

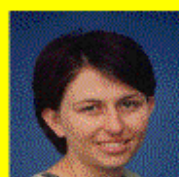
# Adults with Learning Difficulties in England 2003/4



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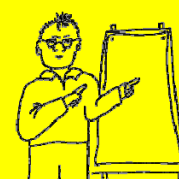
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We have decided to use 'learning difficulties' rather than 'learning disabilities' because these are the words that the people themselves said they prefer. It was used throughout the research. In this report we talk about 'people with learning difficulties', meaning people who since they were a child had a real difficulty in learning many things. We do not mean people who just have a specific difficulty in learning, for example, people who only have difficulty with reading which is sometimes called dyslexia.



# Summary

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In 2001 the Government published a White Paper called *Valuing People*.<sup>1</sup> In it the Government said that it would help people with learning disabilities 'to live full and independent lives as part of their local communities'.

In 2005 the Government published a paper called *Improving the Life Chances of Disabled People*.<sup>2</sup> In it the Government said that 'By 2025, disabled people in Britain .... will be respected and included as equal members of society.'

The Government also said in *Valuing People* that they would carry out a survey 'about the lives of people with learning disabilities and their families'. It would be the first time a national survey of adults with learning disabilities in England had been done.

This is the report of that survey.



It tells us how much more needs to be done if people with Learning Difficulties are to be more included and have a better life.



## The Survey



In Section 1 of the report (The Survey) we tell you how we did the survey.

- The survey was carried out by a research team made up of BMRB Social Research (a research company), Professor Eric Emerson (from the Institute for Health Research at Lancaster University) and Central England People First Research Team (an organisation run by and for people with learning difficulties).
- The research team was supported by an Advisory Group. The names of the people who were members of this group are in Appendix 1.
- Between July 2003 and October 2004 we interviewed 2,898 people with learning difficulties who were at least 16 years old.
- We talked to people living in their own homes, people living with their parents or other relatives and people living in different types of supported accommodation. This included people living in supported living schemes, residential care and in NHS accommodation.
- In one in four of the interviews (24%) we just talked to the person with learning difficulties. In the rest of the interviews a support person was present. Most support people were parents, another relative or paid carers.



- In just under half of the interviews (46%), the person with learning difficulties answered most of the questions.

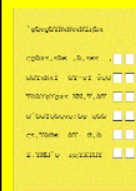
In Appendix 3 of the report we tell you how you can get copies of the questionnaire we used, the information we collected and some very detailed reports on what we did.

## The People



In Section 2 (The People) we tell you about the people with learning difficulties who took part in the survey.

- The youngest person we interviewed was 16 years old, the oldest was 91. About half of the people we interviewed (45%) were under 30 years old.
- We interviewed a few more men (59%) than women (41%).
- Some of the people we interviewed (6%) were from minority ethnic communities.
- Most of the people we interviewed (92%) were single and had always been single.
- Some people were very independent. Other people needed a lot of support.



## What Did We Find Out?



In Sections 3 to 10 of the report we tell you what we found out. Each of these sections contains a lot of information. We have summarised some of the main points below.

### *People with Learning Difficulties are Often Socially Excluded*

Being socially excluded means that you do not get to do many of the things that are important to other people.

- People living in private households and people supported under *Supporting People* were more likely to live in poor and deprived areas
- Only one in six people with learning difficulties who were of 'working age' (17%) had a paid job. Generally in the UK, 67% of men and 53% of women of 'working age' have paid jobs.
- Many people worked part time. Over one in four men (28%) and nearly half of women (47%) who had a paid job worked for less than 16 hours a week.
- Nearly two out of three people (65%) who were unemployed (and said they were able to work) said they would like a job.
- Nearly three in four people (72%) went to a special school. One in ten (10%) went to a special unit in a





mainstream school. Less than one in five (18%) went to ordinary classes in mainstream school.

- We asked people who were not living with their parents or another relative how often they saw members of their family. Nearly half (44%) saw them at least every week or nearly every week. Just under one in five (19%) never saw members of their family. People who had learning difficulties were much more likely not to see members of their family than people who do not have learning difficulties.
- Just over two out of three people (69%) had contact with friends at least once a year. Nearly one in three (31%) said they did not have any contact with friends. People who had learning difficulties were much more likely not to see friends than people who do not have learning difficulties.
- Over two out of three people (69%) had friends who also had learning difficulties. One in four people (25%) had friends who did not have learning difficulties.
- One in twenty people (5%) had no friends and did not see anyone from their family.
- One in fifteen of the people we interviewed (7%) had children. Of the people who had children, just over half (52%) looked after their children.
- Less than one in three people (31%) said that they voted in the 2001 general election. In surveys of the general population nearly four out of five people (73%) said that they voted in the 2001 general election.



People who are socially excluded are also likely to have bad things happen in their lives.

- Nearly half of the people we talked to (43%) said they had been bullied at school.
- We had a list of things that most people in England think others should be able to have. These were things like being able to buy new clothes. We asked people whether they had enough money to buy these things. People with learning difficulties were less likely to have enough money to buy these things than people who do not have learning difficulties.
- One in three people (32%) said they did not feel safe either in their homes, their local area or using public transport.
- Nearly one in three people (32%) said someone had been rude or offensive to them in the last year because they have learning difficulties.
- Nearly one in ten people (9%) said they had been the victim of crime in the last year. People with learning difficulties were less likely to be a victim of crime than other people, but they were slightly more likely to be attacked.
- One in six (15%) said that their general health was 'not good'.
- We asked people how happy they felt about their life at the moment. Nearly half (47%) said they were very happy. But one in twenty (4%) said they were mostly unhappy.
- One in ten people (9-11%) said they felt sad or worried 'a lot', felt left out 'a lot', and felt helpless 'a



lot'. Over one in ten people (13%) said they 'never' felt confident.

### *People with Learning Difficulties Often Have Little Control Over Their Lives*

- Two out of three people in supported accommodation (64%) had no choice over either who they lived with or where they lived.
- One in three people (39%) did not have enough privacy.
- Over one in three of people (38%) said they had heard about Direct Payments. Just under one in five people (19%) were receiving them.
- Just over half of the people we asked (54%) said someone else decided how much money they could spend each week.
- Just over one in ten (12%) said that someone else decided what they could spend their money on.
- About half of the people we talked to (54%) had an independent advocate.
- One in five people (20%) were aware of a self-advocacy group in their area. About one in thirty of all people we talked to (3%) regularly attended self-advocacy groups.

### *People with Learning Difficulties have Few Opportunities to be Independent*

- Half of all adults with learning difficulties (50%) were still living with their parent(s). Another one in



ten (12%) were living with other relatives. Only about one in fifteen (7%) were living either on their own or with a partner. Few adults who do not have learning difficulties live with their parents or with other relatives.

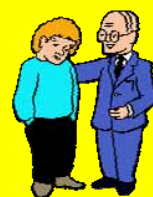
- One in ten people (10%) with learning difficulties living in private households helped care for another adult who was elderly, ill or had a disability.
- One in twenty people (6%) said they had an unmet need for support.
- Nearly two out of three people (63%) said they were very happy with the support they received. A few people (7%) said they were not happy.
- One in ten people (10%) said they had wanted to complain about the support they received.

### *Some People with Learning Difficulties are More Likely Than Others to Have Bad Things Happening in Their Lives*

The survey showed that some good things and some bad things were happening in the lives of people with learning difficulties. We wanted to find out whether some people were more likely to have good or bad things happening to them.

Some people were much more likely to have bad things happen to them than other people.

- **Being poor or living in a poor area** had an impact on just about every aspect of peoples' lives. This is important because people with learning difficulties





are much more likely to be poor than people who do not have learning difficulties.<sup>3</sup> People who were poor or lived in poor areas were more likely to live in unsuitable accommodation and to have less privacy at home. They were also more likely to be unemployed, not have a voluntary job, not have enjoyed school, be bullied at school, not be taking a course and not attend a day centre. They were also more likely to not have control over their money. They were also more likely to see members of their family less often, be an unpaid carer, see their friends less often, do a smaller range of community activities, not have voted and not know about local advocacy groups. They were more likely to not feel safe, be bullied and be a victim of crime. Finally, they were more likely to have poor health, have a long-standing illness or disability, smoke, not be happy, be sad or worried, feel left out, feel helpless, not feel confident, have unmet need and to have wanted to complain about the support they receive.

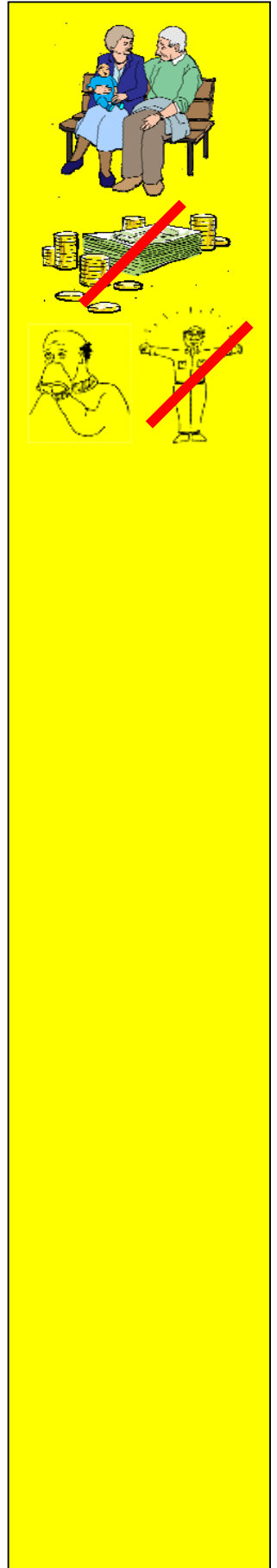
- **People who described themselves as Black or Asian** were more likely to be unemployed, poor, see their friends less often, have poor health and be sad or worried a lot. In addition, people from Asian communities were more likely to have less privacy, feel left out and not feel confident.
- **People with higher support needs** were more likely to be living in supported accommodation, to have less privacy, to have less choice, to be unemployed and not to have a voluntary job. They were more likely to not to have gone to a mainstream school, not to be taking a course, not to



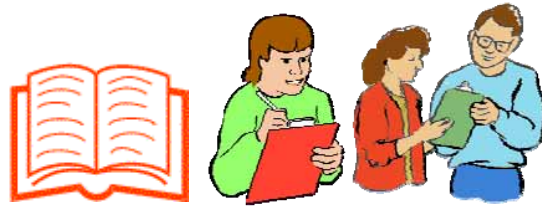


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- **Older people** were more likely to not be taking a course, have no control over their money, see friends who do not have learning difficulties less often, do fewer community-based activities, have poor health and to not exercise.



# The Survey



In 2001 the Government said (in a 'White Paper' called *Valuing People*) that it would carry out a national survey of people with learning disabilities in England. It wanted to find out three things

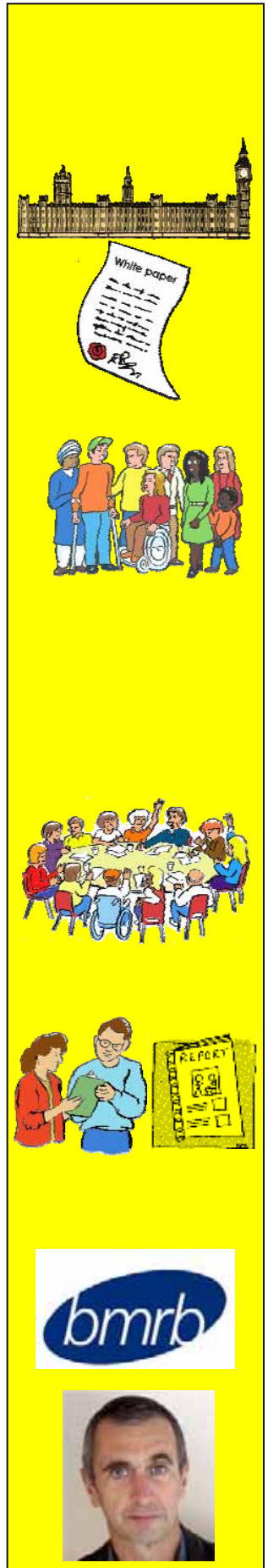
- What is life like for people with learning difficulties?
- What support do they get?
- What do they want and need?

It wanted to do this in a way that involved people with Learning disabilities at all stages of the research. To do this the Department of Health made sure that people with learning disabilities:

- were part of the committee that decided who would be asked to do the survey
- were included as full members of the research team and the advisory group
- could participate in the survey by answering as many questions as possible
- were involved in writing the report of the survey
- got to see the results of the survey. (This report is one of the ways we are doing this.)

The Department of Health asked a research team to do the survey. The team was made up of

- BMRB Social Research (a research company);
- Professor Eric Emerson (from the Institute for Health Research at Lancaster University)



- Central England People First Research Team (an organisation run by and run for people with learning difficulties).

The Department of Health also put together a team of advisors to help make sure the survey was done in the best way. This team included people from the Department of Health, the Office of the Deputy Prime Minister and the National Forum of People with Learning Difficulties. The names of the people on this group are given at the end of this report (Appendix 1).

## Deciding How to Do the Research

There has never been a national survey of people with learning difficulties in England. So, first of all, we needed to find the best way to do the research. Between May and September 2002 we came up with lots of ideas about:

- What questions to ask
- How to make sure that people with learning difficulties could answer the questions (if they wanted to)
- How to find people to take part in the survey.

The next part of this report explains how we worked out the best way to do these things.

### *What Questions To Ask*

We did three things to work out what questions we needed to ask.

- We talked to 30 people with learning difficulties and 30 people who supported them about what they thought.



- Central England People First held a two day conference. 48 people came to the conference. 35 of them were people with learning difficulties. People talked in workshops about what questions should be asked, and how we should ask them.
- We looked at questions that had been asked in other surveys. We looked at surveys done by the government on housing, health, jobs and so on. We also looked at surveys done in other countries on what life was like for people with learning difficulties.

After doing these things we came up with the questions we wanted to ask. Next we needed to check that these were the right questions.

We asked 21 people with learning difficulties the questions to check they were OK and that we were asking them in the right way. We found that most of the questions were OK but that we needed to make some changes.

The questions we asked in the main survey can be downloaded from:

[http://www.dh.gov.uk/PublicationsAndStatistics/PublishedSurvey/ListOfSurveySince1990/GeneralSurveys/GeneralSurveyArticle/fs/en?CONTENT\\_ID=4081207&chk=u%2Bd5fv](http://www.dh.gov.uk/PublicationsAndStatistics/PublishedSurvey/ListOfSurveySince1990/GeneralSurveys/GeneralSurveyArticle/fs/en?CONTENT_ID=4081207&chk=u%2Bd5fv)

## *How to Ask the Questions*

Talking to people with learning difficulties also told us a lot about how to ask the questions so that as many people as possible could answer them (if they wanted to).

We thought about how to make the questions easy to understand. We decided to:



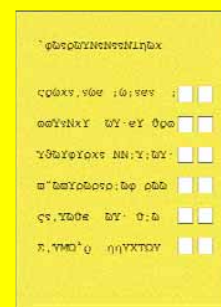


- Use words that are easy to understand
- Use pictures to help people understand what the words mean
- Explain what the questions mean. (In big surveys we don't usually explain what the questions mean, but people can sometimes understand things better if they are said in a different way.)



We used three kinds of questions

- Simple questions that could be answered with 'yes' or 'no'
- Questions where the person chose the answer from a short list
- More complicated questions.



Then we thought about other things, which might be important to help people answer the questions.

We wanted to make sure we talked to people when they wanted us to. We decided to:

- Send a letter to all of the people we wanted to talk to. This was written in a way that was easy for them to understand.
- Call people first to arrange a time to visit them. Sometimes we needed to talk to a support person to help arrange this.



We wanted to make sure that people were happy to take part in the survey.

- First, the interviewer explained why we were there, and what the interview would be like



- Then they checked if the person had understood what we were asking them to do, and if they were happy to take part
- If they did not understand this, we asked a support person if it was OK to do the interview. (This could not be a paid support worker, unless there was no-one else to ask.)

We tried to make sure that, if they wanted it, the person with learning difficulties would have someone else to be there to support them.

- We asked if they would like someone else there. If they said no, we did the interview with them on their own.
- If they said they would like someone to support them, we asked if it was OK to ask the support person some questions as well. If they said no, we did not ask the support person any questions.
- Our interviewers made sure the support person was there to help, and did not take over the interview.

### Training the Interviewers

We wanted to make sure the interview was done in a way that helped people with learning difficulties to participate. We asked the interviewers to:

- Take some time at the start of the interview to get to know the person they are talking to
- Ask the person with learning difficulties the questions – don't talk about them to a support person
- Allow plenty of time for people to think about their answers
- Go at the pace of the person they are talking to and take plenty of breaks



We trained our interviewers to make sure they really understood about these things. The training was run by BMRB and Central England People First.

- BMRB made sure the interviewers understood what they needed to do
- Central England People First helped them understand what it might be like to interview people with learning difficulties. They did this by talking with them about:
  - What speaking up means for people with learning difficulties
  - What life can be like for people with learning difficulties and
  - How people with learning difficulties might react to being interviewed.
- The interviewers asked lots of questions and felt they had learnt a lot from their training.

### *How to Find People to Take Part in the Survey*

We wanted to make sure that the people we talked to were as similar as possible to other adults with learning difficulties in England. This meant that we needed to talk to people:

- in different parts of the country
- who were living independently, with their families and in supported accommodation
- who had a wide range of needs and abilities.

We think that about one in fifty adults in England has a learning disability. Of these, only about one in four use specialised 'learning disability' health or social services. So we needed to find a way of talking to people who would not be known to specialised services.



## People in Private Households

Every week BMRB do a survey that talks to 4,000 people from all over England. We added some questions to this survey to try to find people living in private households who would be willing to take part in the survey. This would include people who are living alone, living with a partner or living with their parents or another relative.

We explained what we meant by learning difficulties. We then asked them if they had learning difficulties, or if they lived with or supported an adult with learning difficulties.

When we tested it, we found that this was a good way to find people in private households. There were also some problems with finding people in this way.

- We could only find about 30 people every week to try to talk to. Because of this it would take quite a long time to find and interview enough people in this way.
- We did not find many people from minority ethnic communities.

To get round these difficulties we also decided to try to find people through Social Services Departments.

## People in Supported Accommodation

People with learning difficulties may be living in three main kinds of supported accommodation:

- Housing provided under the government's '*Supporting People*' programme. The Office of the Deputy Prime Minister (ODPM) had a list of all places in the schemes that they thought were supporting people with learning disabilities.



- *Registered Residential Care Homes*. At the time we did the survey an organisation called the National Care Standards Commission (NCSC) had a list of all registered residential care homes that supported people with learning disabilities.<sup>4</sup>
- *Hospitals and residential homes* run by the NHS. The Department of Health had a list of all NHS Trusts that provide supported accommodation for people with learning disabilities.

We got these lists. Then we tested out how easy it would be to find people to talk to who lived in supported accommodation.

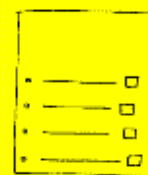


### Testing Out Our Ideas

By September 2002, we thought we knew how to do the survey. We tried out our ideas by doing a full 'dress rehearsal' for the survey. This involved interviewing 176 people with learning difficulties across England. These were people in both private households and supported accommodation.

We wrote a report about what we had done in May 2003. A copy of this report can be downloaded from [http://www.dh.gov.uk/PublicationsAndStatistics/PublishedSurvey/ListOfSurveySince1990/GeneralSurveys/GeneralSurveyArticle/fs/en?CONTENT\\_ID=4081207&chk=u%2Bd5fv](http://www.dh.gov.uk/PublicationsAndStatistics/PublishedSurvey/ListOfSurveySince1990/GeneralSurveys/GeneralSurveyArticle/fs/en?CONTENT_ID=4081207&chk=u%2Bd5fv)

We also wanted to make sure that our survey was fair to people with learning difficulties. To do this we talked to a NHS 'Ethics Committee'. It is their job to make sure that research is fair. They said they were happy for us to do the survey, but that we had to check that all the NHS Trusts in the survey were happy that the survey was fair. This took a very long time.





# The Main Survey



We started work on the main survey in July 2003. By October 2004 we had interviewed 2,974 people.

## *Who We Talked To*

### People from BMRB's Survey of People Across England

We used BMRB's survey for over a year to find people in private households with learning difficulties. Through this we found 1,072 adults with learning difficulties who might be able to help us. We interviewed 750 of these people.

### People in Private Households Identified from Social Services Departments

We asked 28 Social Services Departments to help us. Of these, 19 co-operated with the survey. Through them we identified 675 people with learning difficulties living in private households to talk to. We interviewed 480 of these people.

### People in Supporting People Schemes

We chose 190 schemes that supported adults with learning difficulties. Of these, 134 schemes said they would help us. These schemes identified a total of 822 people to talk to. We interviewed 562 of these people.



## People in Registered Residential Care Homes

We chose 340 residential care homes. Of these, 202 said they would help us and they identified a total of 1,312 people to talk to. We interviewed 919 of these people.

## People Living in Accommodation Provided by NHS Trusts

We chose 40 NHS Trusts and asked them to help us. Of these, 14 Trusts said they would help us and they identified a total of 326 people to talk to. We interviewed 263 of these people.

A report which gives more details of how we chose people to take part, and how we made sure the results represented all people with learning difficulties can be downloaded from

[http://www.dh.gov.uk/PublicationsAndStatistics/PublishedSurvey/ListOfSurveySince1990/GeneralSurveys/GeneralSurveyArticle/fs/en?CONTENT\\_ID=4081207&chk=u%2Bd5fv](http://www.dh.gov.uk/PublicationsAndStatistics/PublishedSurvey/ListOfSurveySince1990/GeneralSurveys/GeneralSurveyArticle/fs/en?CONTENT_ID=4081207&chk=u%2Bd5fv)

## The Interviews

We tried to make sure that people with learning difficulties could take part in the interviews. To do this we

- Made the questions as easy to answer as we could
- Trained the interviewers how to include people with learning difficulties. This training was done by Central England People First and BMRB.

## How Much Were People Able to Take Part in the Interviews?

In just under half of the interviews (46%), the person with learning difficulties answered most of the questions. In less than one in three interviews (31%) the support person



answered most of the questions. In the rest (23%), the person with learning difficulties answered some of the questions, the support person also answered some.

Who Took Part in the Interviews?

Figure 1 shows who took part in the interviews. One in four of the interviews (24%) just involved the person with learning difficulties (the focus person). When a support person was present they tended to be a parent, another relative or a paid carer.

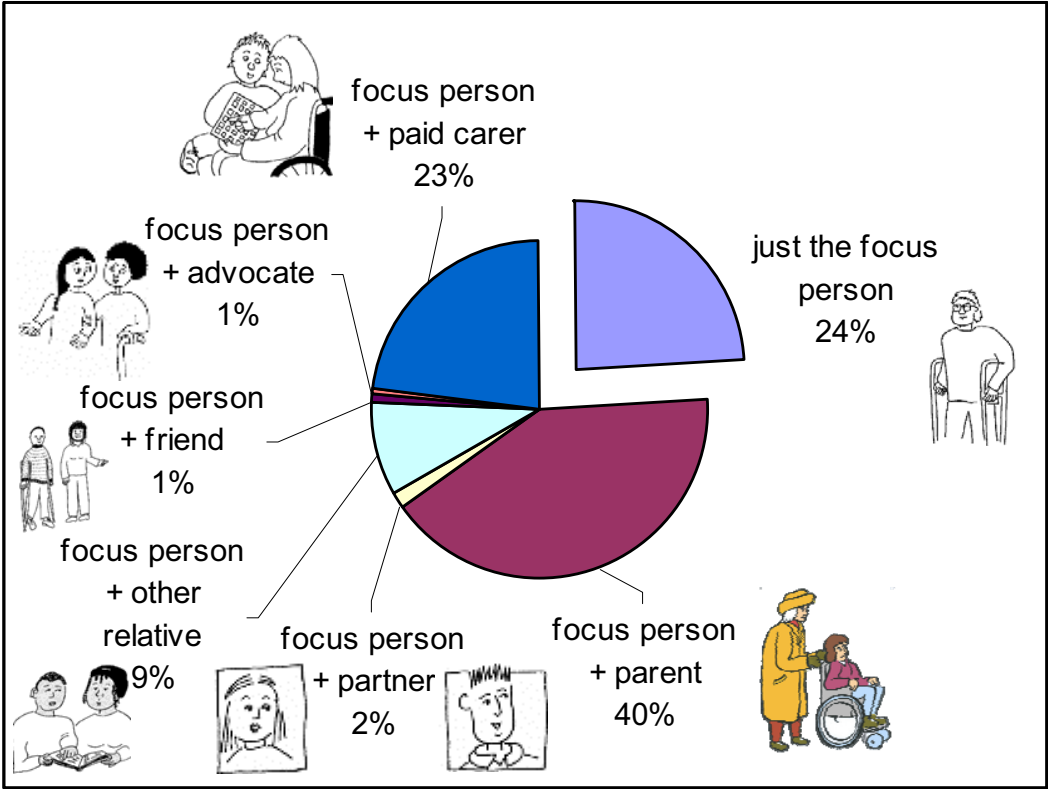


Figure 1: People who took part in the Interview



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# The People



We interviewed 2,974 people. Of these, 76 probably did not have learning difficulties.<sup>5</sup> This left us with 2,898 interviews with people with learning difficulties.

## Sex



Of the people we interviewed, there were more men (59%) than women (41%). We would expect this as more men than women have learning difficulties.<sup>6</sup>

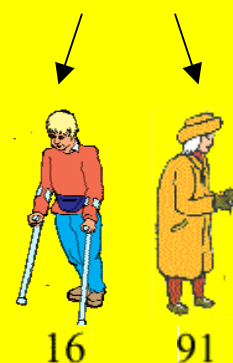
## Age



The youngest person we interviewed was 16 years old the oldest was 91. About half of the people we interviewed (45%) were under 30. Figure 2 shows how many men and women we interviewed at each age group.

We compared the ages of the people we interviewed with our best estimates of the ages of people with learning difficulties in England.<sup>7</sup> We found that we were more successful at finding younger people with learning difficulties to talk to than older people.

We found that this was true for people living in private households and for people living in supported accommodation.



