially by people with learning difficulties, to give people their rights.
- 9 We found that most people did not have full control of their money. Most adults without learning difficulties have full control of their money. But most people seemed happy to have their money controlled. We disagreed in our team about how much control people should have. It could scare people to have more responsibility. It could seem easier to control people's money for them rather than give people support to control their own money. Real choice is not possible without control of money.
 - People with learning difficulties should be respected and treated as adults, and allowed to control their own money. People shouldn't be stopped from having responsibility but the right support is needed. More control means more choice.
- 10 People did not have much control over what they did during the day apart from Linda and Peter, the married couple, who lived on their own and in town. The more access to the community there is, the less control by parents, carers or support there will be. Also the more choice people will have.

We do not have a recommendation for this point. However, overall, it seems the circle diagram that we have used is a useful tool. It helped us understand how people can get independence, choice and control. We need to work towards making the things that it describes happen for everybody.

Appendix 1: Being a research support person in a user-controlled project (by Ian Buchanan)

Introduction

This Appendix looks at some of the issues involved in being a research support person in user-controlled research. In line with the way of working in the project it has been shared with the researchers at CEPF's Fresh Start. It is not, however, written with them and, while their comments are important to me, the only things that have been changed are matters of fact and jargon. It looks closely at the practical ways in which Fresh Start worked from the viewpoint of a 'critical friend'.

I start by saying where I think the project fits into what is often called inclusive research. I then talk about how far it is possible for a group of researchers with learning difficulties and a range of support needs to develop their ideas, big ideas (concepts) and ways of working (skills and techniques) in their own research project. I do this by looking at the influence and effectiveness of a research support person working in the way that Fresh Start wanted.

What is special about *Our Lives, Our Communities*

There are lots of ways of doing inclusive research. It is most important that it is not something that is done to people and that they take part in it. It can be done by academic or professional researchers in some sort of partnership. Fresh Start have worked this way and been part of important research. However, what makes this research special is that:

- they were given the money to do the research
- the ideas are theirs (they had been developing them since 1992)
- they decided how it would be done
- they did it

- they decided what it means
- they describe what it means.

To make sure that this happened the Fresh Start researchers controlled all parts of the work. From the start they decided how work would be shared out (the division of labour). It was very important that the research support person did not take over. This is described in the main part of the report. Writing about it I hope that people will understand better how Fresh Start's research support works and appreciate just what the researchers have done. There are many things in the main report that I would have said differently, some things that I would have added but also many things that I would not have said that people should hear.

Within the strict rules about who should do what work in the project, the research support person was responsible for:

- support for the development of the project (discussing and sometimes explaining ideas, big ideas or concepts, and ways of working or skills and techniques)
- advice on how to do the research and how to analyse or see what the information that is collected means
- support in making sense of the findings
- support in the preparation of reports and other outputs.

All interviews and other research were carried out by the researchers supported by staff that they employ at CEPF. They were not recruited just for research, although they have supported people in a number of research projects. Their role is the support of people in speaking up (as self-advocates). Research is a special activity but is part of speaking up for self-advocacy organisations like CEPF.

Working in this way also means that, within a user-controlled research project, the research support person is a different kind of support person. The research support person is not part of the research team. The research support person doesn't take any of the important decisions and has as little influence in the research as possible. It has been put to me that this deskills a researcher. However, it is more like good research supervision that does not decide what the project is, its ideas or ways of working.

Working on *Our Lives, Our Communities*

All 'inclusive' approaches to research require that there is trust between the academic researcher and the researchers. It was important that there was trust at the start of the project. There was a long-standing working relationship with the research support person and the aims of the project were understood and shared.

Trust was important in meeting a number of big challenges for the researchers. These included the following.

- Professionalism: does working in a support role as outlined here mean that rigorous standards of research are ignored? If it does not, does meeting them mean that the research support person takes control?
- Treating people properly (ethics): how are people treated properly (i.e. how are ethical standards met) in a project of this kind? Ethical standards mean being responsible for the best interests of the people being researched (including how they are treated and whether their stories say the things that people want to say).
- Leadership: how in practice is such a project led if it isn't led by a professional researcher? CEPF aim to work as a co-operative in their decision making and collectively in their work. I have respected this approach by not saying what each researcher did. However, it is important to be clear that the work was spread across the team.

These challenges raise doubts about whether people with learning difficulties have the capacity to do research. Doubting or being sceptical is a valid fear within any profession that has high standards.

Although Fresh Start have a great deal of experience in research, the team was not made up of experienced 'star' researchers. The team lost Nigel Lott, a long-standing self-advocate and trainer, when he moved to another part of the country. The four researchers that undertook the project had varying skills and experience. One had worked in research, consultation and training for over ten years. The other three had been involved in some research, consultation and training, mainly over the previous three or four years. One of the four reads well, one with some difficulty and two only read a few words.