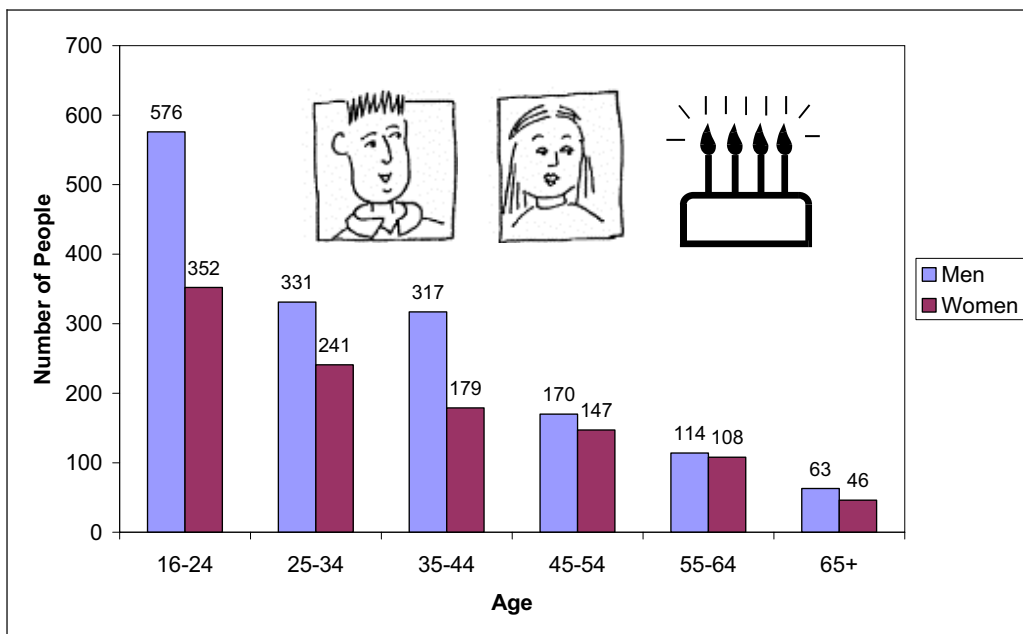
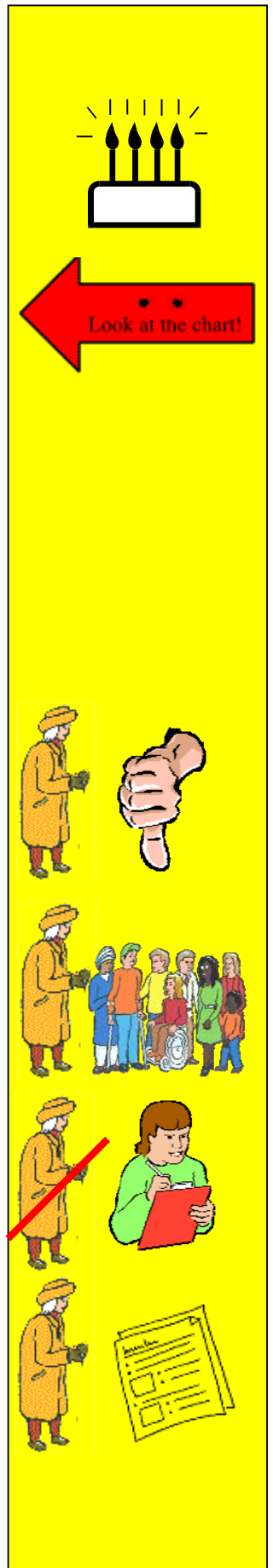


Figure 2: The Age of the People we Interviewed

We are not sure why we were less successful at finding older people. It could be because:

- Older people were less likely to identify themselves as having learning difficulties
- People supporting older people were less likely to identify the person they were supporting as having learning difficulties
- Organisations and homes supporting older people were less likely to participate in the survey
- Older people were less likely to agree to take part in the survey
- If the person themselves could not give consent, people supporting older people were less likely to agree to take part in the survey.





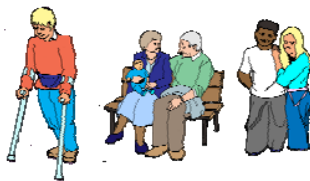
## Ethnicity



Of the people we interviewed, some (6%) were from minority ethnic communities. This is a bit less than the number of adults from minority ethnic communities in England (7%).

Of the people from minority ethnic communities:

- 56% were Asian (people who described themselves as British Asian, Pakistani, Indian, Bangladeshi etc)
- 35% were Black (people who described themselves as Black British, Caribbean, African etc)
- 9% were from other minority ethnic groups (e.g., Chinese).



## Marital Status

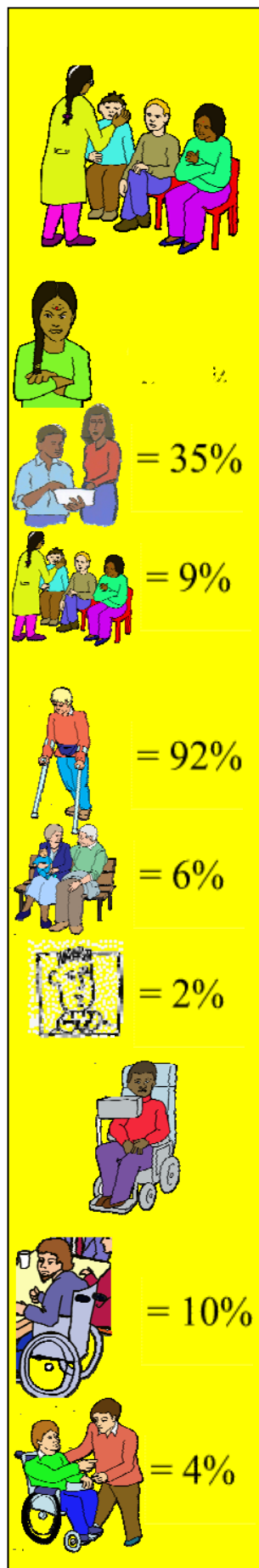
Most of the people we interviewed (92%) were single and had always been single. Some were married or were living with someone (6%), a few were widowed, separated or divorced (2%).



## Support Needs

We asked the people who we interviewed how much support they needed to do 11 different things. These things ranged from drinking a cup of tea to filling in a form.

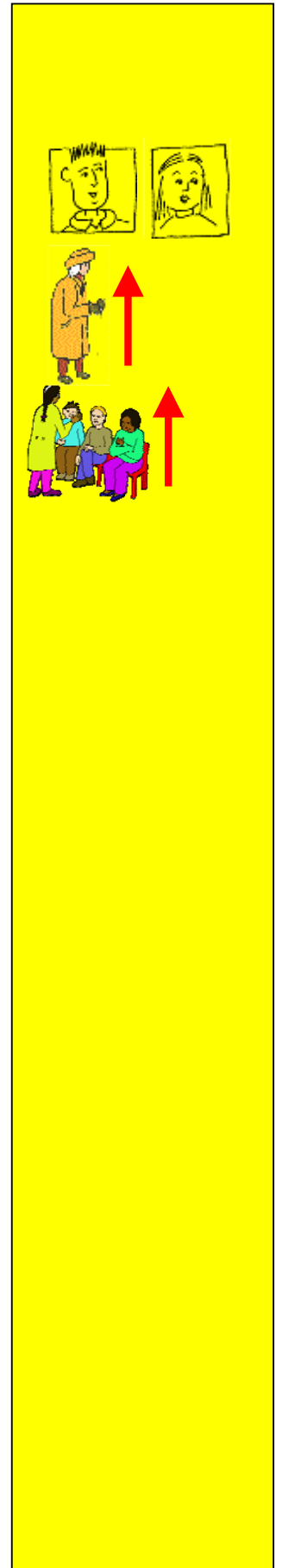
- Some people were very independent. One in ten people (10%) could do all or all but one of these things independently.
- Other people needed a lot of support. A few people (4%) needed someone to do all or all but one of the things for them.



We looked at whether some people needed more support than others.

- Men and women needed the same amount of support.
- Older people needed more support than younger people.
- People from Asian communities needed more support than people from White or Black communities.

We talk more about support needs in the last section (Support).



# A Place to Live



We think too few people (less than one in seven) live on their own or with a partner. Too many young people still live with their parents and too many older people live in supported accommodation. Living independently makes many choices possible but, just like everyone else, people with learning difficulties worry about safety in the area they live in. We don't think this should stop people living independently. They should have the choice of being independent and safe.

We were not surprised that so many people's privacy was not respected and that most people in supported accommodation did not have a choice about who they lived with and where. As people with learning difficulties the right to have choice about a place to live and to privacy are very important.

Ian Davies & Karen Spencer

We asked people about where they lived and who they lived with.

Just over two in three people (69%) were living in private households. This means that they were living alone, with a partner or with their parents or other relatives. Just under one in three people (31%) were living in some form of supported accommodation.

Of the people living in private households:

- nearly three out of four people (73%) were living with their parent(s)
- one in six (17%) were living with other relatives



- just over one in twenty (6%) were living on their own
- just under one in twenty (4%) were living with a partner

Of the people living in supported accommodation:

- nearly two out of three (62%) were living in residential care homes
- one in three (34%) were being supported under the Supporting People programme
- the rest (3%) were living in NHS hospitals.

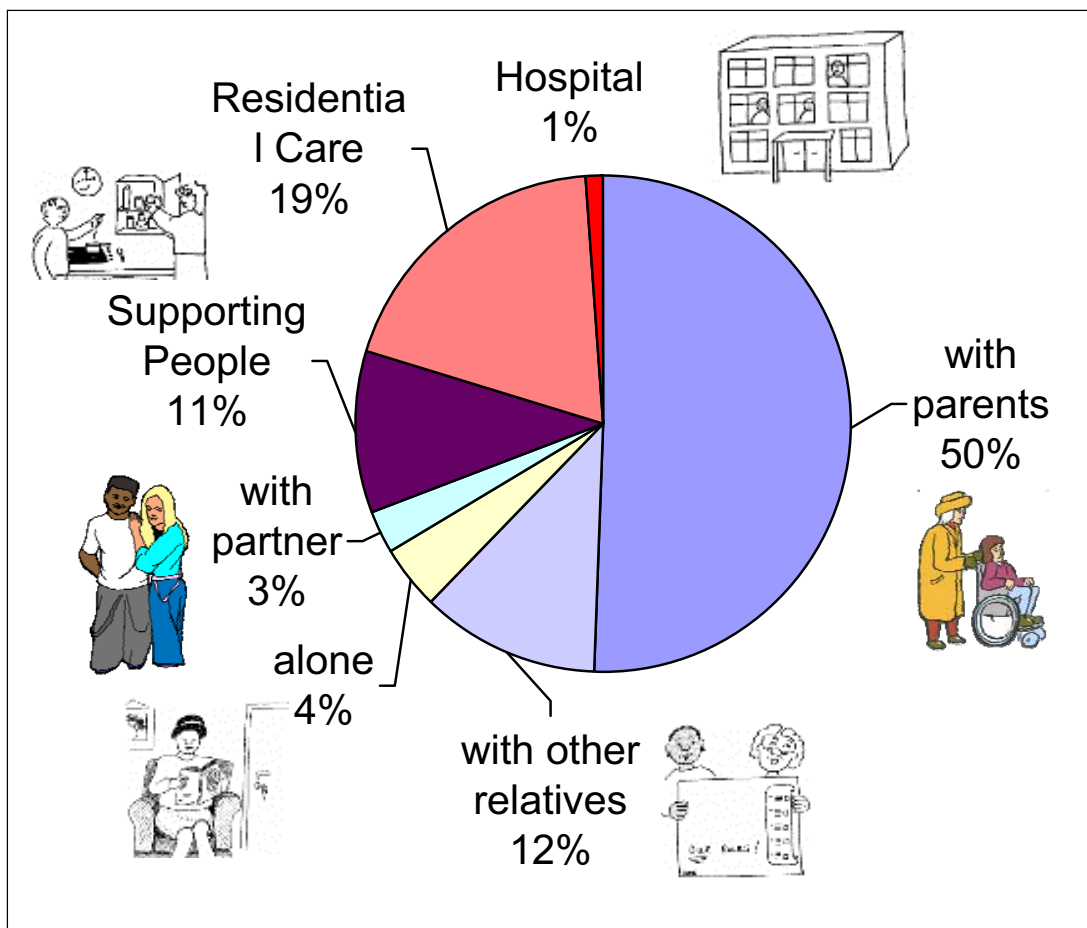
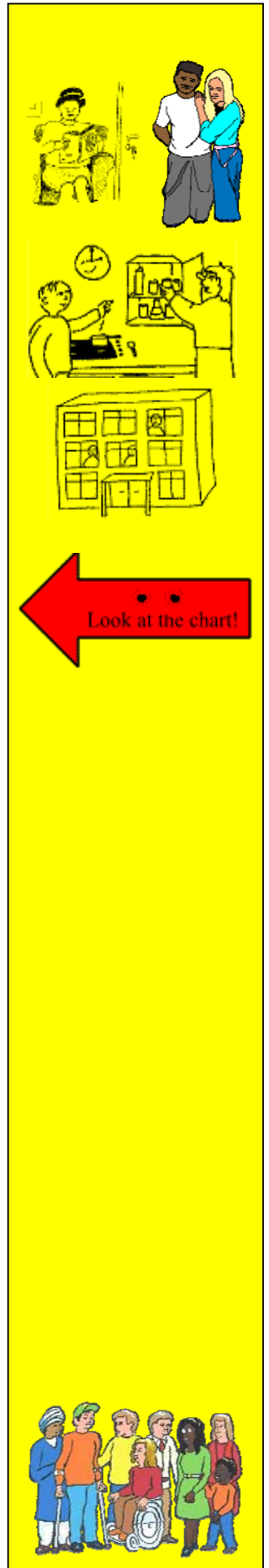


Figure 3: Where People Were Living

These results are summarised in Figure 3. The living arrangements for people with learning difficulties were very different from the living arrangements for adults in



the UK in general. In Figures 4 and 5 we have made some comparisons between the two using information on the general population for 2003/4 reported by National Statistics.<sup>8</sup>

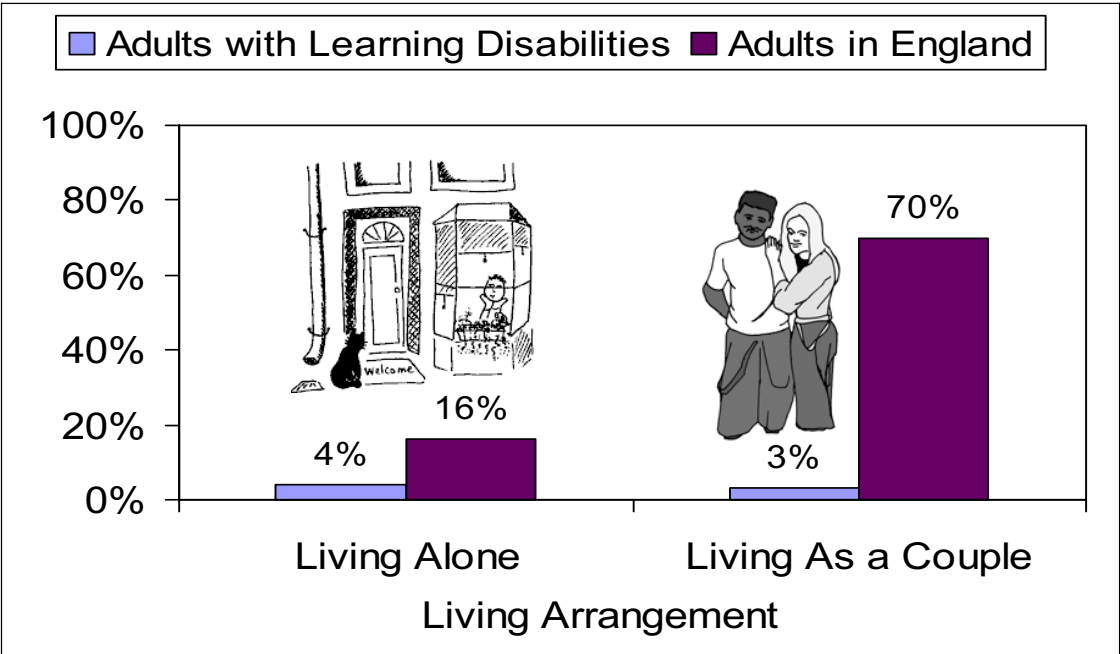
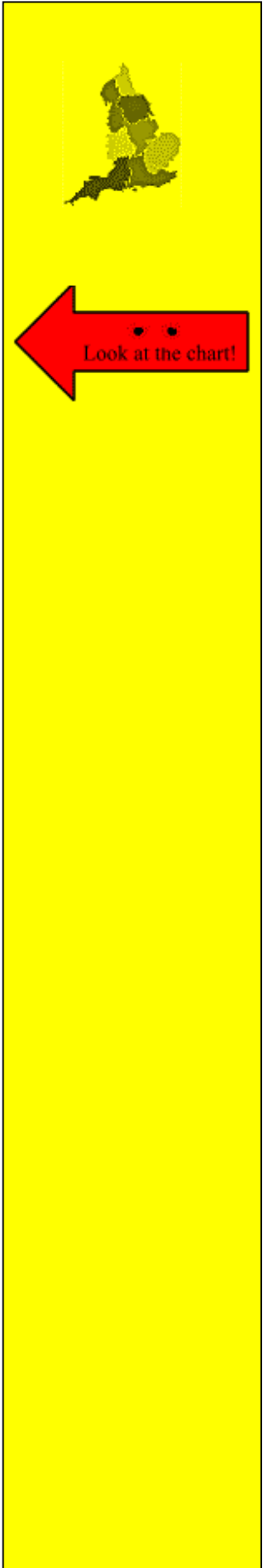


Figure 4: Percentage of Adults Living Alone or Living as a Couple





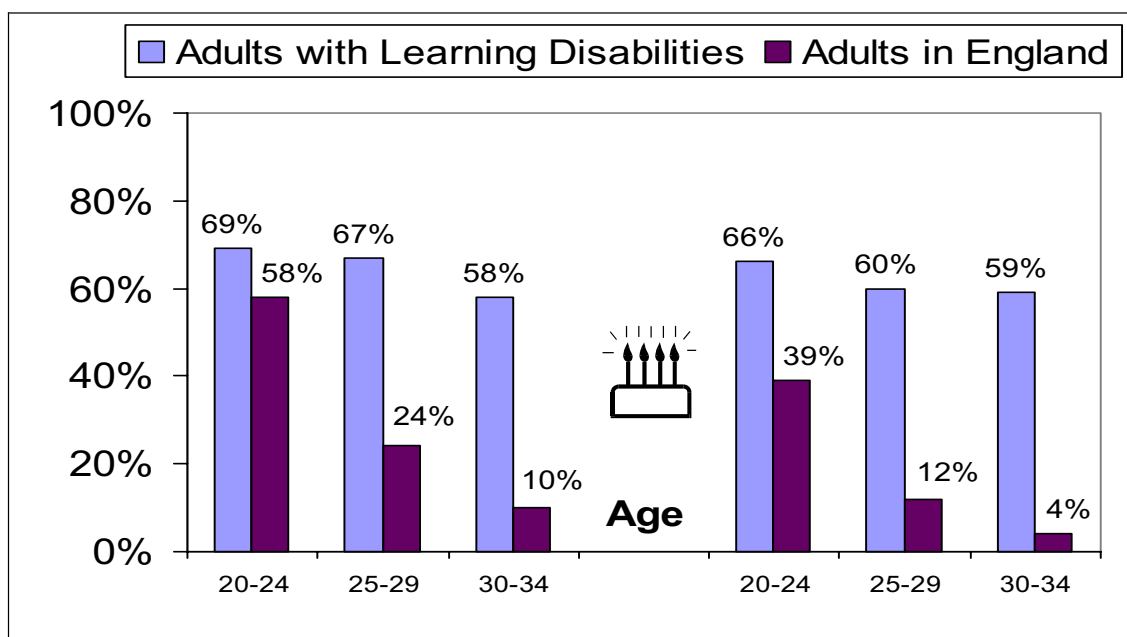


Figure 5: Percentage of Men (on the left) and Women (on the right) Living with Their Parents

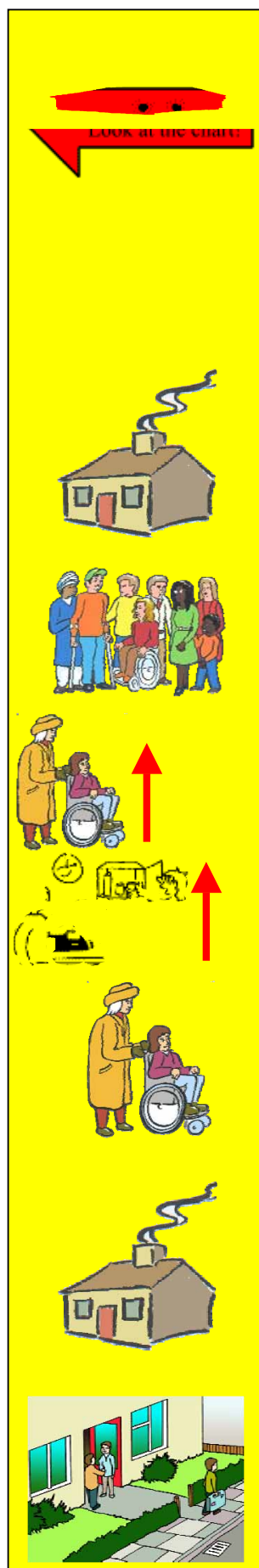
These figures show that people with learning difficulties are much more likely to live with their parents than other people (especially as they get older). They also show that people with learning difficulties are much less likely to live as a couple than other people.

Of the people with learning difficulties living with their parents, one in five (20%) were living with parents who were 65 or older. Nearly one in ten (9%) were living with parents who were 75 or older.

## Who Is More Likely to Live in Supported Accommodation?



First, however, we looked at who was more likely to live in private households and who was more likely to live in supported accommodation. We found that five things were independently related to living in supported accommodation.



This means that each of these things was important, even when we took into account the other four things in the list.<sup>9</sup>

People were more likely to live in supported accommodation if (in order of importance) they

- were older
- had higher support needs
- were not Asian
- did not have poor general health
- did not have a long-standing illness or disability

Age 

Older people were more likely to be living in supported accommodation than younger people. Figure 6 shows (for different ages) how likely it was that the people who took part in our survey lived in supported accommodation. It also shows similar information about the living situation of 15,000 people with learning difficulties in England in 2004.<sup>10</sup>



The figure shows that as people get older they are much more likely to live in some form of supported accommodation. It also shows that at each age the people who took part in our survey were a bit less likely to live in supported accommodation than people who are known to learning disability services.



People with higher support needs were more likely to be living in supported accommodation than people with lower support needs.

We divided the people who we interviewed into three equal groups based on the level of support they needed. One in four (25%) people with the lowest support needs were living

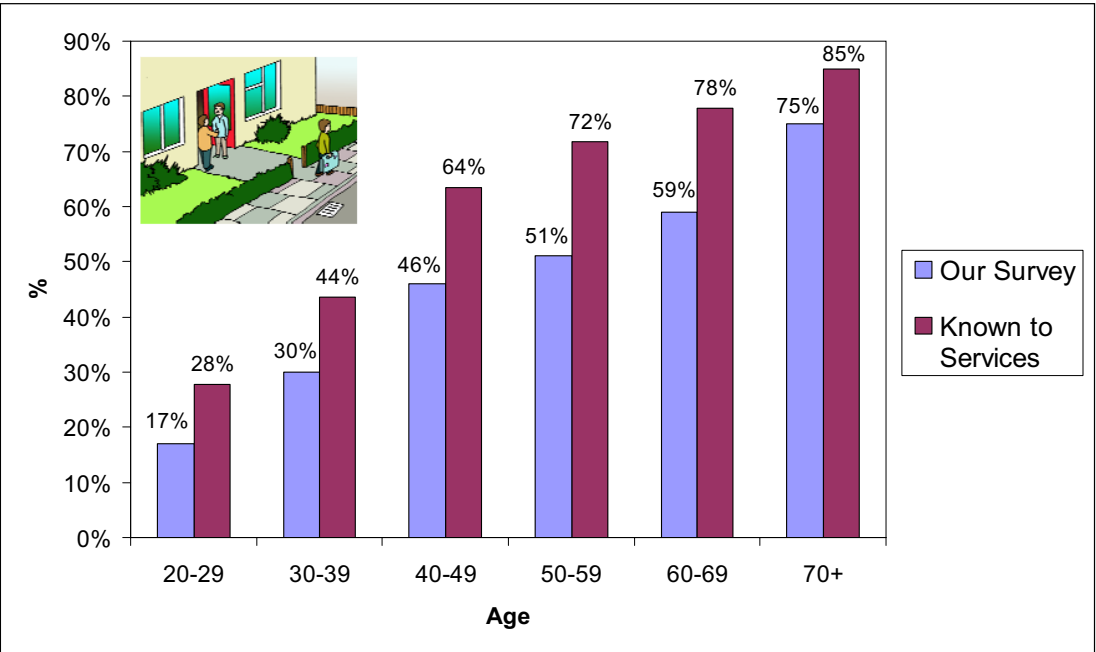
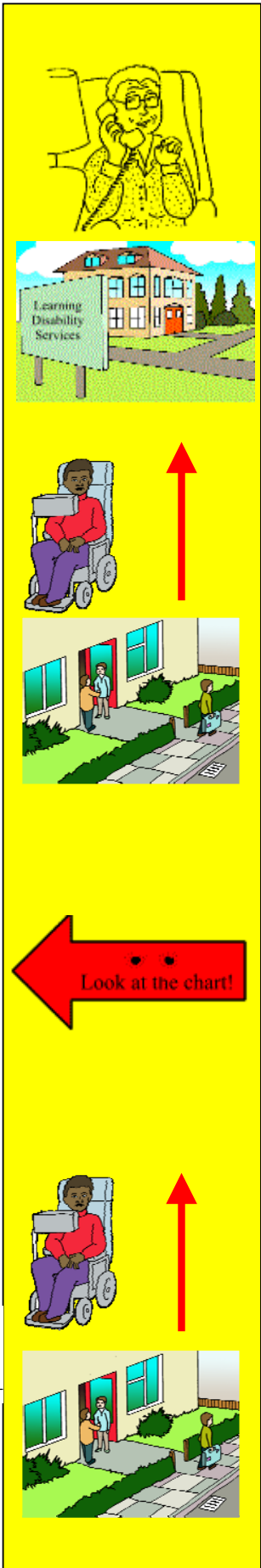


Figure 6: Percentage of People Living in Supported Accommodation at Each Age Group

in supported accommodation. Over one in three (40%) people with the highest support needs were living in supported accommodation. It is important to remember,



however, that the majority of people with the highest support needs were living in private households.

## Ethnicity



Many fewer Asian people were living in supported accommodation than White people or Black people.<sup>11</sup> However, this difference was only true for younger people.

- When we just looked at people under 40, many fewer Asian people were living in supported accommodation (7%) than White people (17%) or Black people (24%).
- When we looked at people who were 40 or older, there was little difference between the percentage of Asian people living in supported accommodation (46%) and White people (51%). (There were very few Black people in this age group.)

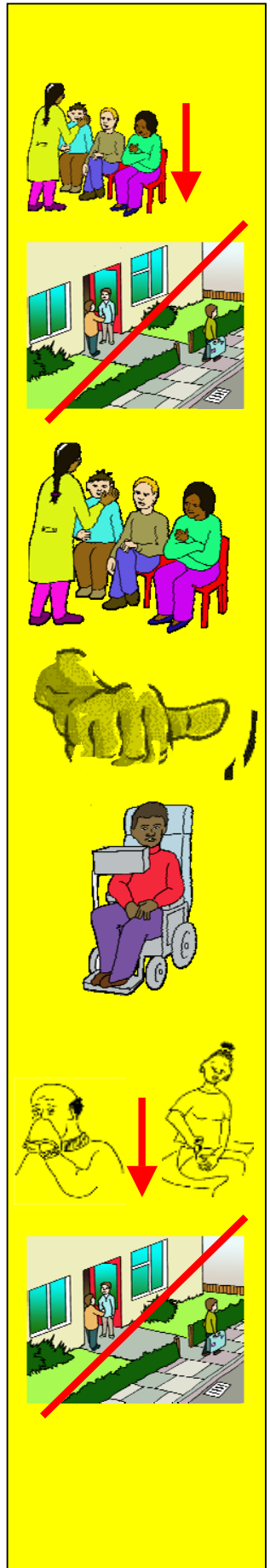
This difference in use of supported accommodation is surprising as Asian people tended to have higher support needs than other groups.

## Health & Disability



When the effects of age, support needs and ethnicity were taken into account, people who either had generally poor health or had a long-standing illness or disability were *less* likely to live in supported accommodation.

Figure 7 shows the percentage of people living in private households and supported accommodation who had poor health or had a long-standing illness or disability.



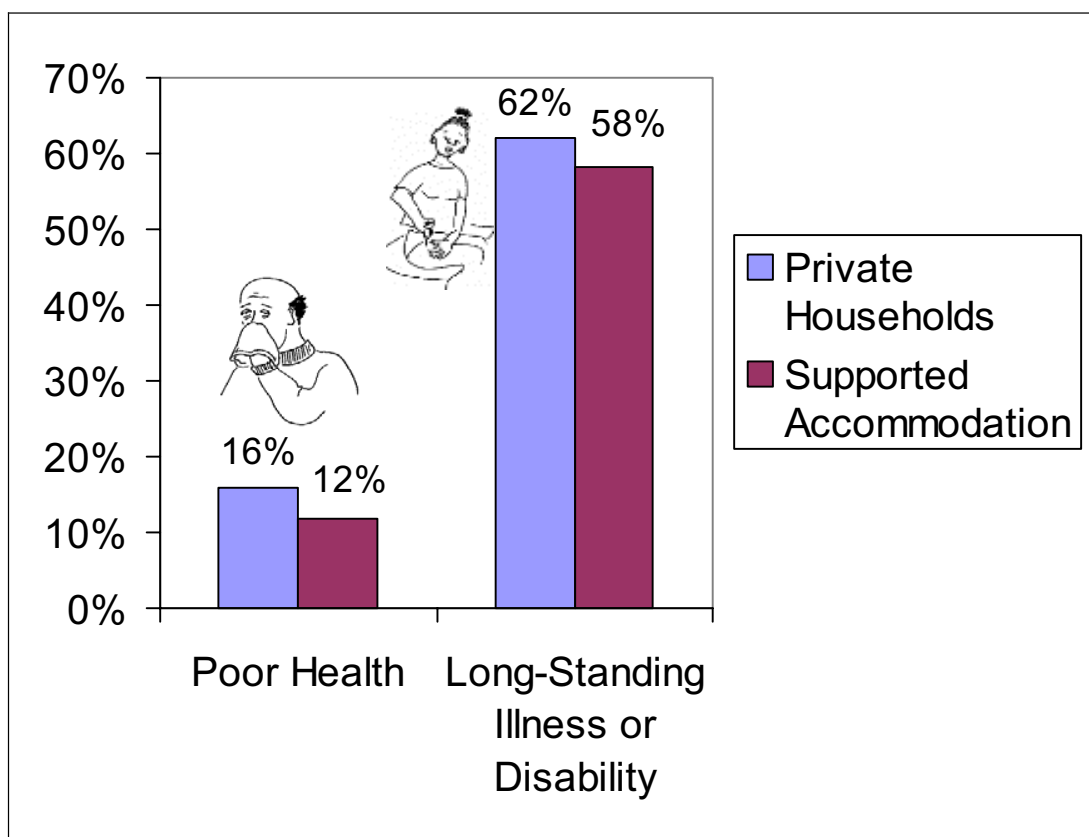
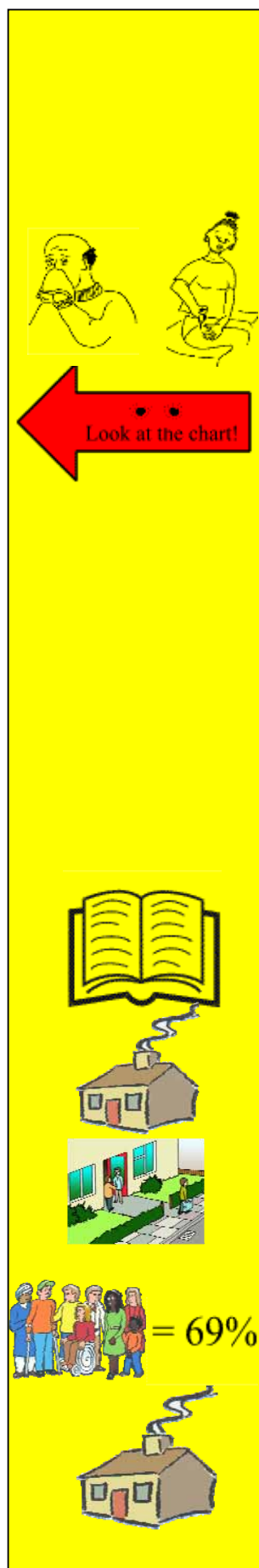


Figure 7: Percentage of people living in private households and supported accommodation who had poor health or had a long-standing illness or disability

In the next two sections we will summarise the information we collected. First, we will do this for people living in private households (people living with their families, a partner or alone). Then we will do this for people living in supported accommodation (people living in supported living, group homes, hostels and hospitals).

## People Living in Private Households

Just over two in three people (69%) were living in private households.





## *Did People Like Where They Were Living?*

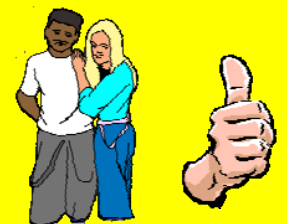


We asked people whether they liked where they were living. It is very difficult to know whether someone else really likes something. Because of this we looked separately at what people with learning difficulties said themselves, and what the support person said when they answered for people with learning difficulties.

- Nearly all people with learning difficulties who were living with their parents (97%) or with other relatives (91%) said they liked where they lived. Most people who were living alone (78%) or with a partner (72%) also said they liked where they lived.
- When the support person answered these questions on behalf of the people with learning difficulties, they also said that nearly all people who were living with their parents (97%) or with other relatives (98%) liked where they lived. Support people very rarely answered these questions when people were living alone or with partners.

We looked in more detail at what people with learning difficulties said when they were interviewed alone compared to when they were interviewed with a support person present.

- People were just as likely to say that they liked living with their parents when interviewed alone (98%) as they were when interviewed with a support person present (97%).
- There was also not much difference between what people said about whether they liked living with their partner when interviewed alone (74%) or when they were when interviewed with a support person present (67%).



- When people were living with other relatives, they were more likely to say that they liked where they lived when a support person was present (96%) than when they were interviewed alone (81%).
- When people were living alone, they were also more likely to say that they liked where they lived when a support person was present (100%) than when they were interviewed alone (72%).

If people said they did not like where they lived, we asked them why. The answers to these questions are shown in Figure 8, separately for when the question was answered by the people with learning difficulties and when it was answered by the support person.

This figure shows that we got very different answers to this question depending on who answered.

- People with learning difficulties were most concerned about the area they were living in.
- Support people were most concerned about how independent people could be.

These differences may reflect the different views of people with learning difficulties and support people. They may also reflect what matters most to people with different levels of support need (people with low support needs answered themselves, the support person tended to answer for people with high support needs).



When a support person was present we asked them whether they thought the house was suitable for the person in light of their needs.

- Most support people (91%) did think the person's accommodation was suitable.
- The main things that they complained about were the person needing more space (26% of people who

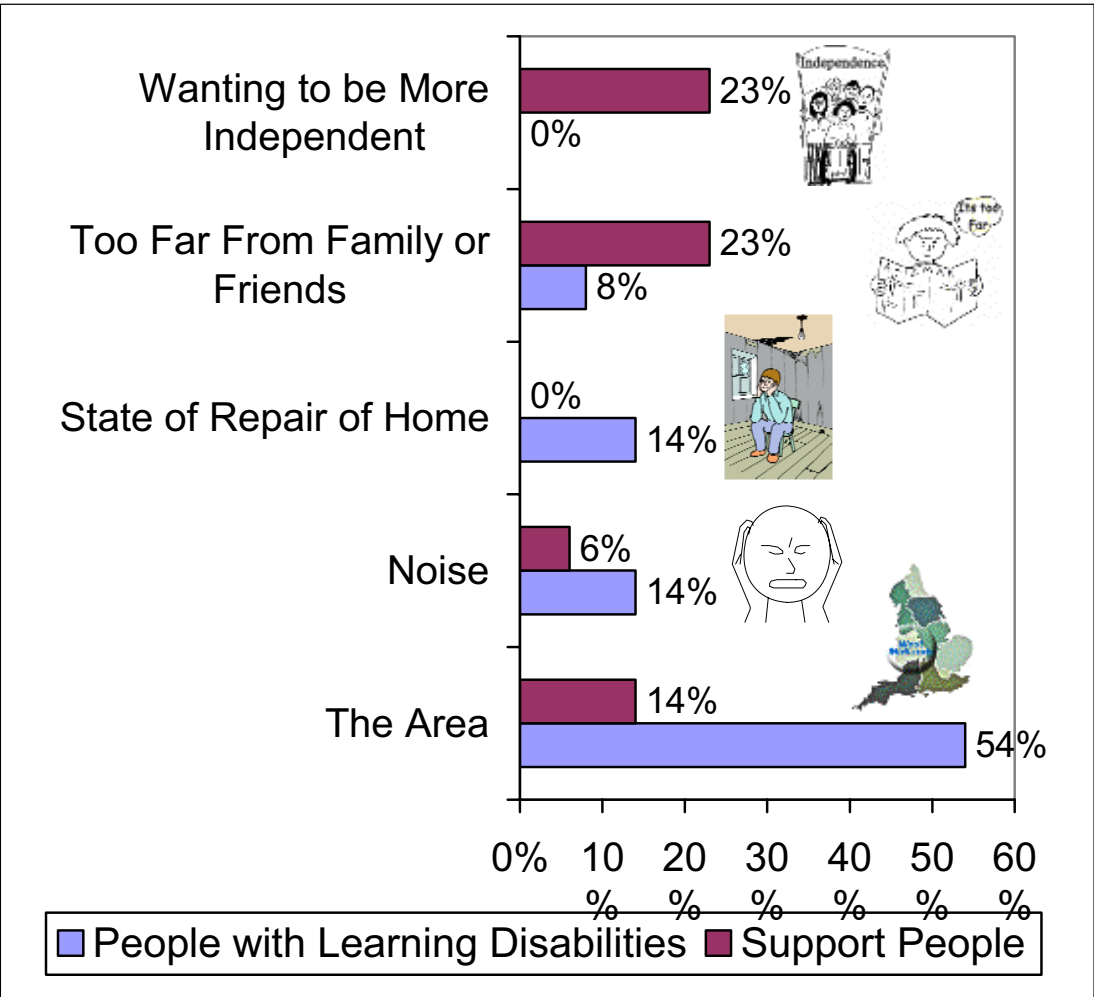






Figure 8: What People Did Not Like About Where They Were Living





thought the accommodation unsuitable), having difficulty with stairs (20%), needing their own room (19%), needing a bedroom or bathroom downstairs (19%) and the general state of repair (8%).

## Feeling Safe



We asked people about whether they felt safe at home at night and felt safe in the local area.

- A few people (5%) living in private households did not feel safe in their home at night. One in seven people (14%) said that they did not feel safe in the local area.
- When we just looked at what people with learning difficulties said themselves, one in six (17%) said they did not feel safe in the local area.

## Support At Home



We asked whether people living in private households had someone to help them at home. Four out of five (80%) people said they did have someone to help them.

- In nearly all cases (93%) the person who provided support was a relative.
- A small number of people (8%) had a paid support person to help them at home.
- A few (2%) had a friend to help them at home.
- Of the people who did not have anyone to help them, a few (12%) said they would like someone.



## Privacy



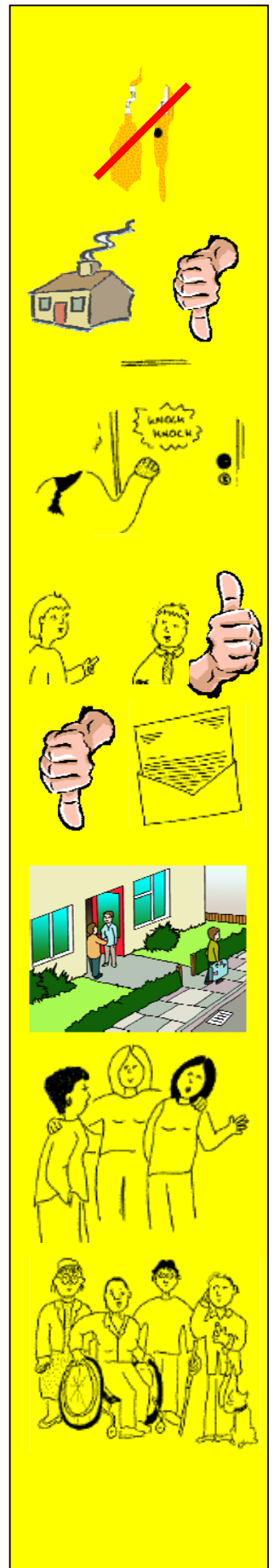
We asked people about their privacy.

- In a few cases (8%) people said that someone sometimes comes into their home without asking, or when they did not want them to.
- More people (14%) said that someone sometimes comes into their room without asking, or when they did not want them to. They said this was most likely to be someone they lived with (59% of those who said this happened), a relative or friend they didn't live with (39%) or a paid support worker (8%).
- Most people said they could be alone with people who come to visit them (82%) and that they could be alone as much as they liked (86%).
- Just over one in four people (27%) said that sometimes people opened their letters without asking them.

## People Living in Supported Accommodation

Just under one in three people (31%) were living in some form of supported accommodation.

The number of other people with learning difficulties that shared the person's home is shown in Figure 9. Three in four (75%) people were living in houses for four or more people. Just under one in four (22%) were living in houses for more than 10 people.





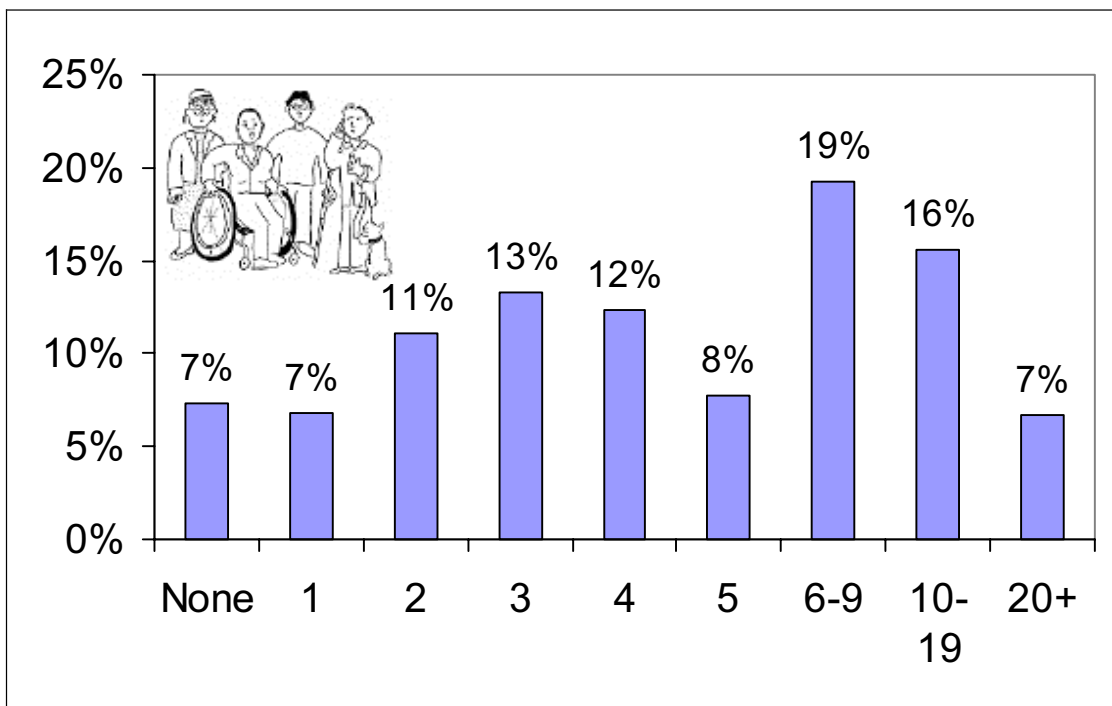


Figure 9: Number of Other People with Learning difficulties That Share the Person's Home

## Choice



We asked people in supported accommodation about the choice people had over who they lived with and where they lived.

- Two in three people (67%) said they had no choice (or were reported to have no choice) over who they lived with.
- Just over half the people (54%) said they had no choice (or were reported to have no choice) over where they lived.

We also looked at choice just for those people who answered most of the questions in the survey themselves. Even among this group of people who could do lots of things themselves, most people (58%) said they had no choice over



who they lived with. Though most of them (63%) said they did have some choice over where they lived.

When we studied all the answers to the questions we decided that people did not have enough choice if they had no choice over either who they lived with or where they lived. Overall, we found that two out of three people (64%) in supported accommodation did not have enough choice.

Next we looked at whether some people were more likely to have choice than others. Two things were strongly related to having more choice: living with fewer people and having lower support needs.

### *Did People Like Where They Were Living?*



We asked people whether they liked where they were living. Because it is very difficult to know whether someone else really likes something we looked separately at what people with learning difficulties said themselves, and what support people said.

Most people with learning difficulties who were living in supported accommodation (93%) said they liked where they lived. When the support person answered this question, they also said that most people with learning difficulties who were living in supported accommodation (96%) liked where they lived.

If people said they were unhappy about where they lived, we asked them about why they were unhappy.



The answers to these questions are shown in Figure 10

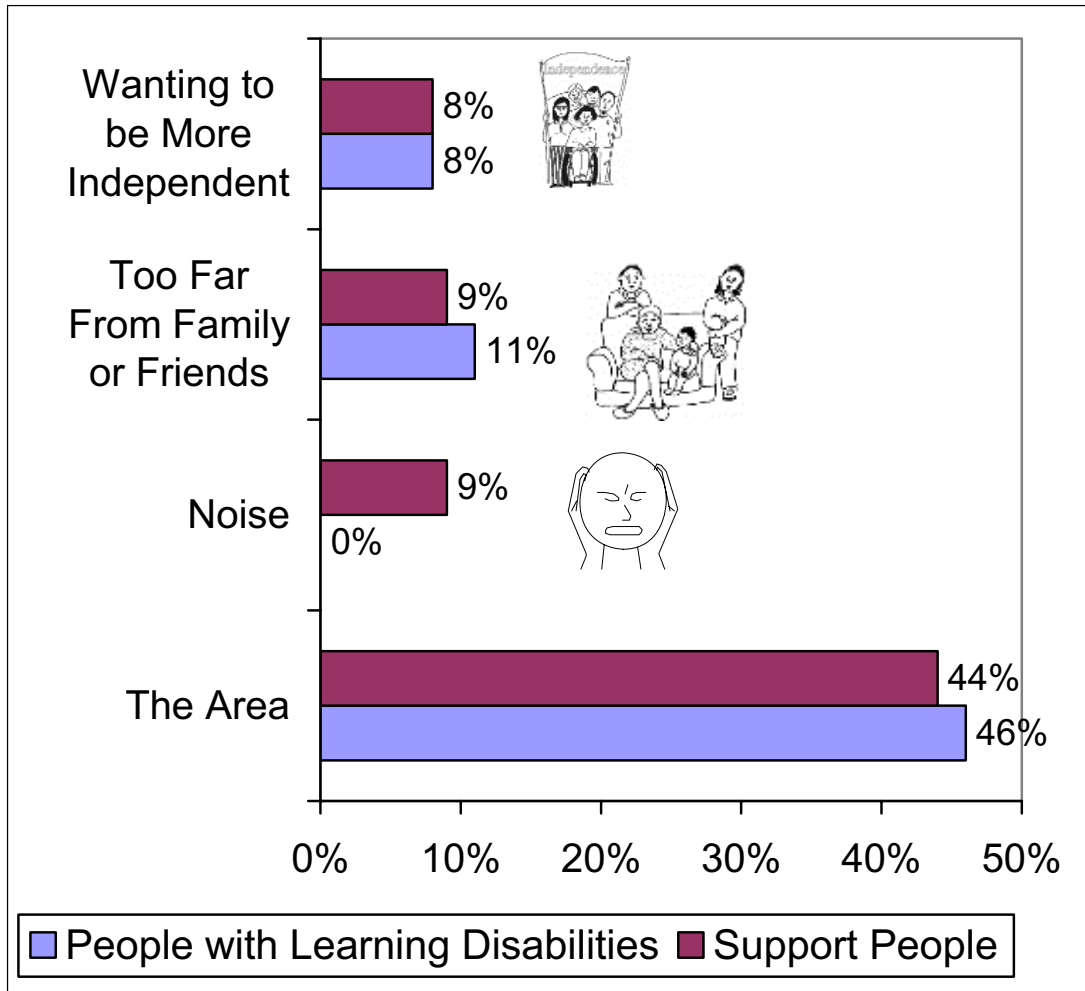


Figure 10: What People Did Not Like About Where They Were Living

separately for when the question was answered by the people with learning difficulties and when it was answered by the support person.

There were no really big differences between people with learning difficulties and support people. Not liking the area in which the person was living was the most common reason for not being happy with where people were living.

When a support person was present we asked them whether they thought the house was suitable for the person in light of their needs.

A yellow vertical sidebar on the right side of the page. It contains several illustrations: at the top, a man and a woman looking at a document; below that, a small yellow box with illegible text; a large red arrow pointing left with the text 'Look at the chart!'; and at the bottom, two rows of illustrations showing people interacting with a computer or tablet.

- Most support people (94%) did think the person's accommodation was suitable.
- The main things that they complained about were the person needing more space (32% of people who thought the accommodation unsuitable), needing a bedroom or bathroom downstairs (17%), having difficulty with stairs (16%), needing their own room (11%) and the general state of repair (3%).



## Feeling Safe

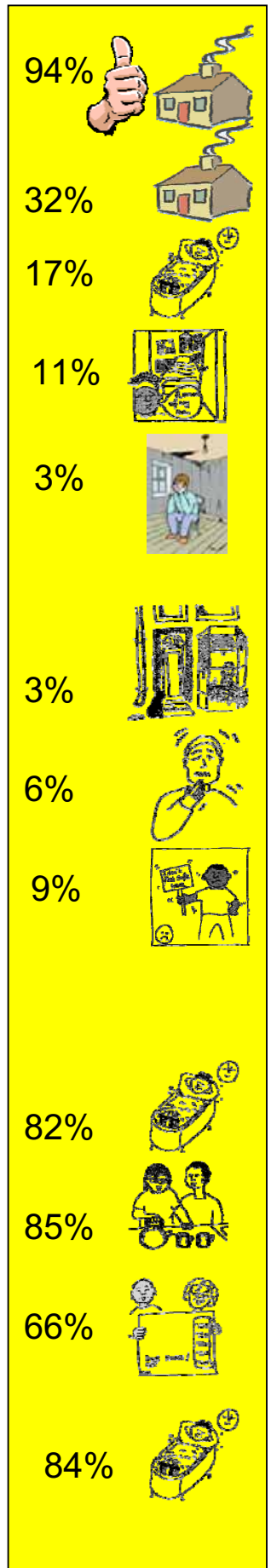
We also asked people about whether they felt safe at home at night and felt safe in the local area. A few people (3%) living in supported accommodation did not feel safe in their home at night. A few more (6%) did not feel safe in the local area. When the person with learning difficulties answered this question nearly one in ten (9%) said that they did not feel safe in the local area.

## Sharing & House Rules

We asked people in supported accommodation about whether they had to share rooms (e.g., bathrooms) and about any house rules. We also asked them about how happy they were about sharing.

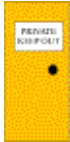
- Most people in supported accommodation had to share a bathroom (82%) and a kitchen (85%).
- People said that two out of three homes had some kind of house rules (66%).

Most people with learning difficulties said they were happy about sharing a bathroom (84%), sharing a kitchen (93%)



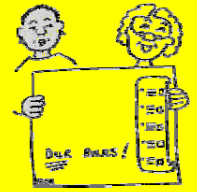
and the house rules (91%). When these questions were answered by a support person, they also said that the person with learning difficulties was happy about sharing a bathroom (90%), sharing a kitchen (95%) and the house rules (94%).

## Privacy



We asked people about their privacy.

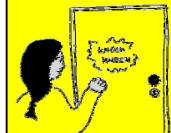
- Nearly one in six people (15%) said that someone sometimes comes into their home without asking.
- Nearly one in five people (18%) said that someone sometimes comes into their room without asking, or when they did not want them to. They said this was most likely to be someone they lived with (60% of those who said this happened), a paid support worker (40%) or a relative or friend they didn't live with (4%).
- Most people said they could be alone with people who come to visit them (93%) and that they could be alone as much as they liked (93%).
- Just over one in five people (22%) said that sometimes people opened their letters without asking them.



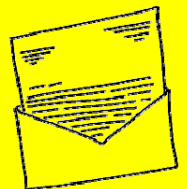
91%



15%



18%





# Suitability and Privacy



This section is about people living in private households and people living in supported accommodation.

## *Suitability*

When we studied all the answers to the questions we decided that the person's accommodation may be unsuitable if people said that any of the following things were true:

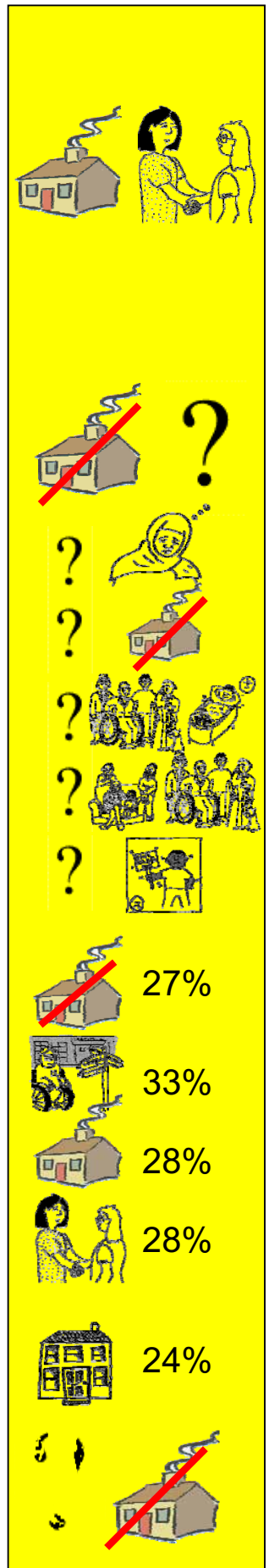
- The person was unhappy where they were living
- The support person said the house was unsuitable
- The person has to share a bathroom or kitchen and did not like sharing
- We were told the house was too crowded, cold, or needed a lot of repairs
- The person did not feel safe at night or in the area

Overall, we found that over one in four people (27%) may be living in unsuitable accommodation. This included:

- 33% of people in NHS accommodation
- 28% of people living in private households
- 27% of people supported under the Supporting People programme
- 24% of people in Registered Residential Care Homes

Next we looked at whether some people were more likely to be living in unsuitable accommodation. People were more likely to live in unsuitable accommodation if (in order of importance) they:

- were poor<sup>12</sup>



- lived in a deprived neighbourhood<sup>13</sup>
- had poor general health<sup>14</sup>
- were younger.