Fresh Start wanted to prove themselves in their own project in which they carry out the complete research process. It is important to know whether *Our Lives, Our Communities* represents a good enough piece of research. Was it done professionally? Does it tell us things that are important?

Professionalism

The research was planned and carried out in the way that most research is. The team worked out questions that they wanted to ask and things that they were looking for. It also did pilots to test the questionnaire and other ways of finding out. The main report tells us how this was done. The part played with the research support person is set out here.

Supporting the development of ideas and understanding how to do research was not done through conventional teaching methods. The researchers did not do a course. They built their knowledge through learning by doing – by getting help and solving problems as they carried out their plans.

The circle diagram was developed in 1992. CEPF have used the ideas in the diagram in most of their work. Their relationship with me as a research support person has lasted around ten years. This project developed from a failed research bid.¹ In developing that large bid:

- I advised the researchers in using knowledge that they had gained in filming people at CEPF's different branches talking about their lives.
- Around six years ago I began talking to the researchers about ways that they could find out about people's lives. This including the network diagrams (circle of friends) and hanging about with people (non-participant observation).

Many of the big ideas in *Our Lives, Our Communities* came from the filmed interviews and discussion of them. Before writing the proposal two researchers watched them again. The network diagrams seemed suitable because they have 'the person' in the centre. In the pilot, making a diagram was very enjoyable and worked well. Observation was harder and, when they could not film what they saw, the researchers worked at a different way of doing it themselves. In this way they changed ways of doing things or using techniques so that they could do the research properly. The researchers did not learn much research jargon because they did not need to. They 'went around with people' or 'hung around with people'. They did not see themselves as 'observers'. At first the researchers struggled with a diary that was used to record what had happened and not appointments. This was not part of their practical experience before the project.

Ethics or treating people properly

The team found the Social Research Association (SRA) ethical framework, which was provided by JRF, impossible to understand. However, treating people properly and with respect is a very important part of the way CEPF and other self-advocacy organisations work. All of the researchers understand what ethics means through personal experience of being treated disrespectfully.

The guidelines for researchers in the main report were produced by one of the researchers drawing on experience within CEPF and Fresh Start that demands respect for people, and within services where there had often been too little respect. The guidelines came as a complete surprise to me after a long meeting struggling with the SRA framework. Using the guidelines in the pilots got the researchers used to working 'ethically' in research.

Leadership

Project management was the key to leadership. The collective approach did not work well during the delay following on from the support worker's injury and absence from work. At that time the project competed for time with several other projects. There was concern that it would drift and not be finished. An important change to the way of working came after the researchers decided to collect the information themselves when training and supervising other people did not work well in First Town. It was important that one researcher took responsibility for making sure that things happened. That person made appointments, looked after the data and 'progress chased'. This work sometimes made the researcher unpopular but it was important and appreciated by the team and the research support person.

There were some ways of doing research that did not work for the team. Using N6 to make sense of the interview information was not successful. As the main report makes clear, the researchers were able to code interviews against the ideas in the circle diagram. This helped them understand their ideas better but the output from N6 did not suit their way of working. It was not accessible. The researchers found the best way to make sense of the information was using two individuals' interviews and comparing them. They did not like the bits of lots of interviews that N6 produced.

The researchers decided to ask me to write up the research in the way that is described in the main report. This showed a lot of trust. As far as possible I used their own words as noted at their meetings, which I did not attend. The main report describes how extra guidance was needed when I got stuck writing. There was

also one part in the conclusion (point 5) where I found it difficult to interpret the researchers' meaning. To make it clear I added some comment about the benefits system. This was not their intention and the researchers removed it.

Conclusion

The aim in writing about the research support role is not to justify or judge the researchers' work, it is to look at their thorough approach and the importance of many years of learning by doing. The project has tried to get their own view of how people live in their communities through research carried out by people with learning difficulties, with as little outside input as possible. By pushing the boundary of user research as far or further than any others, they have tried to get people's real or authentic 'voices' and experiences using ideas that they have developed over many years.

Note

- 1 The much larger user-led project proposal in 2001 to the Department of Health's 'Learning Disability Research Initiative', which was entitled 'Taking the Lead'. Other partners were Jan Walmsley and Roger Smith.

Appendix 2: Questions that we asked

The questionnaire

Name of person who the research is about

Name of researcher

Name of support worker

Date

Name of person being interviewed

Relationship to person taking part in research

Ethnic background

How well do you get on with the person taking part in the research?