## Privacy



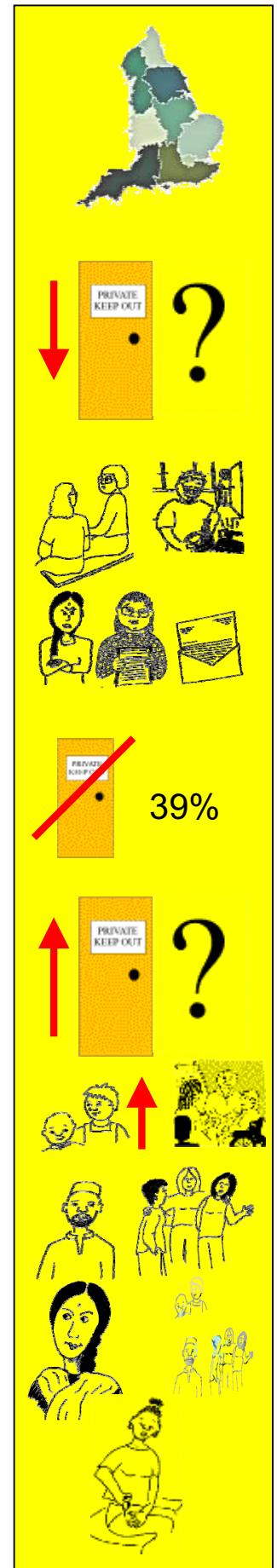
When we studied all the answers to the questions we decided that the person may not have enough privacy if people said that any of the following things were true:

- Someone sometimes comes into their room without asking, or when they did not want them to
- They could not be alone with people who come to visit them
- People opened their letters without asking them.

Overall, we found that over one in three people (39%) did not have enough privacy.

Next we looked at whether some people were more likely to have less privacy than others. People were likely to have less privacy if (in order of importance) they:

- Had higher support needs
- Were younger
- Did not live alone
- Were a man
- Lived in a more deprived neighbourhood
- Were from a minority ethnic community (especially Asian)
- Had a long-standing illness or disability



# Work



We were not surprised at so few people being in work. In our experience this is because of poor information and support (only about half of people in work or looking for a job had support). The survey also showed that it is because people don't think they can work or will get a job. Fear of losing benefits is also an important reason why people with learning difficulties haven't got a job. We were very surprised that people didn't say more about benefits and work.

Ian Davies & Karen Spencer

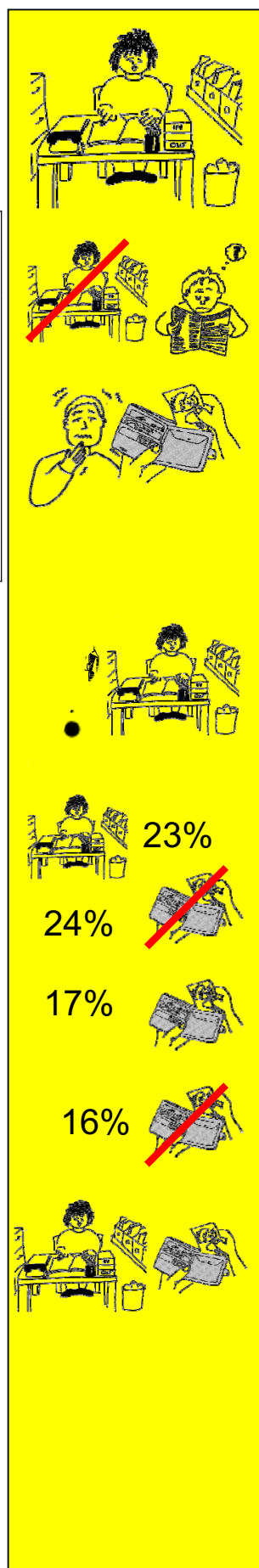
We asked people who were of 'working age' whether they had a job.<sup>15</sup> If they did, we then asked them about their job. If they didn't have a job we asked them whether they would like a job.

- Just under one in four people (23%) said they had a job. Of these, one in four (24%) said they did not get paid for working.
- This means that about one in six people with learning difficulties (17%) had a paid job and that about one in twenty people with learning difficulties (6%) had an unpaid job.

## Paid Employment



About one in six people with learning difficulties had a paid job (17%). This is much less than people in the UK in general. Figure 11 shows the percentage of men and women with learning difficulties (with high, medium and low support needs) who had paid jobs, and the percentage of men and



women in general in the UK who had paid jobs in 2004.<sup>16</sup> All the figures are about people of working age.

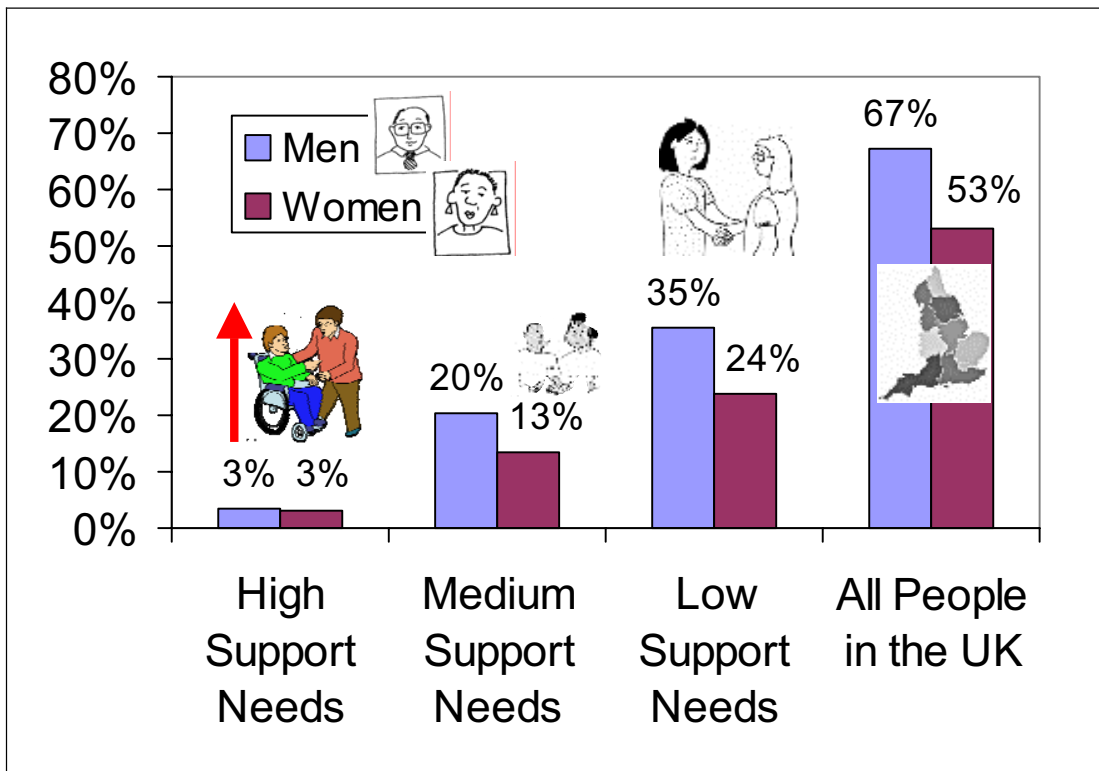
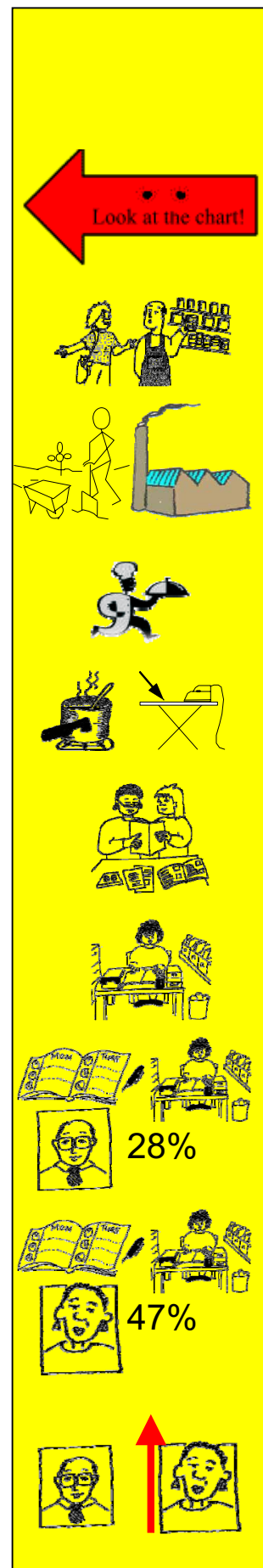


Figure 11: Percentage of Men and Women of Working Age in Paid Work

The types of paid jobs that people had are listed below.

- Shop or warehouse for shop (19%)
- Gardener or labourer (18%)
- Catering/waiting tables (15%)
- Factory or assembly line (15%)
- Domestic work (14%)
- Apprentice/trainee (3%)
- Office work (2%)

Many people worked part time. Over one in four men (28%) and nearly half of women (47%) who had a paid job worked for less than 16 hours a week. These rates of part-time work are much greater than for men (4%) and women (15%) in



general in the UK. Figure 12 shows the percentage of men and women with learning difficulties (with high, medium and low support needs) who worked for 16 or more hours a week in paid jobs, and the percentage of men and women in general in the UK who worked for 16 or more hours a week in paid jobs in 2004.<sup>17</sup>

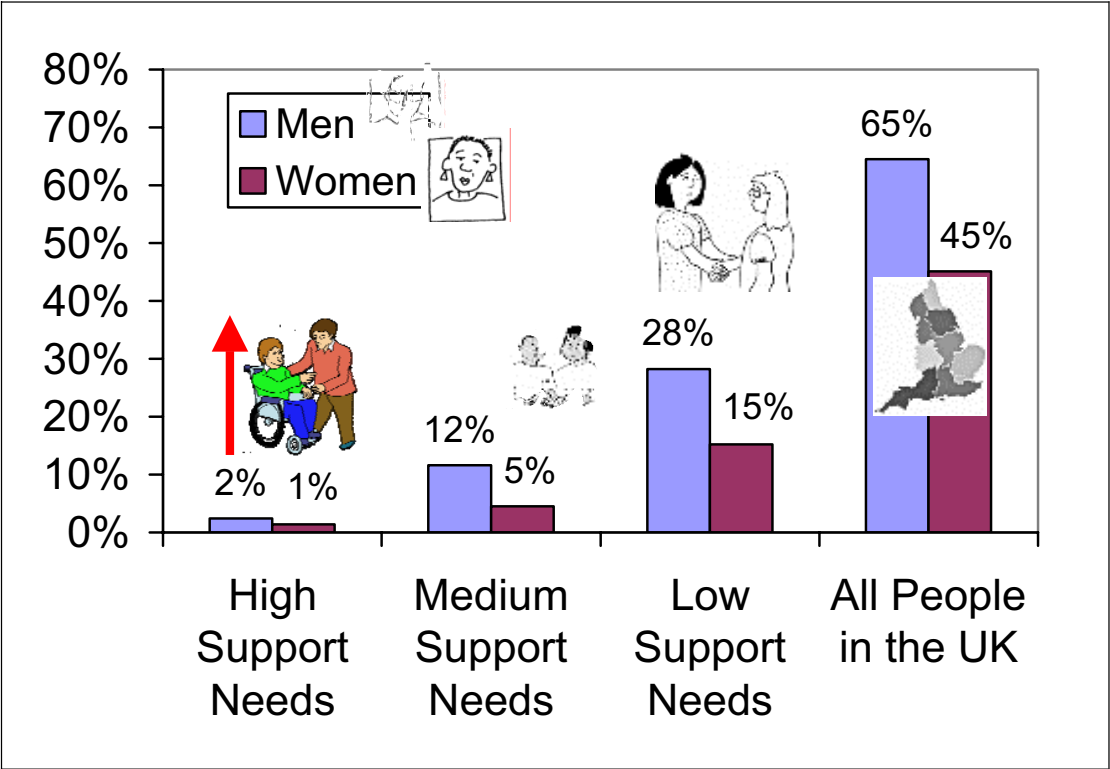
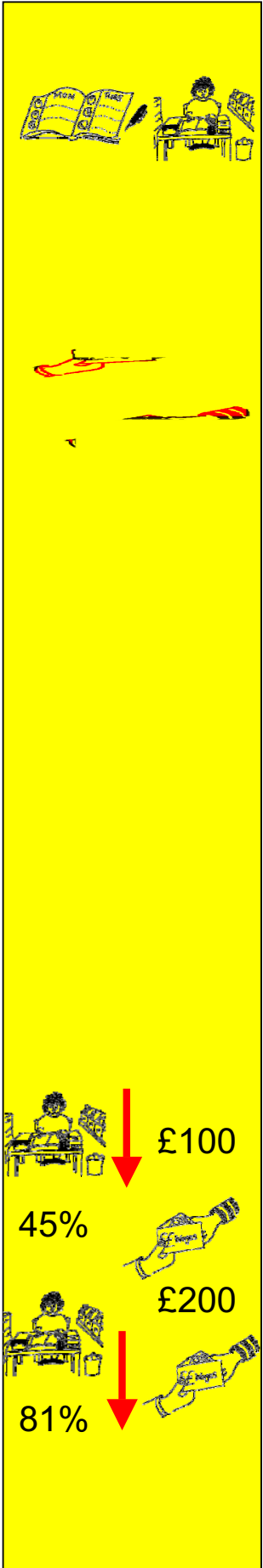


Figure 12: Percentage of Men and Women of Working Age Who Worked for 16 or More Hours a Week and Were Paid for This

Of the people who were paid for the work they did, approximately half (45%) earned less than £100 a week and just over four in five (81%) earned less than £200 a week. One in twenty people (4%) said that their money was not paid to them, it was paid to someone else.





Some people (16%) said that they lost some benefits when they started working. Most of them (77%) said that it did not cause them any problems.

Nearly everybody (92%) liked their job. Three in four people (76%) said they chose their jobs. One in five people (21%) said they would like to work longer hours, a few people (5%) said they would like to work fewer hours. Some people (13%) said they had been bullied at work.

We looked at whether some people were more likely to get a paid job than others.<sup>18</sup> Below we have listed the things that are related to people getting a paid job. The list begins with those things that are most important and finishes with those things that are less important. People were more likely to have a paid job if they:

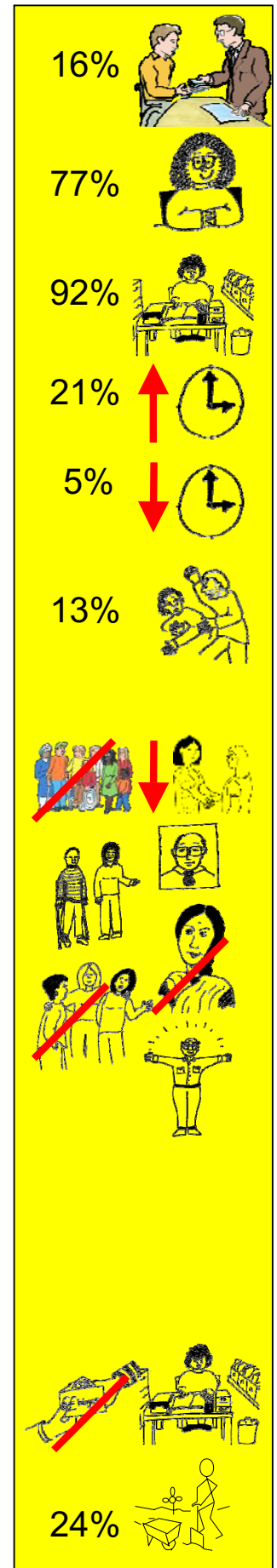
- Had lower support needs
- Did not have a long-standing illness or disability
- Were a man
- Lived with fewer people
- Saw friends who had learning difficulties less often<sup>19</sup>
- Were White
- Lived in an area with higher employment
- Had good general health
- Saw friends who did not have learning difficulties more often

## Voluntary Work



About one in twenty people with learning difficulties (6%) had an unpaid job. The types of unpaid jobs that people had are listed below.

- Gardener or labourer (24%)



- Catering/waiting tables (17%)
- Factory or assembly line (17%)
- Shop or warehouse for shop (16%)
- Domestic work (10%)
- Apprentice/trainee (2%)
- Office work (1%)

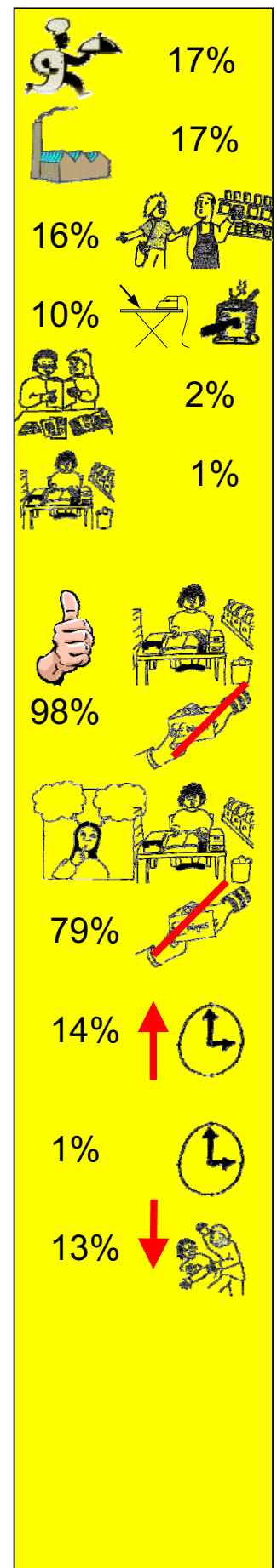
These are very similar to the kinds of paid jobs that people with learning difficulties had.

Most people worked part time. Nearly two out of three people (60%) worked for less than 16 hours a week. Just over one in ten people (11%) worked for more than 30 hours per week in a voluntary job.

Nearly everybody (98%) liked their voluntary job. Nearly four out of five people (79%) said they chose their jobs. One in six people (14%) said they would like to work longer hours, a few people (1%) said they would like to work fewer hours. Nearly one in five people (21%) said they had been bullied at work.

We looked at whether some people were more likely to have a voluntary job than others. Below we have listed the things that are related to people getting a voluntary job. The list begins with those things that are most important and finishes with those things that are less important. People were more likely to have a voluntary job if they:

- Had lower support needs
- Saw friends who had learning difficulties more often
- Were not poor
- Were older



# Looking for a Job

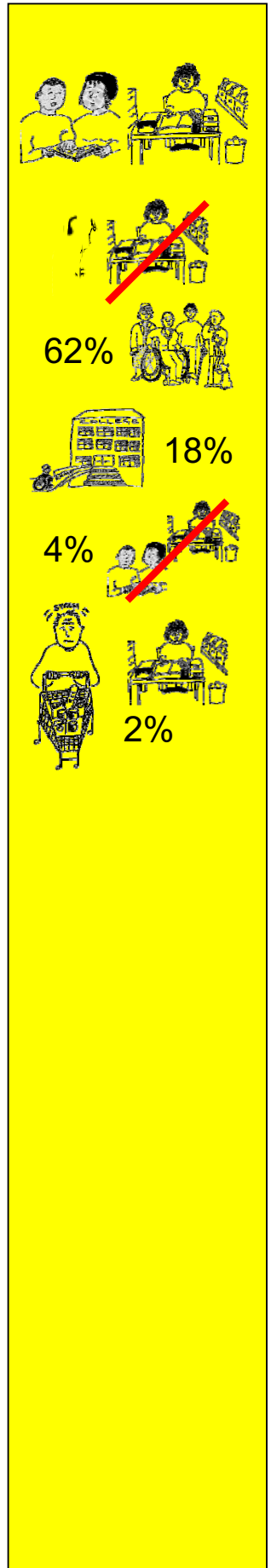


If people were unemployed, we asked them why they did not have a job. The reasons people gave are listed below.

- Cannot work or nobody would employ them because they have a disability (62%)
- Attending school or college or a day centre (18%)
- Looking, but can not find a job (4%)
- Doesn't want a job (2%)

We asked all the people who did not have a job whether they would like a job. Nearly two out of three (65%) said they would like a job.

We look at the support people received to get a job in the last section of the report.



# Education and Training

It is sad but true that there is so much bullying in schools. The survey also shows how for people with learning difficulties it goes on in later life. It affects people badly, has on-going effects and more action to tackle it is needed. Bullying is one of the things that people with learning difficulties have always spoken up about.

In our experience the potential of people with learning difficulties has been missed. Training and education of people with learning difficulties is not linked to work. The survey shows that there is a gap in training directly linked to employment opportunities, including workplace training.

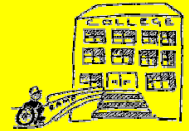
Ian Davies & Karen Spencer

We asked about different types of education and training. We asked people about:

- the school that they went to when they were children
- whether people were going to college at the moment
- whether they were doing any training courses at the moment
- whether they went to a day centre.

## Schooldays

Overall, nearly three in four people (72%) went to a special school, one in ten (10%) went to a special unit in a mainstream school and just under one in five (18%) went to ordinary classes in mainstream school.



72%



10%



These figures changed a lot with the age of the person we interviewed. This is shown in Figure 13. These changes are probably due to changes in the way people with learning difficulties have been educated. It was only in 1971 that children with severe learning difficulties had a right to an education in England.

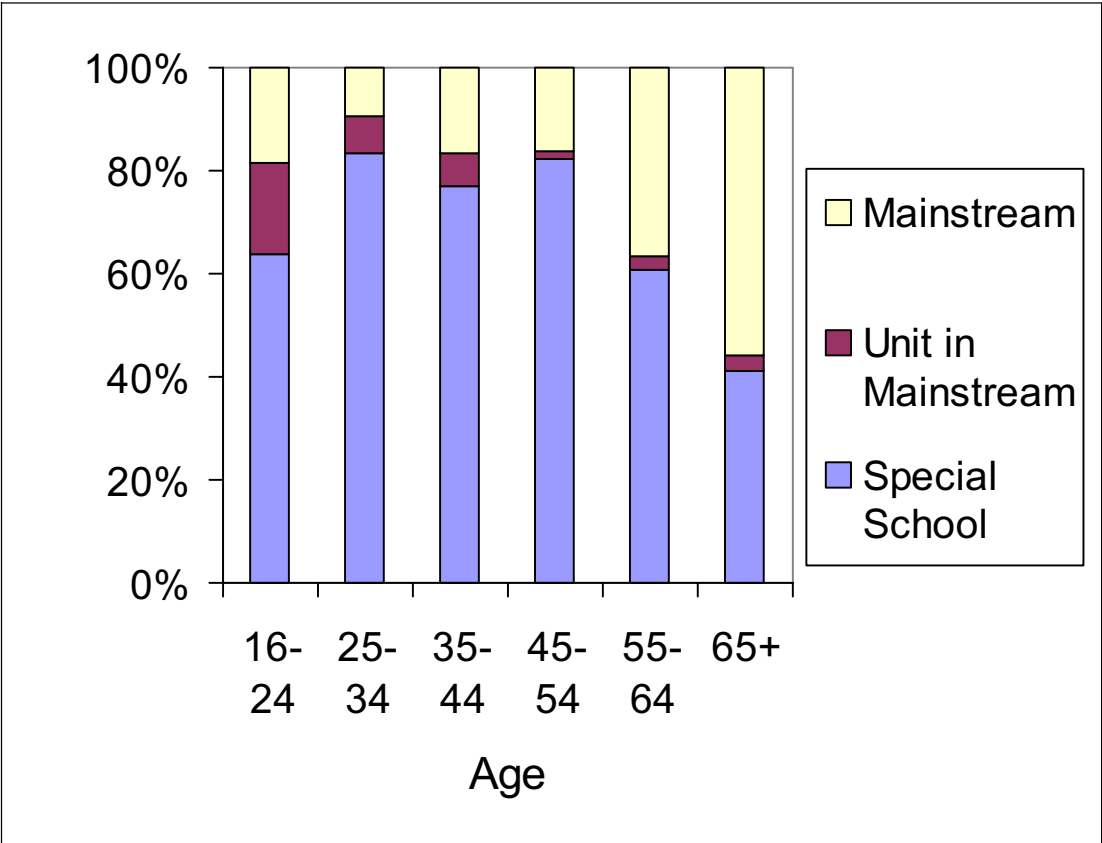


Figure 13: The Percentage of People in Each Age Group Who Went to Special School, a Special Unit in a Mainstream School or a Mainstream School Mainstream

We wanted to know whether some people were more likely than others to have gone to a special school. Because the Government has made lots of changes to the way special schools are used, we just looked at this for people under 30 years old.<sup>20</sup>



There were only two things that were associated with having gone to a mainstream school: being younger and having lower support needs.

We asked people whether they liked school. Overall, three out of four people (75%) said they did like school. We looked for things that predicted whether people said they enjoyed school.

The following list starts with the things that were most important and ends with the things that were least important. People were more likely to say they enjoyed school if they:

- had not been bullied at school
- went to a special school
- were not poor
- did not live in a more deprived area
- were Asian.

Nearly half of the people we talked to (43%) said they had been bullied at school. We looked for things that predicted whether people said they had been bullied at school.

The following list starts with the things that were most important, and ends with the things that were least important. People were more likely to say they had been bullied at school if they:

- were younger
- went to a mainstream school (especially a special unit in a mainstream school)
- had lower support needs
- had a long-standing illness or disability
- had poor health
- were women
- were poor
- lived in more deprived areas





We asked people what type of school they would have preferred to go to. Overall, people said that they would prefer to go to the same type of school that they attended. Three out of four (72%) people who went to a mainstream school said they would prefer to go to a mainstream school. Four out of five (81%) people who went to a special school said they would prefer to go to a special school.

Finally, we asked people about what qualifications they got while at school. Because exams and qualifications have changed so much, we only looked at what younger people (aged under 25) told us. Overall, just under half (43%) of people said they had left school with at least one qualification. The most common qualifications younger people left school with were

- GCSEs (gained by 19%)
- NVQs (12%)
- City & Guilds (4%)
- Asdan (3%)
- A certificate (3%)

## Current Education and Training

In the survey we talked to 928 people who were under 25 years old. Just over half (52%) of these people were attending school or college.

Over one in three people of all ages (36%) said they were currently doing some kind of course or training. Of the people who were not doing a course, nearly half (40%) said they would like to do one.

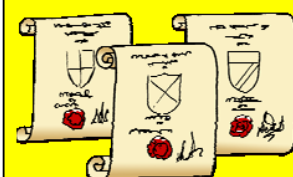
- Colleges (74% of people taking courses)
- At a day centre (22%)
- At work (5%)



72%



81%



52%



The most common places people were taking courses were

- Colleges (74% of people taking courses)
- At a day centre (22%)
- At work (5%)

The most common types of courses people were taking were:

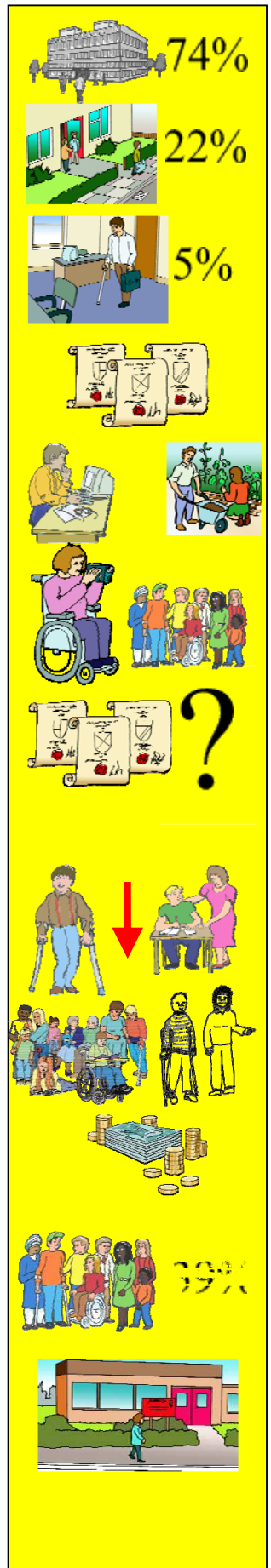
- Life skills (26%)
- Arts, craft or drama (24%)
- Information technology or typing (19%)
- Literacy and numeracy (15%)
- Farming, gardening or horticulture (9%)
- Caring (2%)

We wanted to know whether some people were more likely than others to be doing a course. The following list starts with the things that were most important, and ends with the things that were least important. People were more likely to be doing a course if they:

- were younger
- had low or moderate support needs
- did a wider range of community-based activities
- saw friends with learning difficulties more often
- were not poor
- did not have a paid job
- saw friends who did not have learning difficulties less often

## Day Centres

We asked people about going to day centres. Just over one in three people (39%) said they went to a day centre. Of the people who went to a day centre, nearly half (42%) went for five days a week. Of the rest, similar numbers went one, two, three and four days a week.



Nearly everyone (96%) who went to a day centre said they liked going to a day centre. Nearly everyone (98%) who went to a day centre said the staff were nice and polite to them.

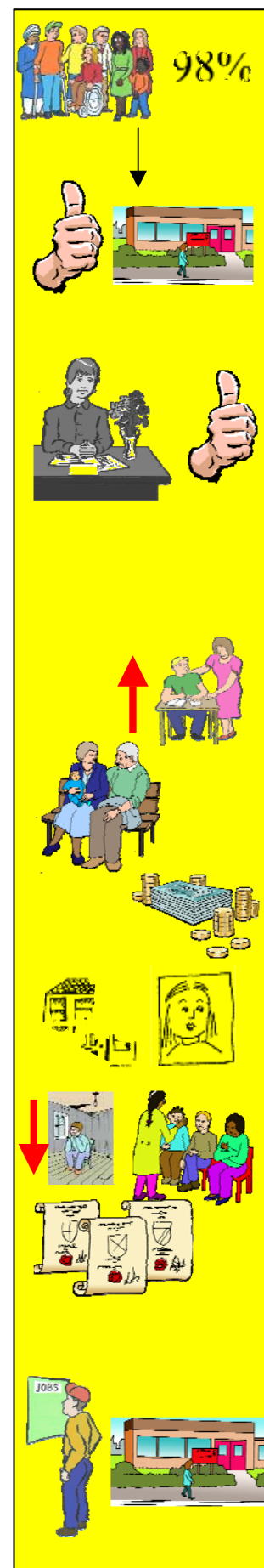
Because it is often difficult for others to know what people really like, we looked at how happy people were when the answers were only given by people with learning difficulties. They were just as positive. Nearly everyone (96%) who went to a day centre and could tell us about it said they liked going to a day centre. Nearly everyone (98%) who went to a day centre and could tell us about it said the staff were nice and polite to them.

We wanted to know whether some people were more likely than others to go to a day centre. The following list starts with the things that were most important, and ends with the things that were least important. People were more likely to go to a day centre if they:

- had higher support needs
- were older
- were not poor
- lived in residential care or a *Supporting People* scheme
- were women
- lived in a less deprived area
- were Asian

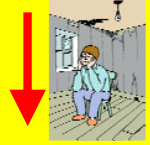
## Work, Training & Day Centres

Finally, we looked at whether people either had a job or were doing a course or went to a day centre. Just under one in three people (29%) did none of these things. A small number of people (3%) did all three.



We wanted to know whether some people were more likely than others to have a job, go to a day centre or be doing a course. The following list starts with the things that were most important, and ends with the things that were least important. People were more likely to have a job, go to a day centre or be doing a course if they:

- Were not poor
- Lived in a less deprived area
- Did not live in NHS accommodation
- Did not live alone



# Money



Being poor is a very important reason why people with learning difficulties can't have choice, be independent and have control of their lives. The survey shows how big an issue this is. Too many people who choose to live independently are poor. Things such as not being able to go on holiday, not having new clothes, not being able to go out and being able to go for a pint really affects our lives.

In our experience as people with learning difficulties Direct Payments for our support should help. People need support with Direct Payments. We need to be careful that this support is not used as a way of controlling people with learning difficulties. The survey shows that this is an issue too.

Ian Davies & Karen Spencer

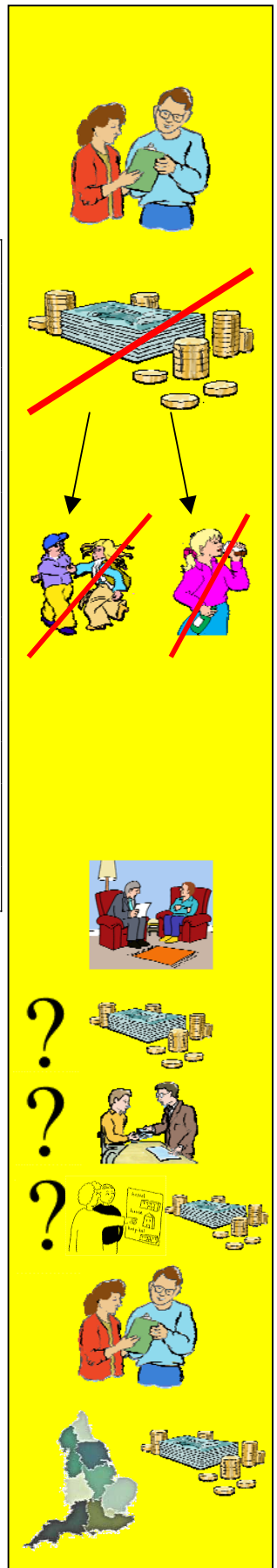
In this part of the interview we asked people about:

- whether they had enough money to pay for things they might want
- the benefits they received
- the control they have over their money.

## Poverty & Hardship

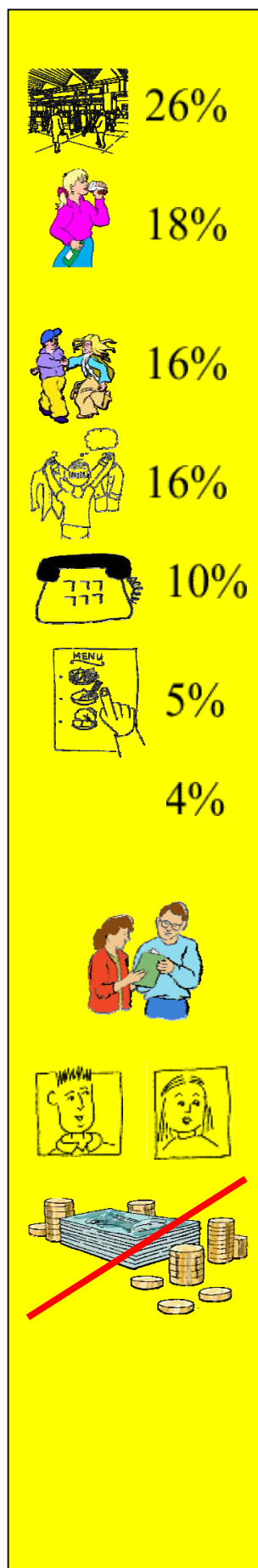


First we asked people whether they could afford nine things that people in England think people should be able to have<sup>21</sup>. The things that people could not afford are listed below. The list starts with the things that more people cannot afford, and finishes with the things less people cannot afford.



- A holiday (26%)
- Going to the pub or club (18%)
- A hobby or sport (17%)
- Going out (16%)
- New clothes (16%)
- New shoes (15%)
- Telephoning friends and family (10%)
- Food (5%)
- Heating (4%)

A similar list of items was included in the *Millennium Poverty and Social Exclusion Survey* (PSE survey).<sup>22</sup> Figure 14 shows the percentage of adults (aged 16+) with learning difficulties in our survey and the percentage of adults (aged 16+) in the PSE survey who could not afford particular things.





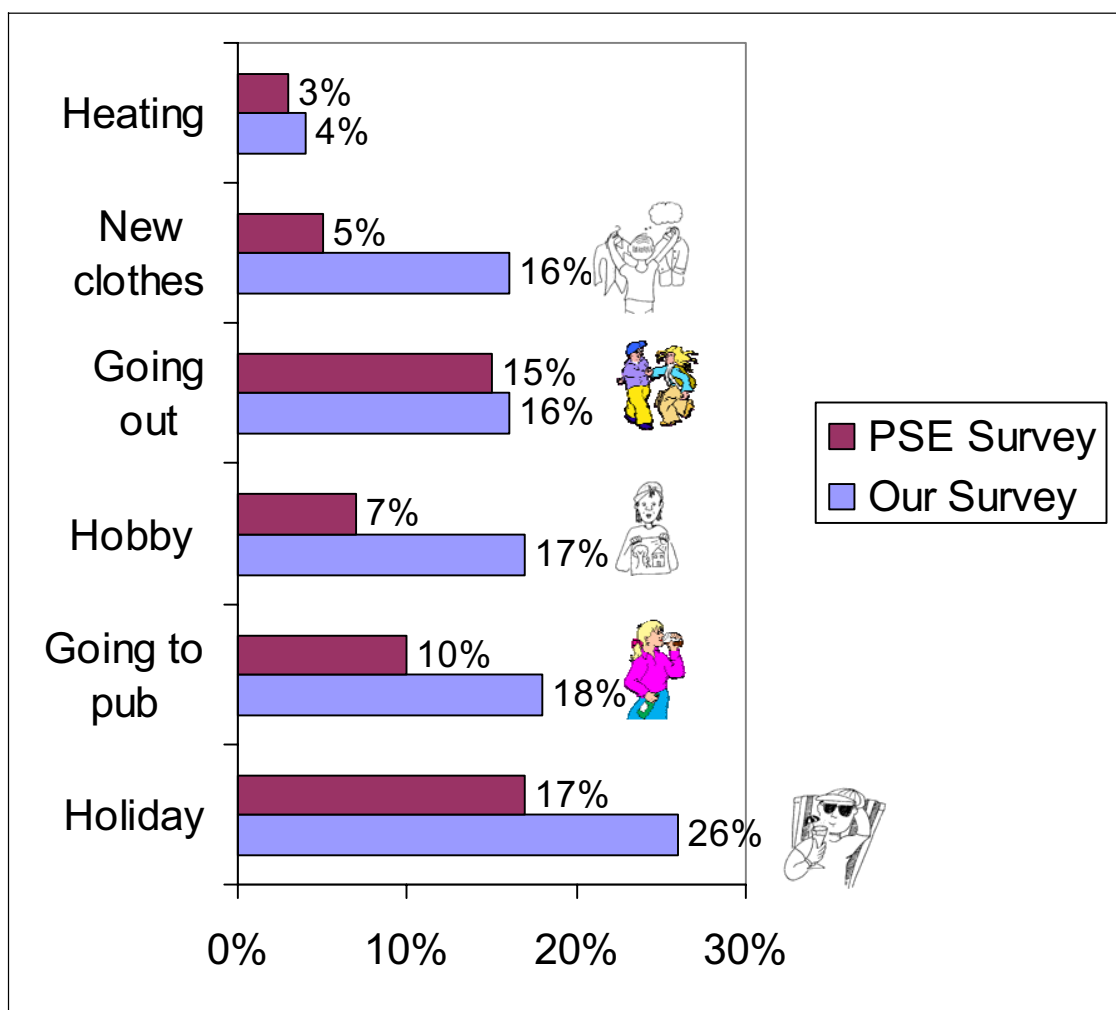


Figure 14: Percentage of People Who Want But Cannot Afford Items in Our Survey and the 2000 PSE Survey

Figure 15 shows that people with learning difficulties are much more likely not to be able to afford things than people in general.

More than one in three people (38%) in our survey could not afford at least one of these things.

When we studied all the answers to the questions we decided that people were poor if they could not afford two or more of these things. This meant that we thought that just under one in four people were poor (23%). We wanted to find out which people were more likely to be poor.<sup>23</sup> The

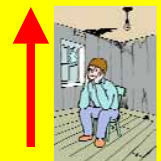
Look at the chart!

38%

following list starts with the things that were most important and ends with the things that were least important. People were more likely to be poor if they:

- had lower support needs
- had poor general health
- lived in private households
- lived alone
- were Black or Asian
- lived in more deprived areas
- were younger

Figure 15 shows the percentage of people who could not afford particular things among three groups of adults (aged 16+).



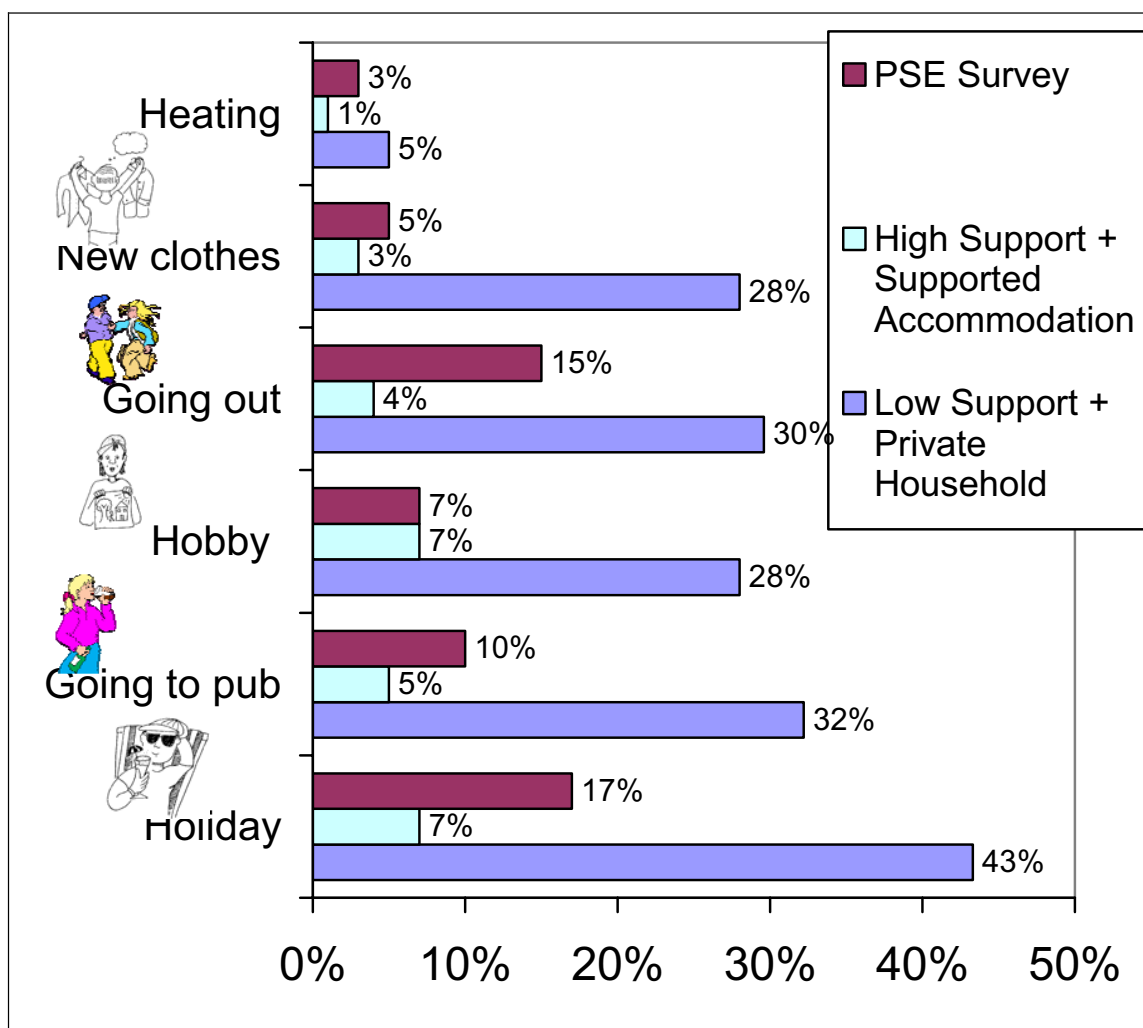


Figure 15: Percentage of Adults with Low Support Needs Who Were Living In Private Households, with High Support Needs and Living in Supported Accommodation and Adults in the PSE Survey Who Want But Cannot Afford Items

This figure shows that people with learning difficulties who have low support needs and are living in private households are much more likely to not be able to afford lots of the things that everyone thinks they should have. It also shows that people with high support needs living in supported accommodation are more likely to be able to afford many of the things that people in England think people should be able to have.



We also asked whether people had enough money to do the things they wanted to do. Nearly half of the people we asked (48%) said they did not have enough money. Nearly everyone we thought was poor (84%) said they did not have enough money.

## Benefits

We asked people about the benefits they received. Most people (89%) said they did receive some benefits. They were most likely to receive

- Disability Living Allowance (70%)
- Income Support (52%)
- Severe Disability Allowance (21%)
- Incapacity Benefit (14%)
- Housing Benefit (13%)
- Mobility Allowance (4%)
- Job Seekers Allowance (3%)
- Attendance Allowance (1%)
- Tax Credit (1%)
- Invalid Care Allowance (<1%)

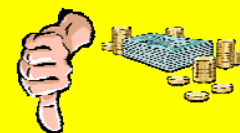
## Direct Payments

We asked people about Direct Payments

- Just over one in three of the people we asked (38%) said they had heard about Direct Payments.
- Of the people who had heard of Direct Payments, over half (60%) had applied for them. This means that just over one in five people (23%) had applied for Direct Payments.



48%



84%



89%



- Of the people who had applied for Direct Payments, most (84%) had received them. This means that just under one in five people (19%) were receiving Direct Payments.

We wanted to find out which people were more likely to be receiving Direct Payments. The following list starts with the things that were most important and ends with the things that were least important. People were more likely to receive Direct Payments if they:

- Had lower support needs
- Did not live in a residential care home or NHS accommodation
- Lived alone or with fewer people
- Had poorer general health

## Control & Support with Money

We wanted to know what control people had over spending their money. We also wanted to know about what support they received.

- Just over half of the people we asked (54%) said someone else decided how much money they could spend each week.
- Just over one in ten (12%) said that someone else decided what they could spend their money on.

We wanted to find out which people were more likely to have control over how much they could spend each week. The following list starts with the things that were most important and ends with the things that were least important. People were more likely to have control over how much they could spend each week if they:

84%



?



54%



Had lower support needs

- Had a paid job
- Lived alone
- Were younger
- Lived in a less deprived area
- Had good general health

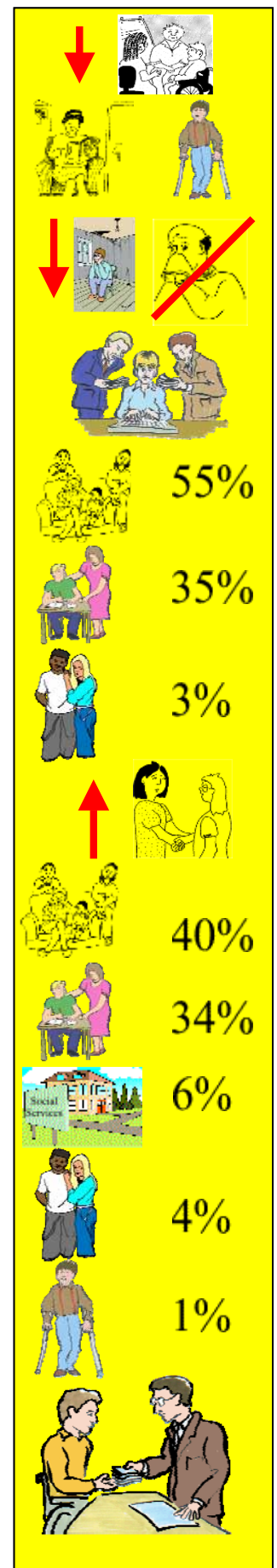
Most people (82%) said they got some help managing their money. They were most likely to get help from

- Their parents (55%)
- Support worker (35%)
- Another relative (10%)
- Their partner (3%)
- A friend (1%)
- Social Services (1%)
- Their child (<1%)

Just over one in ten people (12%) said they would like more support. They would like more support from

- Their parents (40%)
- Support worker (34%)
- Another relative (7%)
- Social Services (6%)
- Their partner (4%)
- Their child (1%)

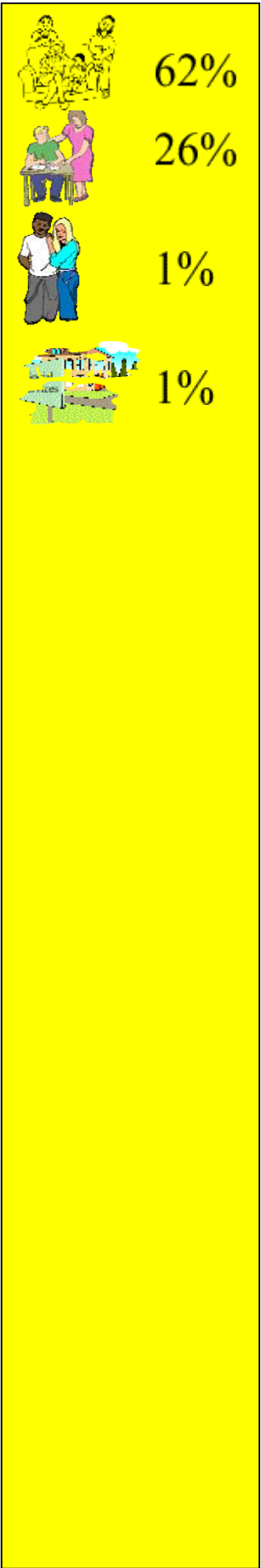
We asked whether people received their benefits themselves or whether someone else received them. Over half of the people we asked (54%) said someone else received their benefits. The people who were most likely to receive benefits were:





Their parent (62%)  
Support worker (26%)  
Another relative (9%)  
Their partner (1%)  
Social services (1%)  
Friend (<1%)

Just over one in ten people (13%) who did not receive their benefits themselves said they would like to receive them.



# Families, Friends and Relationships

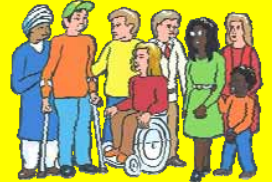
People not seeing their family is a big problem for many of us. The survey shows how big a problem it is. There are lots of reasons for people with learning difficulties not seeing their families including past policies. It is important to make sure that doesn't happen from now on.

Too many parents with learning difficulties don't look after their own children. Most who do live with parents or relatives. In our experience lack of support and poor support is the reason for this unequal treatment happening. This is also true of people with learning difficulties who are carers. The survey shows that half of carers with learning difficulties get no help with caring or want more.

We are worried about how many people with learning difficulties don't see a friend from one year to the next. Friendships need to be encouraged and supported – to help form them and maintain them. This issue is not new to people with learning difficulties. People have spoken up about this over a number of years.

Ian Davies & Karen Spencer

In this part of the interview we asked people about how much contact they had with their family and friends. We also asked people living in private households whether they were a carer for someone else.



## Contact with Families



We asked people who were not living with members of their family how often they saw them.

- One in ten (11%) saw them every day or nearly every day.
- One in three (33%) saw them every week or nearly every week.
- Just over one in three (37%) saw them every year or nearly every year.
- Just under one in five (19%) never saw members of their family.

The same questions were asked in the Millennium Poverty and Social Exclusion Survey (PSE).<sup>24</sup> Figure 16 shows how much contact adults had with members of their family in our survey and the PSE survey.

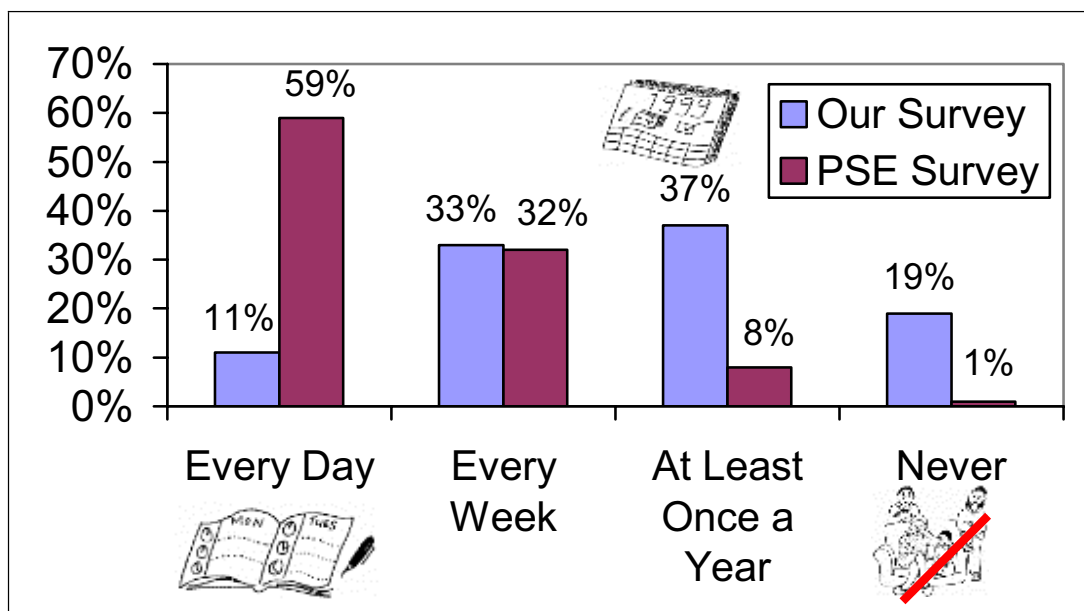


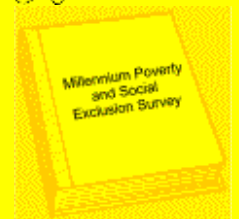
Figure 16: How Much Contact People Had With Members Of Their Family That They Were Not Living With



11%

37%

19%



This figure shows that people with learning difficulties had much less contact with members of their family that they were not living with. It is important to remember, however, that people with learning difficulties were much more likely to be still living with their families.

We wanted to find out which people were more likely to see their families at least (or nearly) every week.<sup>25</sup> The following list starts with the things that were most important and ends with the things that were least important. People were more likely to see their families at least (or nearly) every week if they:

- Lived in a private household or accommodation provided under the *Supporting People* programme
- Were younger
- Lived in more affluent areas

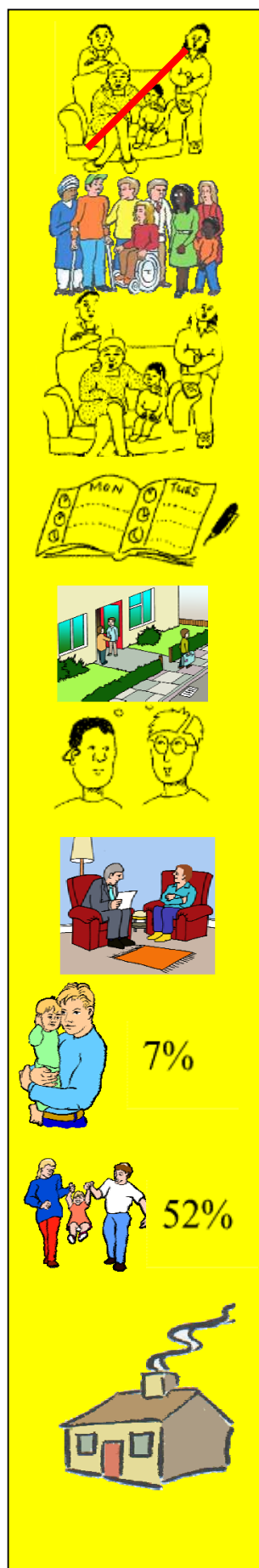
## Caring for Children



One in fifteen of the people we interviewed (7%) had children. Of the people who had children, just over half (52%) looked after their children. Women were slightly more likely to be a parent than men (9% compared to 6%). But men and women were just as likely to be looking after their children if they had any (52% of women, 53% of men).

Nearly all people who were looking after their children were living in private households (98%). Of the people living in private households who were looking after their children:

- Nearly half were living with other relatives (43%)
- Just over one in three were living with partners (34%)
- Nearly one in seven were living with their parents (15%)
- a few (8%) were living alone.