Question	Answer	Controls
<i>Home</i>		
What kind of place do they live in?		
Did they choose to live there?		
Did they choose who they live with?		
How long have they lived here?		
What areas do they have support in?		
Where do they get this support from?		
What times and days do they get support?		
How do they get on with their neighbours?		
Do they do their own food shopping?		
Do they choose their own food?		
<i>Our free time</i>		
Where do they get information about what they can do in their own time?		
What sorts of things do they do on their own?		
What sorts of things do they do with other people?		
Do they choose themselves, or get support to choose or does someone else choose for them?		

Question	Answer	Controls
Are staff and support people trained to help them make choices?		
If they want to change something they were going to do, can they?		
Do they go to any events just for people with learning difficulties?		
Does it cost a lot of money to do these things?		
Can they choose who they have a relationship with?		
Can they be alone with their friends?		
If they have moved, have they been able to keep up friendships?		
Can they follow any religious or political beliefs they have?		
When they go out how do they travel?		
Is it easy for them to travel?		
Can they afford to travel as much as they want?		
Is there anything that makes it difficult for them to travel?		
Do they get treated equally when they are out?		
Do they get treated with respect?		

Question	Answer	Controls
<i>Work, college, training, day activities</i>		
Where do they get information about what they can do in the day?		
Is this information easy to understand?		
Is this information useful?		
What do they do during the day?		
If they work are they paid?		
Does anything stop them from working?		
Are there things that they would like to do but cannot?		
Have they asked to do things and been told they cannot?		
Do they choose the services they get?		
Do they use any services because there is nothing else?		
Which services do they enjoy using?		
When they change services can they keep in touch with friends?		
Are they asked what they think about services they use?		
If they are does it make a difference?		

Question	Answer	Controls
Do they use any services just for people with learning difficulties?		
Do they get labelled – people see their learning difficulty but not the person?		
Do they know when staff are leaving?		
Do they know who the new member of staff will be?		
Are staff friendly?		
Do staff talk to them if they see them out of hours?		
If they want to complain about a service, can they?		
<i>Money</i>		
Do they have their own money?		
Do they have their own bank account?		
Do they choose what to spend their own money on?		
Do they pay their own bills?		
Do they get support to manage their money?		
Have they heard of direct payments?		
Do they understand about direct payments?		
Do they get direct payments?		
Do they understand about benefits?		

Question	Answer	Controls
If they get paid to work, do they keep this money?		
Do they have enough money to live on?		
<i>Health</i>		
Do they get enough information about their health?		
Can they understand this information?		
Who do they talk to about their health?		
Does their doctor listen to them?		
Do they have problems making appointments when they can get there?		
Do they have any problems travelling to these appointments?		
<i>Families</i>		
Who do they see in their family?		
Does their family let them make their own choices?		
Does their family treat them as an adult?		
Does their family support them to do what they want?		
Do they have someone to help them to speak up when they are talking to their family?		

The diary form

Diary – person taking part: _____

	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday	Sunday
Morning							
Afternoon							
Evening							

The friends and family form

Who you know – person taking part: _____

Who you know:	Name 1	Name 2	Name 3	Name 4	Name 5	Name 6	Name 7	Name 8
Name 1	XXX							
Name 2		XXX						
Name 3			XXX					
Name 4				XXX				
Name 5					XXX			
Name 6						XXX		
Name 7							XXX	
Name 8								XXX

Put a 'Y' where people know each other and a 'N' where they don't.

Appendix 3: Forms and information

Consent letter

Dear

[Name of person taking part] is taking part in research about her/his everyday life in a project called 'Our lives, our communities'. This means that she/he is spending two days with [number of] researchers, ([name of researcher] and [name of researcher]), doing ordinary things that she/he normally does. We hope that, as someone that she/he is in contact with regularly you do not mind her/him bringing the researchers along with her/him. They will not interfere with the things that you normally do.

The research is totally confidential. Things that are written down will only be read by members of the research team and individual people will not be identified in the research reports. We would also like to film and record some things during the day. Film and voice recording will also be kept confidential and used to help the researchers remember some things that happened. If you are not happy about being filmed or recorded you do not have to be. We have a form that we will ask you to sign *only* if you are happy to take part. You can choose to take part but not be filmed or recorded if you like.

If you agree to being filmed and recorded, the material will not be shown to anyone outside the research team without your giving special permission.

The research is being carried out by Central England People First with support from the Open University. It is paid for by the Joseph Rowntree Foundation. Central England People First is a user-controlled organisation of people with learning difficulties.

Central England People First
'Our lives, our communities' research team

Consent form

What I have said yes to

I understand that you are going to ask me about [name of person taking part's] life.
I understand that you will be watching [name of person taking part] go about her/his life when I will be about.



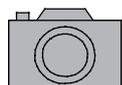
You can use a video camera



'YES'



'NO'



You can use a camera



'YES'



'NO'



You can use a tape recorder



'YES'



'NO'



You can make notes



'YES'



'NO'

Name _____

Signed _____

Date _____