Over two in three people (70%) were very happy looking after their children. Just over one in five were quite happy looking after their children (22%). A few (9%) were not happy looking after their children.

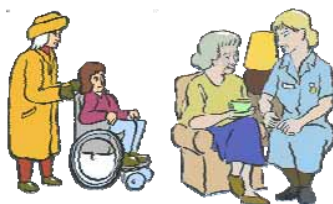
Most people (81%) had help in looking after their children. The most common sources of help were

- The person's partner (67%)
- The person's parent (21%)
- Another relative (16%)
- A support worker (8%)
- Social Services (7%)
- A friend (4%)

One in five people (21%) would like more help in looking after their children. If they wanted more help, people said they would turn to

- Their parent (34%)
- Their partner (31%)
- Another relative (24%)
- Social services (10%)
- A support worker (4%)
- A friend (4%)

## Caring for Adults



We asked some people whether they helped to care for anyone who was elderly, ill or had a disability. The people we asked were people who were living in private households with other people.



One in four people (26%) said they lived with someone who was elderly, ill or had a disability. We asked these people about whether they helped care for this person.

Over one in three (37%) said they did help care for them. This means that one in ten (10%) people living in private households helped care for another adult who was elderly, ill or had a disability.

They were most likely to be caring for

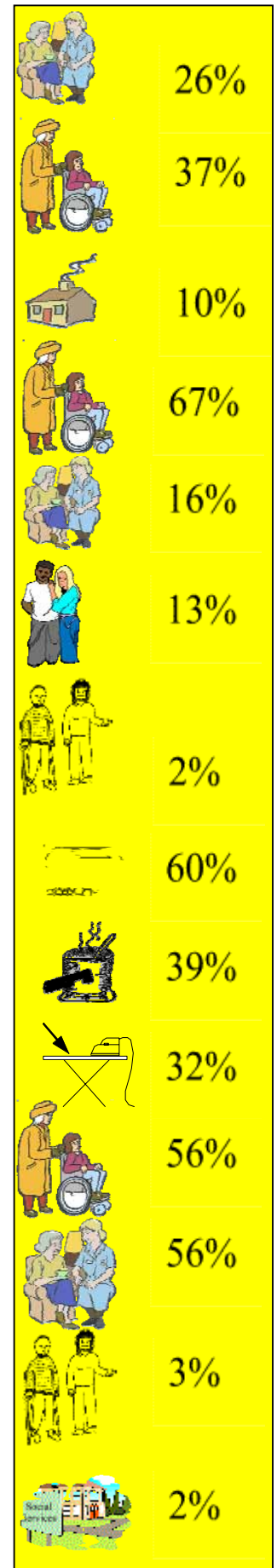
- A parent (67%)
- Another relative (16%)
- Their partner (13%)
- A friend (2%)

The most common caring activities they did were

- Cleaning (60%)
- Shopping (57%)
- Cooking (39%)
- Washing/ironing (32%)
- Personal care (23%)

One in three people with learning difficulties who were also carers (32%) said they did not receive any help with their caring responsibilities. If they did receive help it was likely to be from

- A parent (56%)
- Another relative (56%)
- A friend (3%)
- Social Services (3%)
- A support worker (2%)
- Their partner (2%)





Nearly everyone (98%) said they were quite or very happy with the support they received. But quite a few people (18%) said they would like more support.

We asked people who were carers who they would turn to for help in caring. The most likely people they said they would turn to were

- A parent (43%)
- Another relative (33%)
- Their partner (7%)
- Social services (6%)
- A friend (5%)
- A support worker (4%)

We wanted to find out which people were more likely to be caring for another adult. The following list starts with the things that were most important and ends with the things that were least important. People were more likely to be caring for another adult if they:

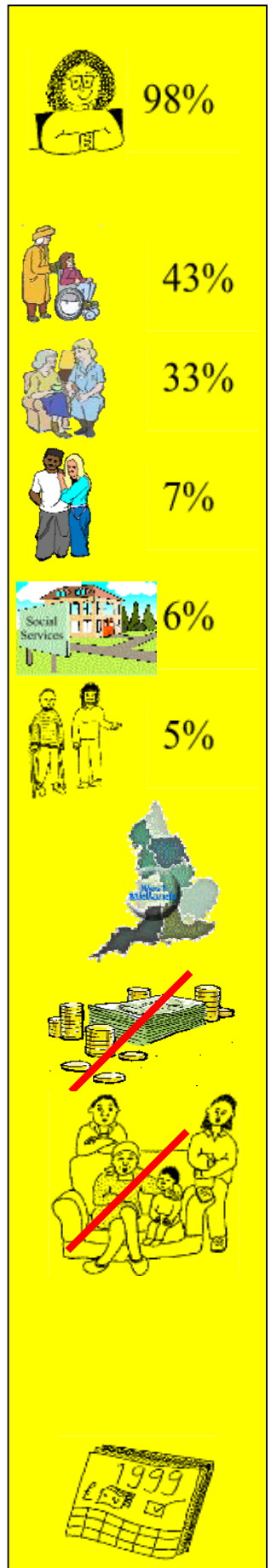
- Had lower support needs
- Lived in more deprived areas
- Were poor
- Were older
- Saw members of their family less often
- Had better general health

## Friends



We asked people if (other than their family) they had friends they liked to talk to or do things with.

Just over two out of three people (69%) had contact with friends at least once a year. Nearly one in three (31%) said



they did not have any contact with friends. One in twenty people (5%) had no friends and also did not see anyone from their family.

- Over two out of three people (69%) saw friends who also had learning difficulties.
- One in four people (25%) saw friends who did not have learning difficulties.

Figure 17 shows how often people saw their friends. It shows that the friend's people saw often were friends who also had learning difficulties.

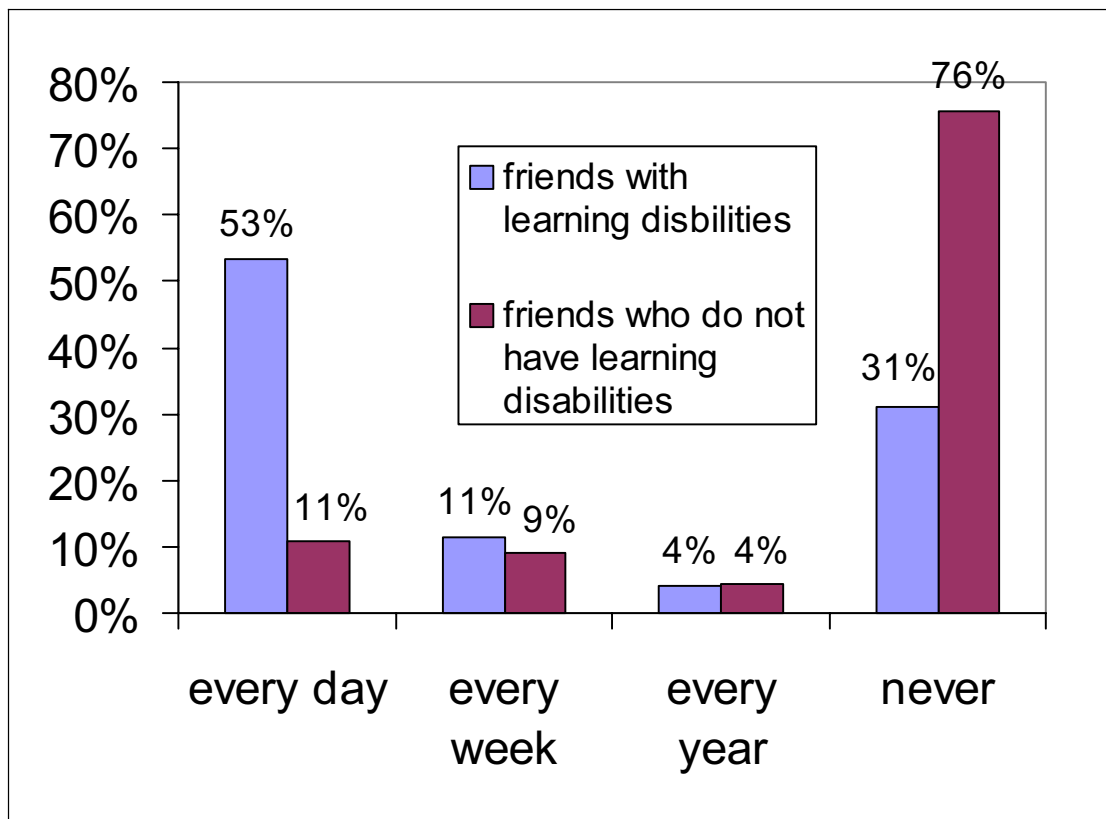


Figure 17: How Often People Saw Their Friends

Questions were also asked in the Millennium Poverty and Social Exclusion Survey (PSE) about how often people had contact with their friends.<sup>26</sup> Figure 18 shows how much



contact adults had with friends in our survey and the PSE survey. In this figure we have combined friends who do and do not have learning difficulties. (The PSE survey just asked about friends in general).

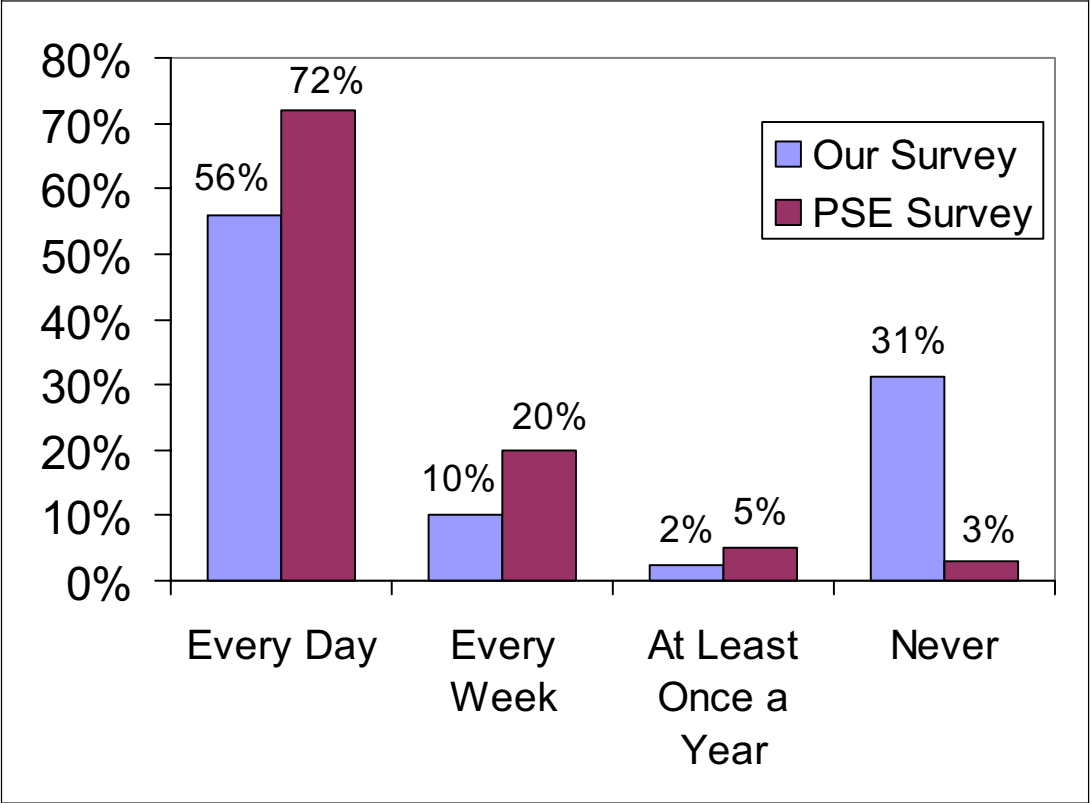
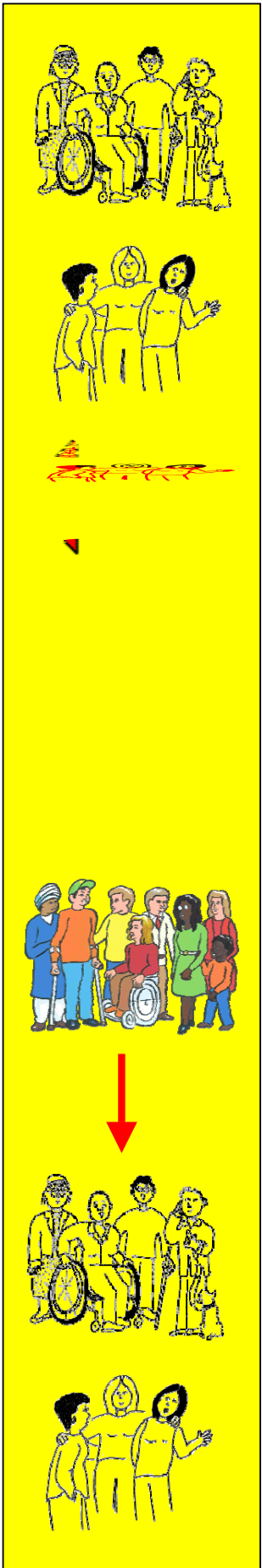


Figure 18: How Much Contact People Had With Friends

This figure shows that people with learning difficulties had much less contact with friends that people in Britain in general. In particular it shows that many more people with learning difficulties have no contact at all with friends than other people in Britain.

We wanted to find out which people were more likely to see their friends who also have learning difficulties at least (or nearly) every week. The following list starts with the things that were most important and ends with the things that were least important.

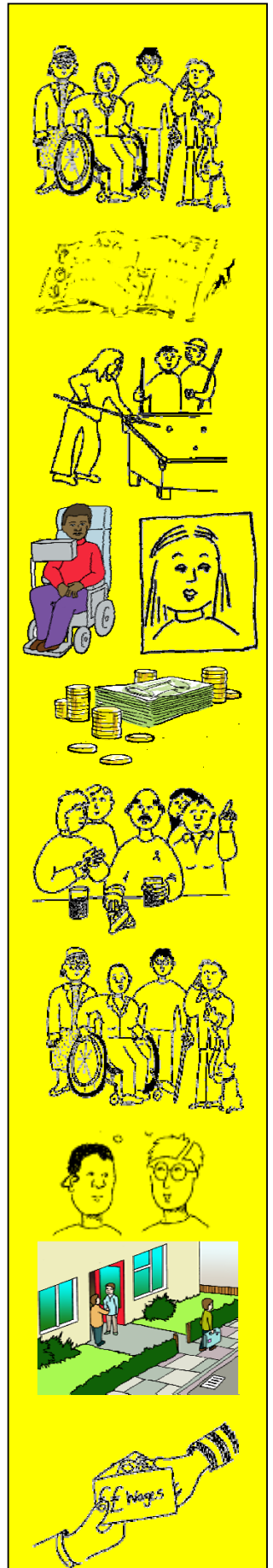


People were more likely to see their friends who also have learning difficulties at least (or nearly) every week if they:

- Saw friends who did not have learning difficulties more often
- Did a wider range of community-based leisure activities
- Lived in either a Registered Residential Care Home or were supported under the Supporting People programme
- Had higher support needs
- Had better general health
- Did not have a paid job
- Were not poor
- Did not have a long-standing illness or disability
- Did not belong to a minority ethnic community
- Were women

We also wanted to find out which people were more likely to see their friends who did not have learning difficulties at least (or nearly) every week. The following list starts with the things that were most important and ends with the things that were least important. People were more likely to see their friends who did not have learning difficulties at least (or nearly) every week if they:

- Saw friends with learning difficulties more often
- Had lower support needs
- Were younger
- Lived in either a Registered Residential Care Home or were supported under the Supporting People programme
- Lived in more affluent areas
- Had a paid job
- Saw members of their family more often



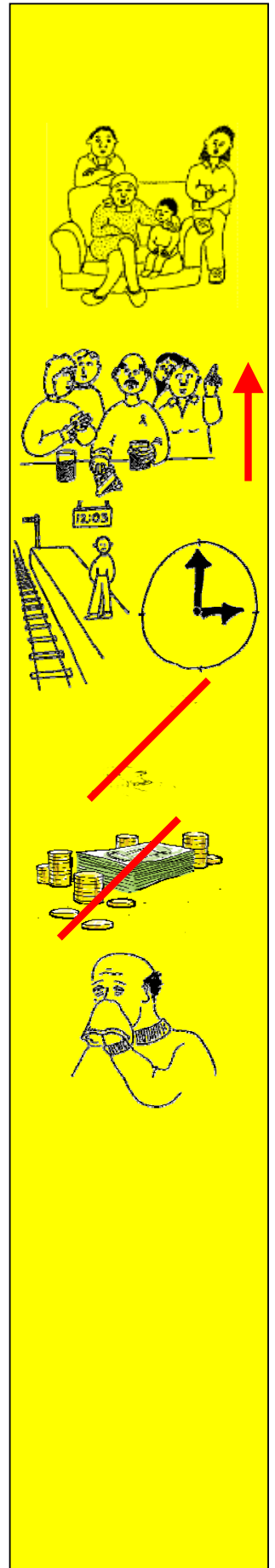
# Barriers to Relationships



Finally, we asked people whether they could see their family and friends as often as they wanted.

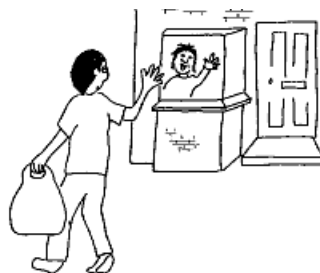
Nearly one in three people (30%) said they would like to see their friends more often. We asked these people what stopped them seeing their family and friends as often as they wanted. The most common things they said were:

- They live too far away or problems with travelling (44%)
- Not enough time (21%)
- Lack of money (13%)
- Not always enough support (11%)
- They or I am too busy (10%)
- Can not get out or too ill (4%)
- Afraid of going out (4%)





# Being Part of the Community



We think that it is good that people do lots of different things. As people with learning difficulties we are often given limited choices over what we do. For example we may be given the choice of going to the cinema or to bowling when we really wanted to go and see our friends. Sometimes our choices are further limited. For example when many people with learning difficulties go to the cinema they go in a large groups which means they don't get to choose which film they watch.

For us and our friends transport is one of the most important things in our lives. Without it we can't do what we want. Most people use public transport and find it difficult to use. We are not surprised that the survey says that so many people had trouble using it and that they don't feel safe. However, it is also expensive for many people with learning difficulties and information, like timetables, are inaccessible, especially when they change. For all these reasons most people need support to use public transport.

It is important that more people with learning difficulties vote. Many people with learning difficulties don't vote because they don't get the support they need to find out about the policies of the different parties and candidates. It is also important to recognise that some people with learning difficulties choose whether to vote or not at different times. Speaking-up, often in a group, is how people with learning difficulties often try to change things. It is also important that people with learning difficulties are involved in all activities which influence our communities





As people with learning difficulties we know that like everyone else we sometimes don't feel safe. What is important in the survey is that it shows how some members of the general public are often rude and offensive to us.

Ian Davies & Karen Spencer

We collected information about:

- the areas that people lived in
- what they did in their leisure time
- their use of transport
- whether they voted and took part in meetings
- how safe they felt
- whether they had been the victim of crime or had been bullied.

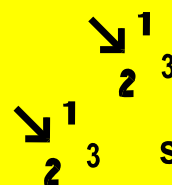
## The Areas People Lived In



We collected information about the kind of areas people lived in. We got this information by using peoples' postcodes. From this we could work out the kind of areas people lived in (from 2001 ACORN codes)<sup>27</sup> and how deprived the areas were (from the English Indices of Deprivation 2004).<sup>28</sup>

ACORN codes describe 57 different types of areas. These range from 'Wealthy executives' to 'Multi-ethnic crowded flats'. These 57 types are grouped into five main kinds of area: 'wealthy achievers', 'urban prosperity', 'comfortably off', 'moderate means' and 'hard pressed'.

We know that different numbers of people live in these different kinds of areas. So we worked out how many people took part in the survey for each 100,000 people who lived in



that kind of area. This tells us whether people with learning difficulties are more or less likely to live in these different kinds of areas. The figure below shows what we found for people with learning difficulties living in general households and in supported accommodation.

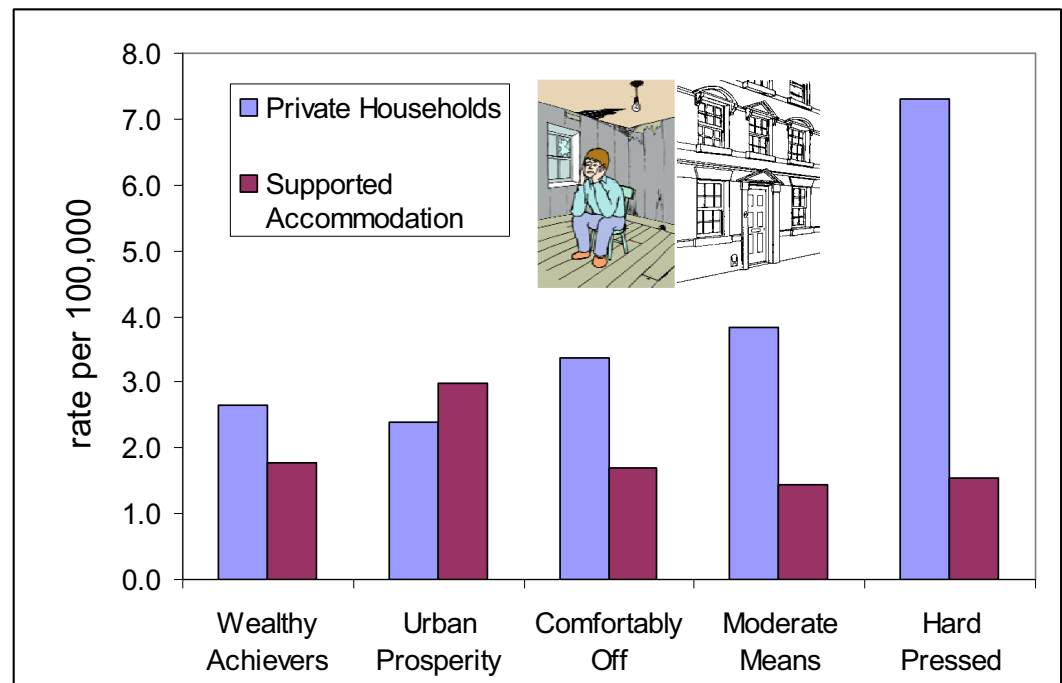
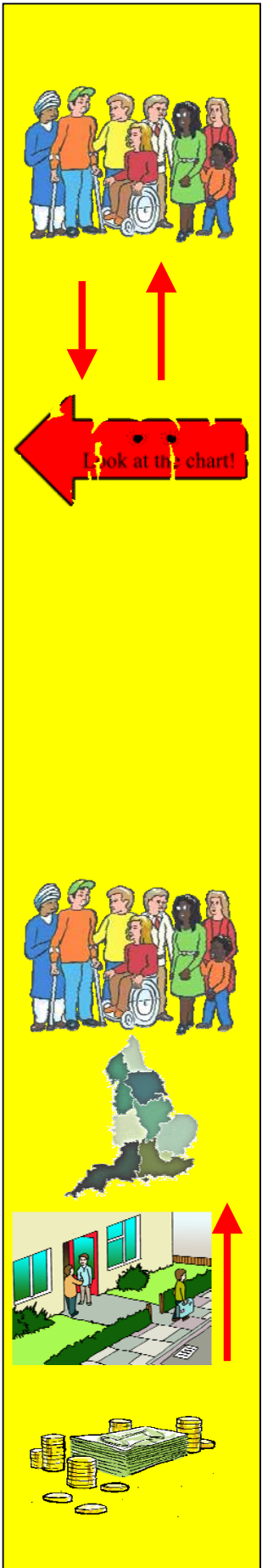


Figure 19: Rate of People with Learning Disabilities we Interviewed per 100,000 of General Population Living in Different Types of Areas

What it shows is that people living in private households are much more likely to live in hard pressed communities than more affluent communities. It also shows that people in supported accommodation were more likely to live in prosperous urban communities than other types of communities.

The English Indices of Deprivation tell us how deprived an area is.<sup>29</sup> We split all the areas in England into 10 groups from the most deprived (number 1) to the richest (number 10). Similar numbers of people live in each of these 10 types

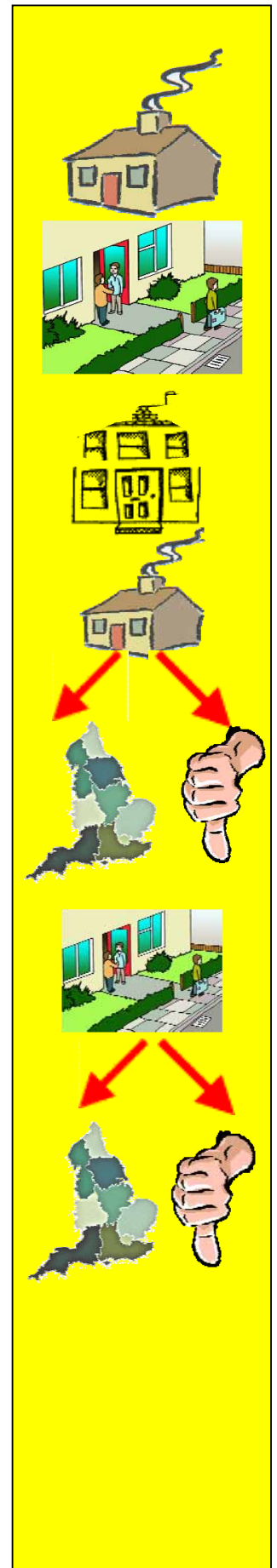


of areas. Figure 20 shows where people who participated in the project lived. It shows this separately for

- people living in private households
- people supported under the 'Supporting People' programme
- people living in Registered Residential Care Homes.

There were too few people living in NHS accommodation for us to work out how deprived an area they were living in.

What the figure shows is that people living in private households and people supported under the *Supporting People* programme were more likely to live in more deprived areas (the columns are above the expected 10% line) and much less likely to live in richer areas (the columns are below the expected 10% line). It also shows that people living in Registered Residential Care Homes were more likely to live in areas that were not too deprived and not too rich.



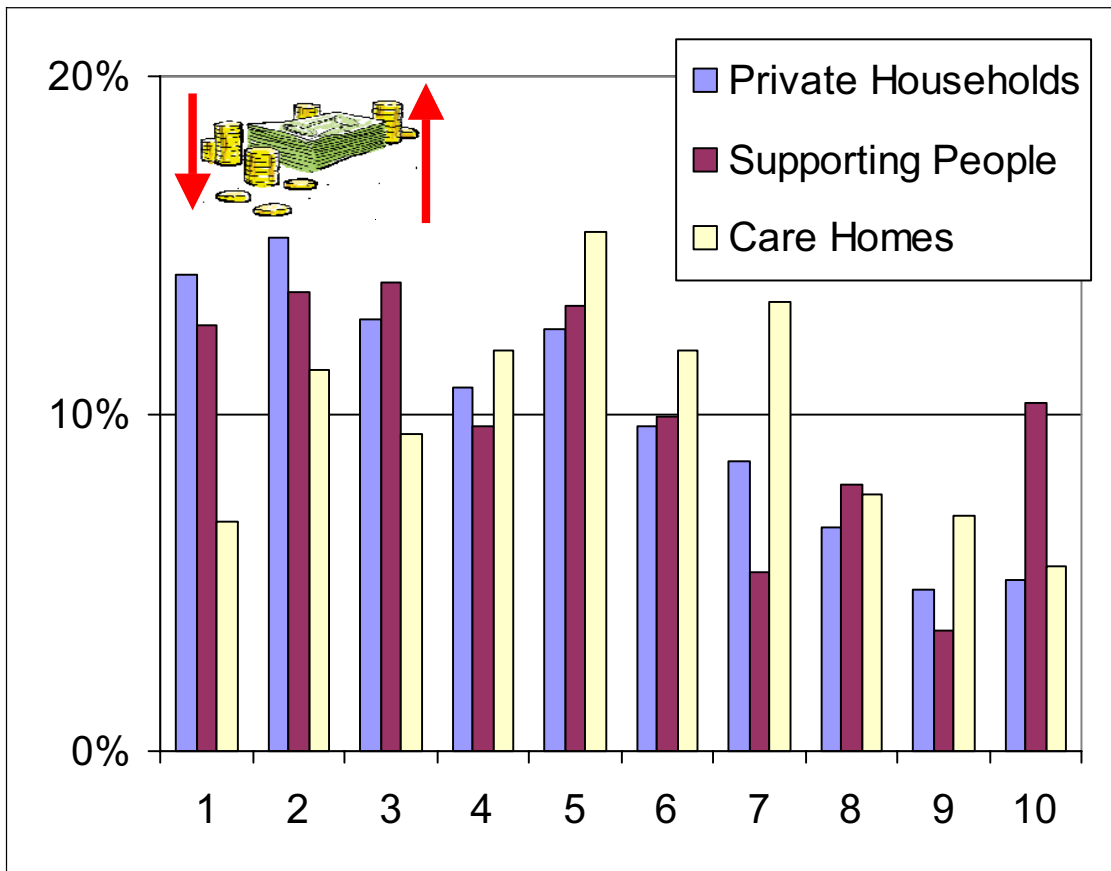


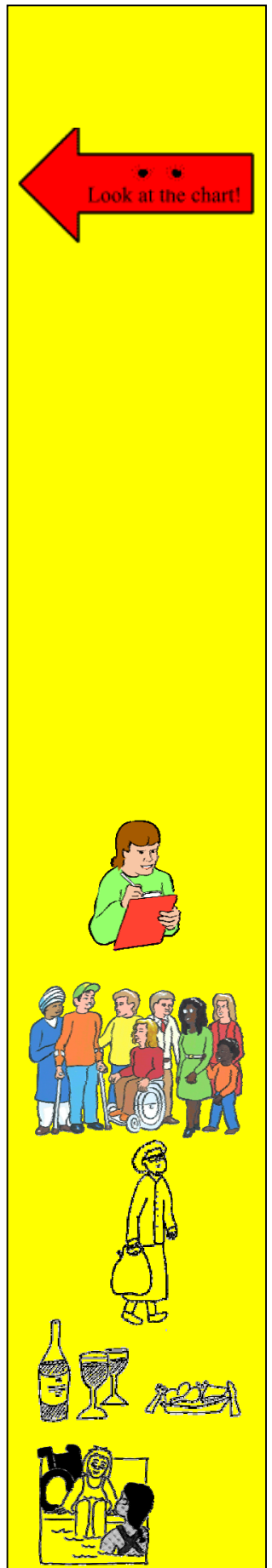
Figure 20: Participants By Level of Deprivation (1 = most deprived, 10 = richest)

## Leisure & Recreation



We asked people about the kinds of things they did in their spare time. We asked whether they had done nine kinds of different things in the last month. From this list they were most likely to have been

- Shopping (87%)
- To visit friends or family (77%)
- For a meal in a restaurant or pub or café (71%)
- To the pub or a club (62%)
- To a hairdresser (59%)
- To play sport or go swimming (41%)



- To the cinema, or to plays or concerts (40%)
- To the library (22%)
- To watch sport (19%)

A few people (5%) had done none or only one of these things. A few people (6%) had done them all, or all but one.

The UK Time Use Survey 2000 asked similar questions for just under 10,000 adults in the UK.<sup>30</sup> In this survey, in the last month

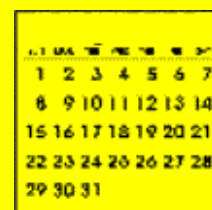
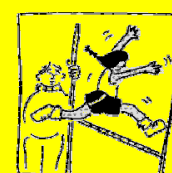
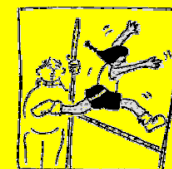
- 15% of people had been to the cinema
- 16% had been to a concert
- 15% of people had been to watch sport.

This suggests that people with learning difficulties are at least as likely to participate in some types of community based activities as people in general.

We also wanted to find out which people were more likely to have done five or more of these things in the last month.<sup>31</sup>

The following list starts with the things that were most important and ends with the things that were least important. People were more likely to have done five or more of these things in the last month if they:

- Saw their friends who also had learning difficulties more often
- Lived in richer areas
- Lived in supported accommodation
- Were younger
- Were not poor
- Did not have a long-standing illness or disability
- Saw their families more often
- Had lower support needs
- Lived with more people



- Had good health
- Saw friends who did not have learning difficulties more often

Over half of the people we talked to (59%) said they had been on holiday in the last year. Three out of four people (75%) said they went out on day trips.

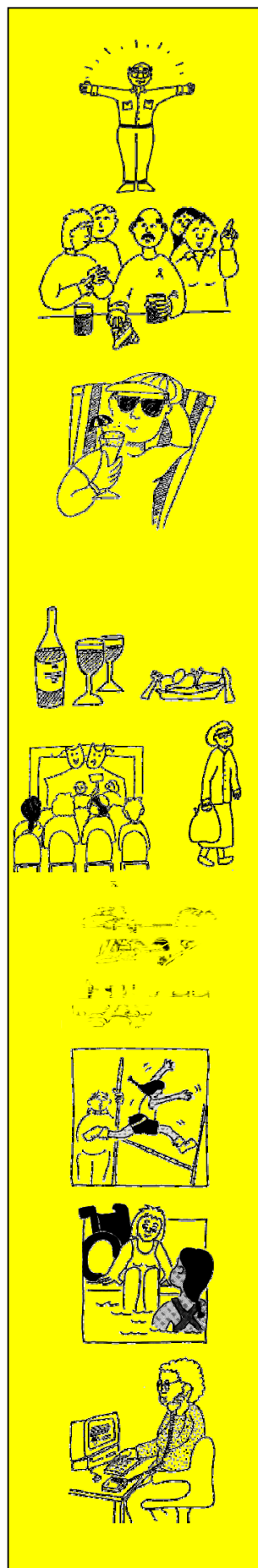
We then asked people whether they liked doing these things. Nearly everyone (at least nine out of ten people) said they enjoyed each of these things.

We then asked people whether they would like to do more of these things. The things they said they would most like to do more often were go:

- For a meal in a restaurant or pub or café (56%)
- To the cinema, or to plays or concerts (47%)
- To visit friends or family (42%)
- Shopping (36%)
- To play sport or go swimming (34%)
- To the pub or a club (27%)
- To watch sport (25%)
- To a hairdresser (23%)
- To the library (18%)

We then asked people what they would like to be different about what they did in the daytime. The things they said they would most like to be different were

- Nothing (26%)
- Go out more (8%)
- Get a job or a different job (7%)
- Do sports (6%)
- Visit people (4%)





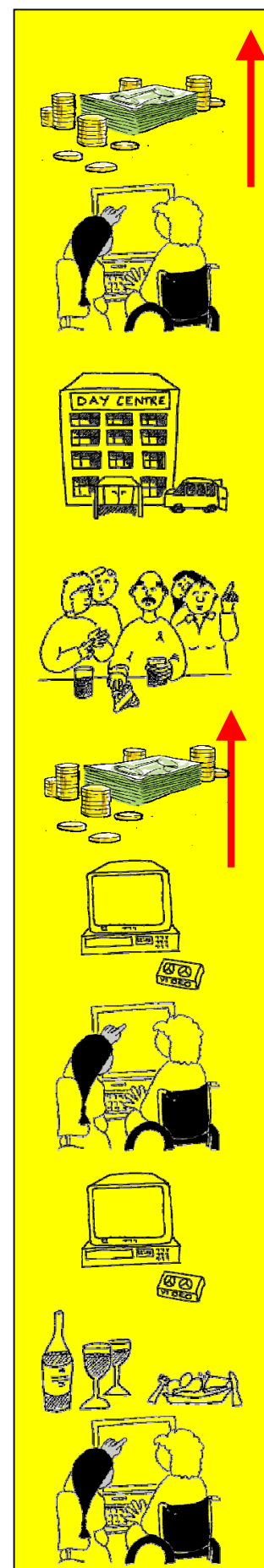
- Generally have more things to do (4%)
- Have money to do things (1%)
- Move on from college/day centre (1%)
- Go shopping (1%)
- Use a computer (1%)
- Go out to pub/meals (<1%)
- Go to day centre more often (<1%)
- Listen to more music (<1%)
- Do more arts/crafts (<1%)

We then asked people what they would like to be different about what they did in the evening. The things they said they would most like to be different were

- Nothing (35%)
- Go out to pub/club/cinema (7%)
- Visit people (5%)
- Go out more (4%)
- Do sports (3%)
- Watch more TV (1%)
- Have money to do things (<1%)
- Use a computer (<1%)
- Listen to more music (<1%)
- Do more arts/crafts (<1%)

Finally, we asked people what they enjoyed doing most in their free time. The things they most enjoyed doing were

- Watching TV/videos (23%)
- Listening to music/singing (19%)
- Going out to pub/club/cinema/café (15%)
- Playing or watching live sport (13%)
- Socialising (12%)
- Using a computer (10%)
- Painting/drawing/crafts (10%)



- Shopping (4%)
- Reading (4%)
- Dancing (2%)
- Cooking (2%)
- Cleaning/tidying up (1%)
- Helping people (1%)
- Having a bath/shower (<1%)

Just over one in three people (34%) said they would like to do their favourite activity more often.

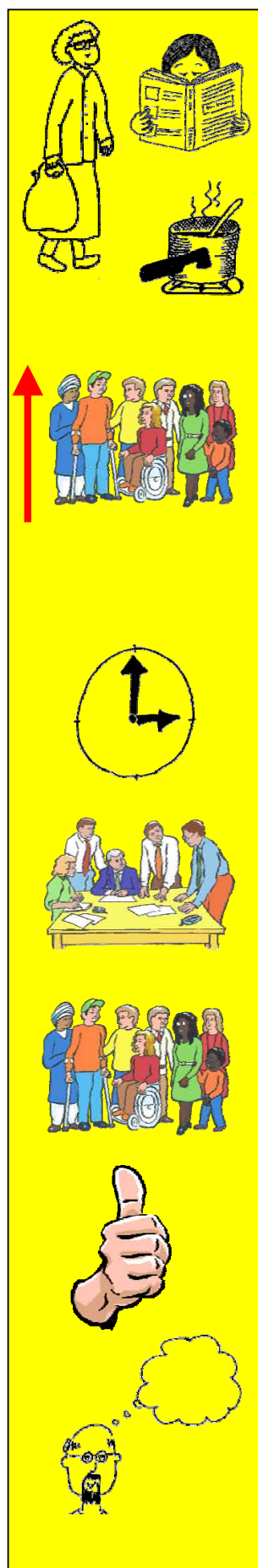
We also asked people about whether they chose what they did in their spare time.

Most people (86%) said that they chose what to do in their spare time during the day. Most people (91%) also said that they chose what to do in their spare time during the evening.

Because it is often difficult for people to know whether someone else is really choosing something, we looked at what support people told us and what people with learning difficulties told us themselves.

People with learning difficulties were much more likely to say that they chose what to do in their spare time during the day than support people (95% compared with 68%). People with learning difficulties were also much more likely to say that they chose what to do in their spare time during the evening than support people (98% compared with 78%). These differences are possibly because people with lower support needs find it easier to make choices.

We also asked people whether they would like more say in what goes on in their everyday life. Just over one in three people (36%) said they would like more say in what goes on in their everyday life. When this question was answered by



people with learning difficulties themselves they were a bit more likely to say they would like more say in what goes on in their everyday life (40% compared with 30% when the question was answered by a support person).

## Mobility & Transport



First, we asked people whether they needed someone to go with them when they needed to get somewhere.

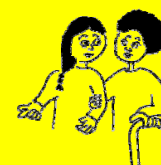
- Over half the people we asked (57%) said that they did need someone to go with them.
- About one in six (14%) said that it depended on where and how far they were going.
- Nearly one in three (29%) said that they did not need anyone to go with them.

Most people (85%) said that there was usually someone free to go with them when they wanted to go somewhere. About one in six (15%) said that they had to wait.

We asked people how they usually got to places. The most common forms of transport they used were

- Public transport (Bus, tram, train, tube) (54%)
- Taken by family or friends in their car (50%)
- Walking or in a wheelchair (48%)
- Special bus or car with other people with learning difficulties (32%)
- Taxi (26%)
- Bike (7%)
- Own car, motorbike or moped (2%)

Of the people who usually used public transport,



- Over one in three (37%) said they had had trouble using public transport
- Over one in four (29%) said they did not feel safe using public transport
- Over one in three (36%) said they did not find it easy using public transport
- Nearly one in six (15%) said they found the staff on public transport unhelpful



## Civic & Political Participation

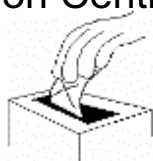


We asked people about whether they went to meetings and took part in politics. We also asked them how they found out about things.

Three out of four people (75%) said it was easy to find out what they want to know. When this question was answered by people with learning difficulties, the number rose to 85%.

Just under one in ten people (9%) had heard of the National Learning Disability Information Centre. Of the people who had heard of it, one in ten (10%) had contacted it. This means that one out of every hundred people we talked to (1%) had contacted the National Learning Disability Information Centre.

### Voting



Less than one in three people (31%) said that they voted in the 2001 general election. In the 2003 Home Office Citizenship Survey 72% of people said that they voted in the 2001 general election.<sup>32</sup> In the Millennium Poverty and Social Exclusion Survey, 73% of people said that they voted in the 2001 general election.<sup>33</sup> The actual turnout for this election was 59%.

We wanted to find out which people were more likely to have voted. The following list starts with the things that were most important and ends with the things that were least important. People were more likely to say they voted if they:

- Had lower support needs
- Were older
- Lived with 2-4 other people
- Were not poor
- Were Asian
- Were not Black
- Had a paid job
- Did not live in NHS accommodation
- Lived in more affluent areas



## *Valuing People & Partnership Boards*

Not many people had heard of Valuing People (14%) or of the Learning Disability Partnership Boards (8%). Of the people who had heard of Partnership Boards, over one in three (38%) had been involved with the Partnership Board.

## Advocacy



About half of the people (54%) we talked to had an independent advocate. Most of the advocates (64%) were paid to do their job.

One in five people (20%) were aware of a self-advocacy group in their area.

- Of the people who were aware, over one in four (28%) had attended a self-advocacy meeting.





- Of the people who attended, half (56%) attended regularly.

This means that about one in thirty (3%) of all people we talked to regularly attended self-advocacy groups. Nearly all (95%) of the people who regularly attended thought that self-advocacy groups help people with learning difficulties to speak up.

We wanted to find out which people were more likely to know about local self-advocacy groups. The following list starts with the things that were most important and ends with the things that were least important. People were more likely to say they knew of a local group if they:

- Did a wider range of community-based activities
- Lived in supported accommodation
- Were not poor
- Saw friends with learning difficulties more often
- Were older
- Saw friends who did not have learning difficulties more often
- Did not have a long-standing illness or disability

Not many people had heard of the National Forum (11%). Most people (83%) who had heard of the National Forum thought it would help people with learning difficulties to have their say. When this question was answered by people with learning difficulties, the number rose to 90%.





# Safety

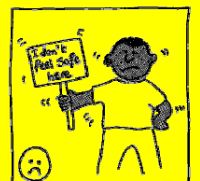
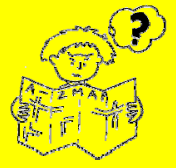
We asked people about whether they felt safe at home at night and felt safe in the local area.

- A few people living in either supported accommodation (3%) or private households (5%) said they did not feel safe in their home at night.
- A few more people living in either supported accommodation (6%) or private households (14%) said they did not feel safe in the local area.
- Nearly one in three people (29%) said they did not feel safe using public transport.

Altogether, one in three people (32%) said they did not feel safe either in their homes, their local area or using public transport.

We wanted to find out which people were more likely to not feel safe. The following list starts with the things that were most important and ends with the things that were least important. People were more likely to say they did not feel safe if they:

- Were poor
- Had higher support needs
- Lived in a private household
- Were younger
- Lived in a more deprived area
- Had a long-standing illness or disability
- Had poorer general health



# Crime & Bullying



We asked people about whether they had been bullied and whether they had been the victims of crime.

## *Bullying*

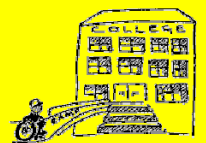
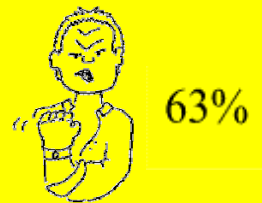


First we asked people whether in the last year anybody had been rude or offensive to them because they have learning difficulties. Nearly one in three people (32%) said someone had been rude to them.

Overall, the kinds of people who were most likely to be rude or offensive to them because they had learning difficulties were:

- A stranger (63%)
- Someone they knew/a friend (14%)
- Someone at the day centre (9%)
- Someone they worked with (8%)
- Someone they lived with (8%)
- Someone at college (4%)
- Paid support workers (4%)

There were some differences to the answer to this question depending on who answered it. The following figure (Figure 21) shows who people with learning difficulties and who support people thought had been rude.



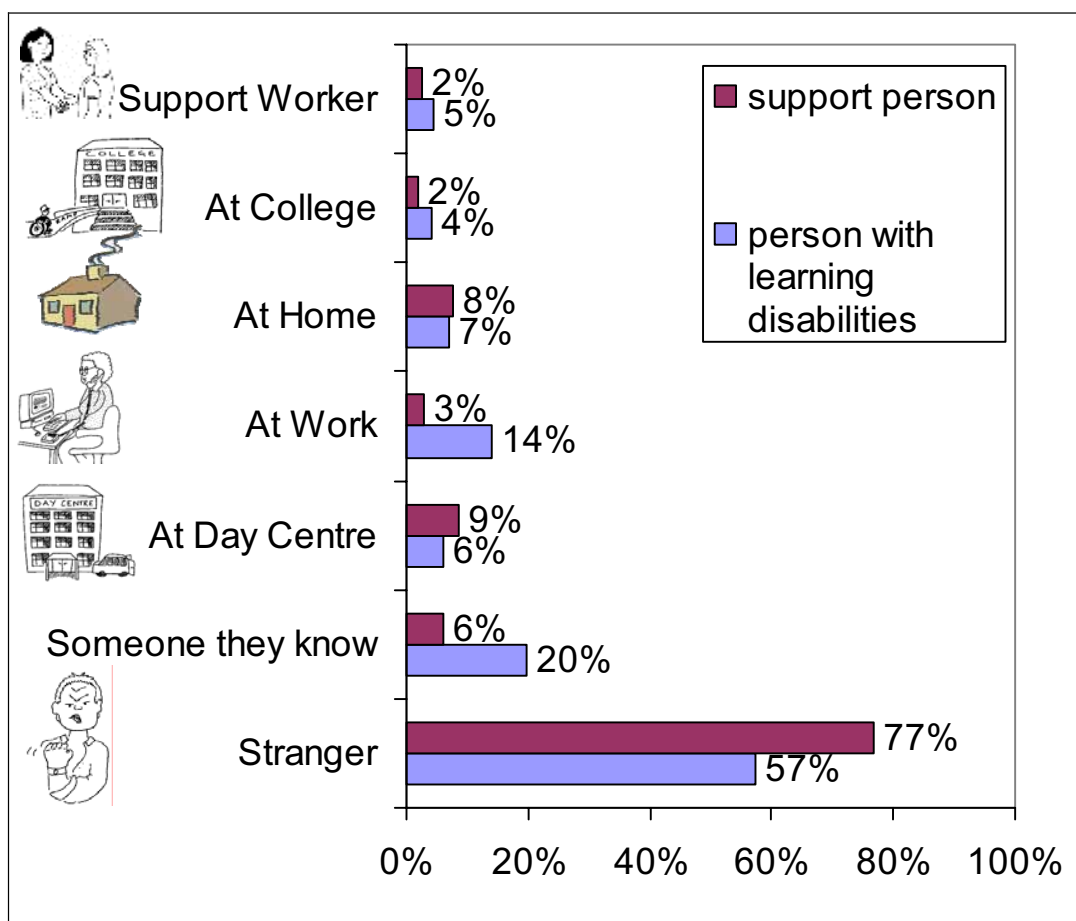


Figure 21: Who Had Been Rude to Person

We wanted to find out which people were more likely to have been bullied. The following list starts with the things that were most important and ends with the things that were least important. People were more likely to say they have been bullied if they:

- Were poor
- Were younger
- Had poorer general health
- Lived alone
- Saw their friends with learning difficulties more often
- Did fewer community-based leisure activities



## Crime



Next we asked people whether they had been victims of crime in the last year. Overall, nearly one in ten people (9%) said they had been the victim of crime. This is much less than the chances of being a victim of crime reported in 2003/4 in the British Crime Survey (26%).<sup>34</sup>

Of the people who had been the victim of a crime, over one in three (34%) had been a victim more than once.

People told us about different types of crime. The percentage of people with learning difficulties who were victims of these different types of crime are shown in Figure 22. It also shows (where it is possible) how this compares with the information from the British Crime Survey (BCS) for 2003/4.

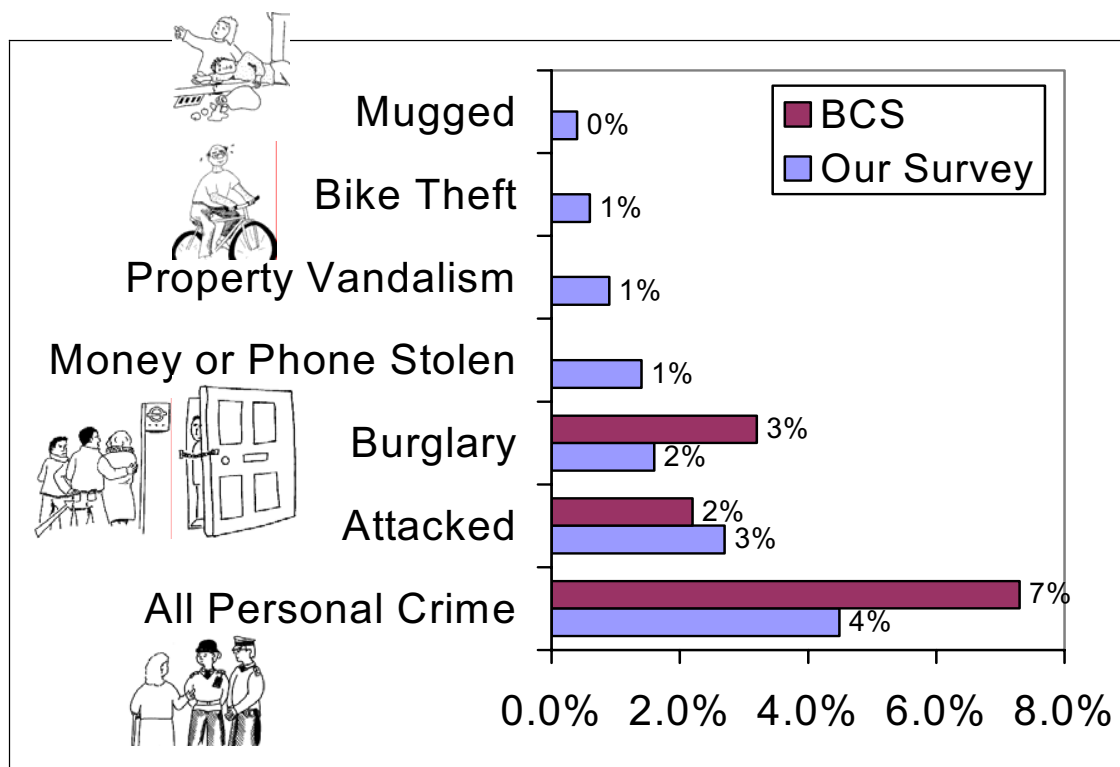
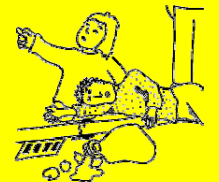


Figure 22: Percentage of People Who Were Victims of Different Crimes



The Figure shows that people with learning difficulties were less at risk of crime in general, but were slightly more likely to be attacked.

Overall, three out of four people (72%) reported the crimes to the police. People told us that about one in six reports (15%) led to an arrest.

The crimes that we were told resulted in arrests were

- Being attacked (11)
- Being burgled or having other things stolen (4)
- Having money or a mobile phone stolen (1)
- Having their house/car/bike vandalised (1)

People were more likely to report some crimes than others. The percentage of people with learning difficulties who were victims of these different types of crime and reported them to the police are shown in Figure 23. It also shows (where we can) comparable rates from the British Crime Survey (BCS) for 2003/4.



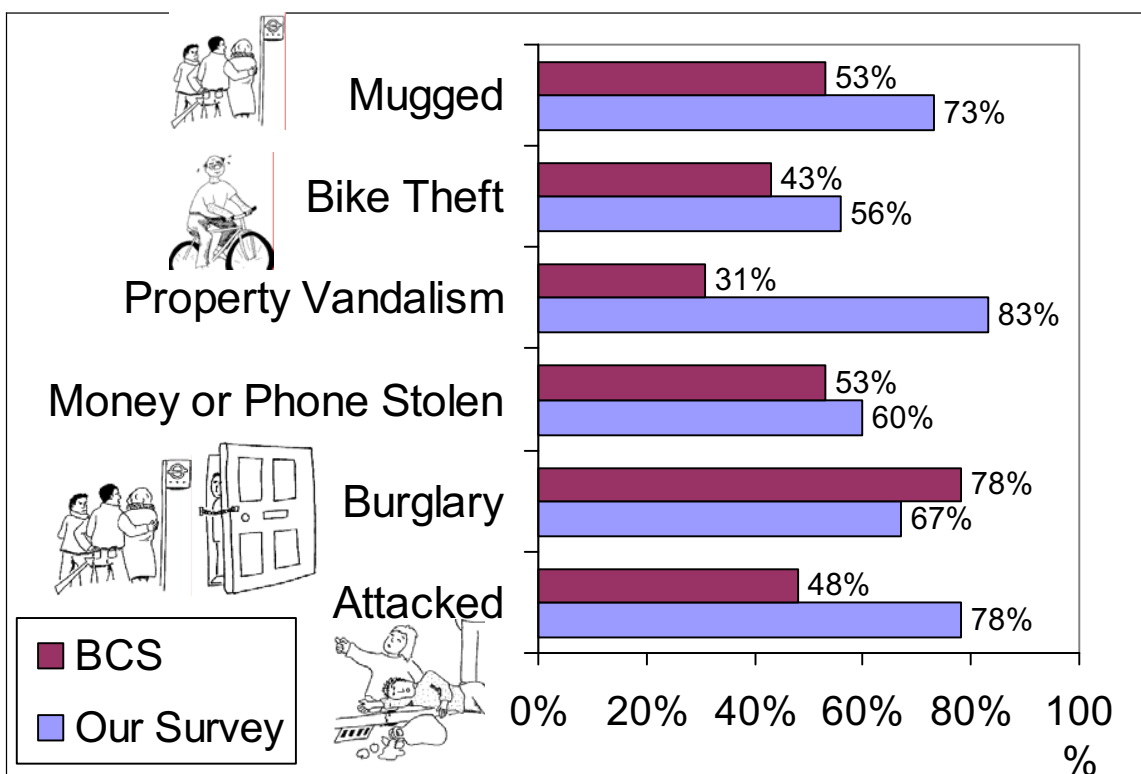


Figure 23: Percentage of People Who Were Victims of Different Crimes and Reported Them to the Police

The Figure shows that people with learning difficulties were more likely to report crimes to the police than people in general.

We wanted to find out which people were more likely to have been a victim of crime. The following list starts with the things that were most important and ends with the things that were least important. People were more likely to say they had been a victim of crime if they:

- Lived alone
- Were younger
- Had lower support needs
- Were men
- Had poorer general health
- Lived in a more deprived area
- Had a long-standing illness or disability



- Were poor

Figure 24 shows the percentage of men and women (aged under 30) with low support needs who were the victims of personal crime in more deprived and less deprived areas. 'Personal crime' includes being attacked and mugged.

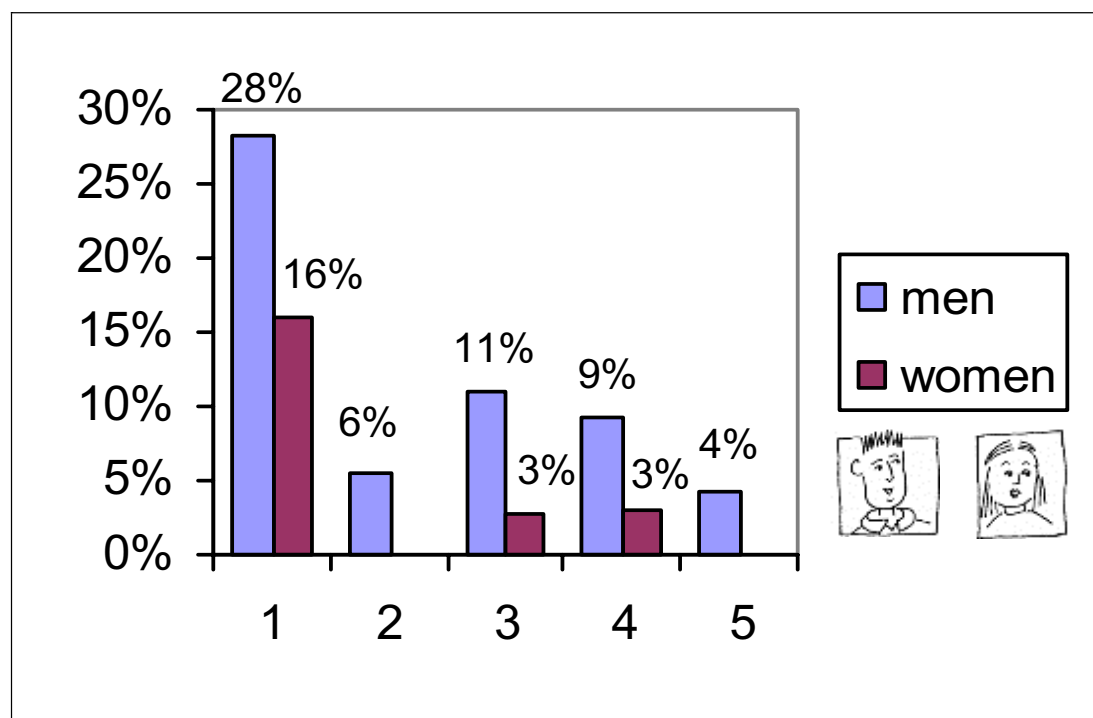


Figure 24: Percentage of men and women aged under 30 with low support needs who were the victims of personal crime in more deprived (1) to less deprived (5) areas



# Health & Well-Being



The survey shows that people with learning difficulties visit their GPs a lot. In our experience it is important to know your doctor and have a doctor that knows you.

Independence is important to us. The survey shows that a lot of people are worried, feel left out, feel helpless and lack confidence. To be independent in the community people with learning difficulties need to have places where they take part, are in control and make their own decisions.

Ian Davies & Karen Spencer

We asked people about their health, their use of health services and how happy they were.

## Health



We asked people about their general health.

- Nearly half of the people (45%) said their health was 'very good'
- Two out of five (41%) said it was 'good'
- One in six (15%) said it was 'not good'.

We wanted to find out which people were more likely to say that their health was 'not good'.<sup>35</sup> The following list starts with the things that were most important and ends with the things that were least important. People were more likely to say that their health was 'not good' if they:

- Were poor



- Lived alone
- Saw friends who had learning difficulties less often
- Did not have a paid job
- Were older
- Did not live in a Registered Residential Care Home
- Were from a minority ethnic community
- Had lower support needs

We also asked people whether they had an illness or disability that they had had for a long time. Nearly two out of three people (61%) said that they had. This is much more than people in the UK in general, just under one in three (31%) have a long-standing illness.<sup>36</sup> The most common types of illnesses or disabilities they told us about are shown in Figure 25.

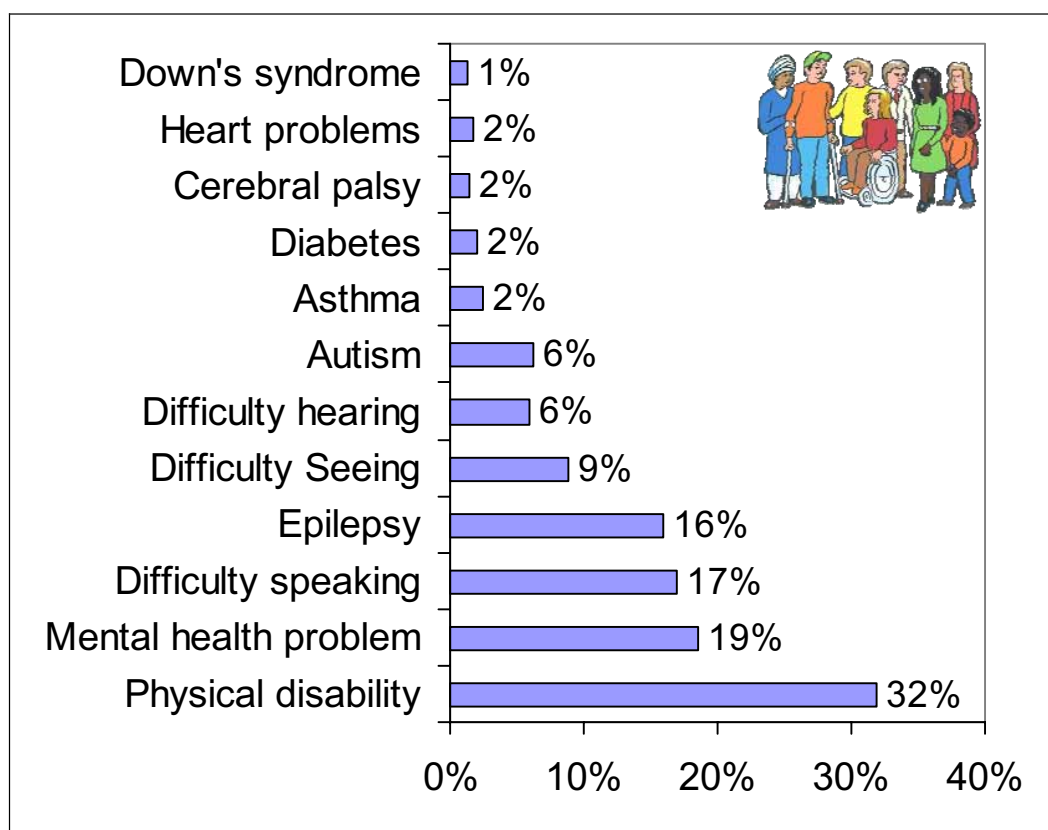
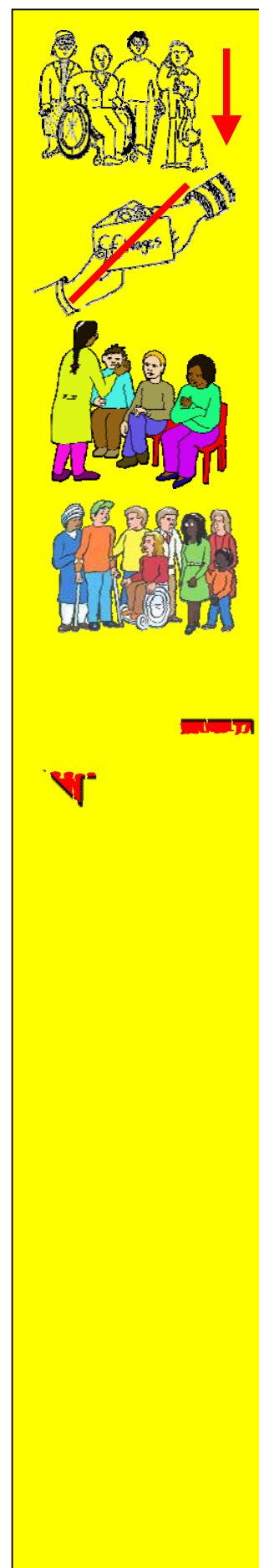


Figure 25: Percentage of People with Specific Long-Standing Illnesses or Disabilities



Again, we wanted to find out which people were more likely to have a long-standing illness or disability. The following list starts with the things that were most important and ends with the things that were least important. People were more likely to say that they had a long-standing illness or disability if they:

- Had higher support needs
- Did not have a paid job
- Lived in NHS accommodation
- Lived alone
- Lived in more deprived communities

We asked people about some of the things that can make you more or less healthy.

- Nearly one in five people (19%) said they smoked cigarettes nowadays.
- Nearly half of the people (46%) said they did exercise that made them out of breath and sweaty. Nearly one in six (15%) said they did this at least three times a week.



We wanted to find out which people were more likely smoke and which people were more likely to exercise at least three times a week. People were more likely to smoke if (in order of importance) they:

- Had low support needs
- Were poor
- Did not see friends with learning difficulties very often
- Lived in more deprived areas
- Were men
- Were White
- Did fewer different types of community activities
- Were younger
- Saw friends who do not have learning difficulties more often

People were more likely to exercise at least three times a week if (in order of importance) they:

- Were younger
- Had lower support needs
- Did a wider range of community-based activities
- Were men
- Were Black
- Did not see friends with learning difficulties very often

## Use of Health Services



Nearly everyone (99%) said they had a doctor and nearly everyone (99%) said they were registered with a GP. Nearly everyone (94%) said they got on with their doctor. Just over three out of four people (78%) said they had seen their doctor in the last year.



We asked people who they would go to for help if they were ill. People said they would go to

- A doctor (50%)
- A relative (26%)
- A support worker (23%)
- A hospital (4%)
- Their partner (3%)
- Their parent (3%)
- A friend (1%)

Just over one in four people (27%) said they had had problems with their teeth in the last six months. We asked people whether they went to the dentists for a check up or only when their teeth hurt. A few people (4%) said they never went to the dentists, nearly one in five (18%) said they only went when their teeth hurt. Over three out of four people (78%) said they had been to a dentist for a check up. Four out of five people (82%) said they were registered with a dentist.

We asked people about different kinds of tests they may have had.

- Just over half (52%) had their eyes tested in the last year
- One in five (21%) had their hearing tested in the last year
- Only one in four women (27%) had ever had a cervical smear
- Only one in four women (24%) had ever had their breasts checked for lumps by a doctor or nurse





## Well-Being

We asked people how happy they felt about their life at the moment.

- Nearly half (47%) said they were 'very happy'
- Over one in four (29%) said they were 'quite happy'
- One in five (21%) said they were 'sometimes happy', and 'sometimes unhappy'
- One in twenty (4%) said they were 'mostly unhappy'

Because it is often difficult for people to know whether someone else is really happy or not, we also looked at what support people told us and what people with learning difficulties told us themselves. When people with learning difficulties answered the question themselves they were more likely to say they were 'sometimes happy and sometimes unhappy' (25% compared with 17% when the support person answered). They were a bit less likely to say they were 'very happy', 'quite happy' and 'mostly unhappy'.

We wanted to find out which people were more likely to be 'very' or 'quite' happy with their lives at the moment. People were more likely to say they were happy if (in order of importance) they

- Had good general health
- Were older
- Were not poor
- Had higher support needs
- Did a wider range of leisure activities
- Did not live alone
- Lived in a Registered Residential Care Home
- Had a paid job



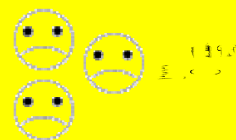
- Saw friends with learning difficulties more often
- Lived in a more affluent community

We also asked people how often they felt sad or worried, left out, helpless, and confident.

- One in ten people (11%) said they felt sad or worried 'a lot'. Another two out of three (65%) said they felt sad or worried 'sometimes'.
- One in ten people (9%) said they felt left out 'a lot'. Another two out of five (41%) said they felt left out 'sometimes'.
- One in ten people (9%) said they felt helpless 'a lot'. Nearly another half (45%) said they felt helpless 'sometimes'.
- Over one in three people (39%) said they felt confident 'a lot'. Another half (48%) said they felt confident 'sometimes'. Over one in ten people (13%) said they 'never' felt confident.

Nearly all people (95%) said they had someone to talk to if they felt sad or down.

Because it is often difficult for people to know what someone else really feels, we also looked at what support people told us and what people with learning difficulties told us themselves. There were no real differences between what support people told us and what people with learning difficulties told us themselves. The one difference was that people with learning difficulties were more likely to say they were confident a lot of the time (42% compared with 31% when a support person answered the question).



A vertical strip of 15 illustrations. The first illustration shows a question mark and a person with curly hair. The subsequent illustrations show various combinations of people with disabilities (using a cane, in a wheelchair, or sitting in a chair) and financial symbols (coins, blocks, a question mark). Some combinations are crossed out with a red line.

A vertical strip of 15 illustrations. The first illustration shows a question mark and a person with curly hair. The subsequent illustrations show various combinations of people with disabilities (using a cane, in a wheelchair, or sitting in a chair) and financial symbols (coins, blocks, a question mark). Some combinations are crossed out with a red line.

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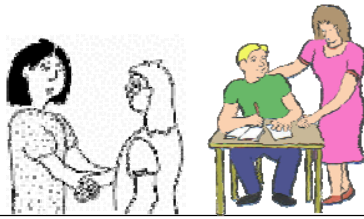
-

People were more likely to 'never' feel confident if (in order of importance) they

- Were poor
- Had poor health
- Were younger
- Lived with fewer people
- Saw friends who do not have learning difficulties less often
- Were Asian
- Had higher support needs
- Lived in a private household
- Lived in more deprived neighbourhoods
- Had a long-standing illness or disability



# Support



Over one in 20 people don't get the support that they need to do everyday things. Not having support often shapes our lives. In our experience this tells us a lot about choice. For example, 3% of people with learning difficulties not getting support that they need to drink a cup of tea means that they can't choose to have a cup of tea and a lot of other people don't choose when to drink their tea. Also, as well as the 3% of people with learning difficulties who don't get the help they need making a sandwich, other people, waiting for support, make a sandwich.

Over the years having lived in different places we have found that people in residential homes find it the hardest to complain. They don't always know how to complain and if they do they don't always complain because they have to live with people (e.g. other residents and/or staff) they complain about. The same happens with other services we use. So we wonder if the number of people who are very happy and happy about support is too large. It is also important to notice that the kind of people who wanted to complain about support include those who need most help to be independent (e.g. the poor and the ill).

Because we think independence is important we were pleased that a lot of people in supported accommodation (residential homes, NHS hospitals or living with the support of the Supporting People programme) received support about their housing and that most of them were very happy with the support. This should make supported accommodation an important step to living in our own places in the community.

Ian Davies & Karen Spencer



We asked the people we interviewed how much personal support they received and who they would turn to if they needed help about housing or work.

## Personal Support

We asked people how much support they needed to do 11 different things. These things ranged from drinking a cup of tea to filling in a form.

We then asked them whether they got help with the things they said they needed support with. For each of the 11 different things, nearly everyone who needed support did get some help. The things that people were least likely to get help with were

- Drinking a cup of tea (3%)
- Making a sandwich (3%)
- Finding out what is on the TV tonight (3%)
- Getting dressed in the morning (2%)
- Putting on a pair of shoes (2%)
- Having a shower or a bath (1%)
- Ordering something to eat or drink at a cafe (1%)
- Washing your clothes (1%)
- Filling in a form (1%)
- Paying money into your bank or Post Office (1%)
- Making an appointment (1%)

Overall, one in twenty people (6%) said they had an unmet need for support in at least one of these areas. We wanted to find out which people were more likely to have an unmet need for personal support.<sup>37</sup>



?





People were more likely to have an unmet need for personal support if (in order of importance) they:

- Had higher support needs
- Were poor
- Saw members of their family less often
- Lived in a more deprived area

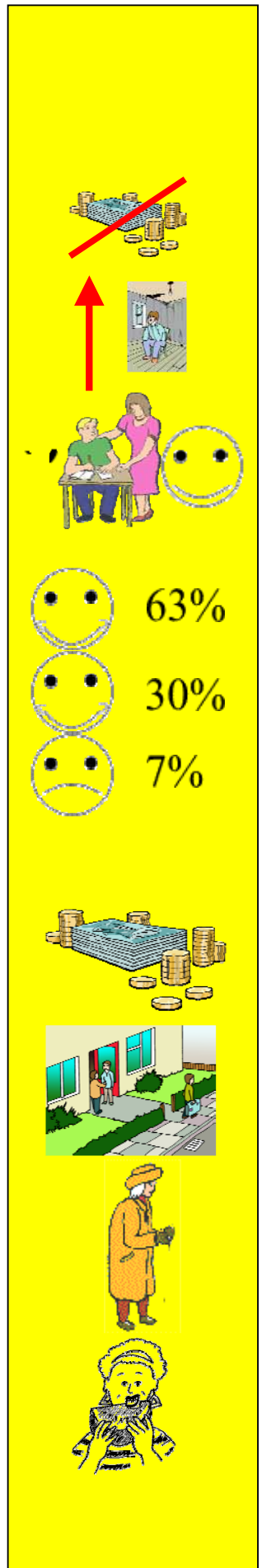
We asked people how happy they were with the support they got.

- Nearly two out of three people (63%) said they were very happy
- Nearly one out of three people (30%) said they were quite happy
- A few people (7%) said they were not happy.

We wanted to find out which people were more likely to have wanted to complain. People were more likely to have said that they were happy with the support provided if (in order of importance) they:

- Were not poor
- Lived in either a *Supporting People* scheme or a Registered Residential Care Home
- Were older
- Did not have a long standing illness or disability
- Had good general health
- Did a wider range of leisure activities
- Lived in a richer area

One in ten people (10%) said they had wanted to complain about the support they received. We wanted to find out which people were more likely to have wanted to complain.



People were more likely to have said that they had wanted to complain if (in order of importance) they:

- Were living in supported accommodation
- Were poor
- Had a long-standing illness or disability
- Had poor health

We also asked people about who organised their support. The people who organised their support were most likely to be

- A member of their family (59%)
- A support worker (30%)
- Key worker (9%)
- Social worker or care manager (8%)
- A friend (2%)
- Teacher (2%)

## Support with Housing



We asked people about where they would go for help about housing. We also asked them about how happy they were with any help they had received.

Figure 26 shows where people living in private households and people in supported accommodation said whom they would turn to if they wanted help about housing.



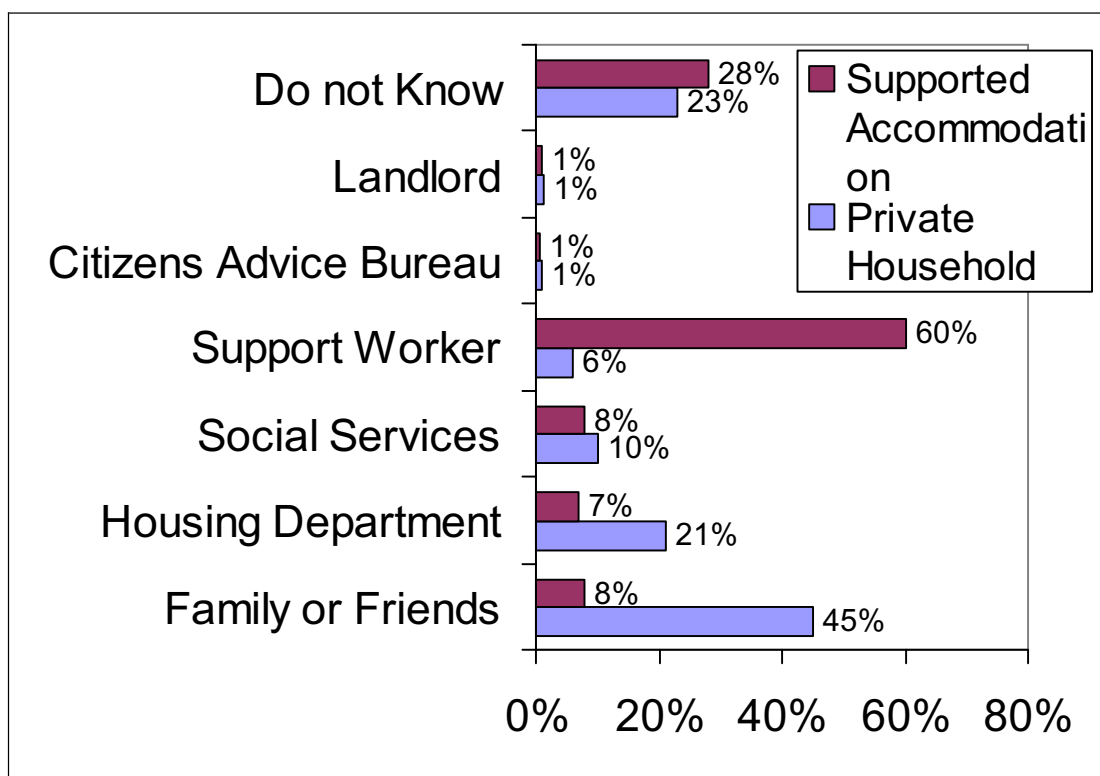
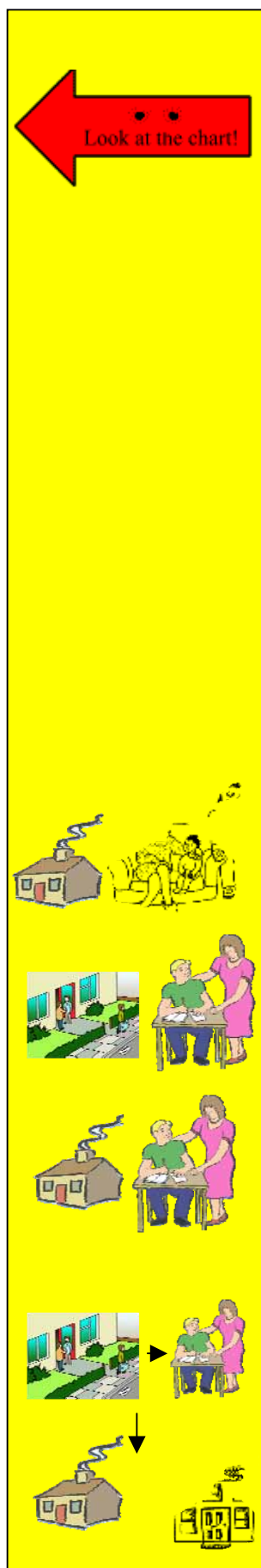


Figure 26: Who People Would Turn to for Help About Housing

This Figure shows that people living in private households were most likely to turn to family and friends for help. People living in supported accommodation were most likely to turn to a support worker for help.

Just over one in five people (23%) in private households said they had received support about housing. They were most likely to have received support from friends or family (43%), Social Services (30%), Housing Department (26%), a support worker (15%), their landlord (2%), the NHS (1%).

Nearly two out of three people (65%) living in supported accommodation said they had received support about housing. They were most likely to have received support from a support worker (61%), Social Services (27%), friends or family (19%), Housing Department (6%), the NHS (3%), their landlord (1%).



People were happier with the support they received from some people than others. Figure 27 shows how happy people living in private households and people in supported accommodation were with the support that they had received about housing.

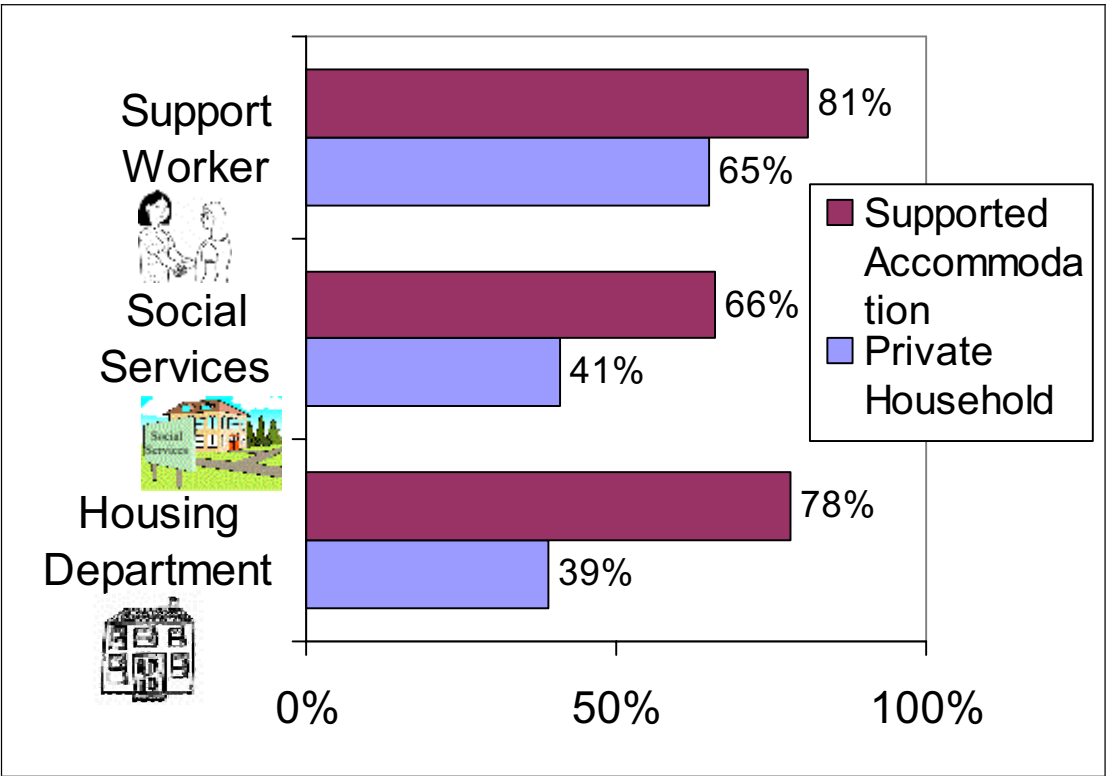


Figure 27: Percentage of People Who Were ‘Very Happy’ with Support About Housing

This Figure shows that people living in supported accommodation were more likely to be happy about the support they received.

## Support About Work, Education & Training

One in six people with learning difficulties (17%) had a paid job and about one in twenty people with learning difficulties



(6%) had an unpaid job. Nearly two out of three (65%) who were unemployed and said they were able to work said they would like a job.

We asked people who had a job and people who said they wanted a job about the support they had received to try to find work.

Only a few people (9%) had heard of the WORKSTEP programme. More had heard of the New Deal for Disabled People (23%). Most people were happy with the support they had received while using the WORKSTEP programme (73%) or the New Deal for Disabled People (69%).

Two out of three people who were 25 or younger (66%) had heard about the Connexions service. Two out of every five (40%) had used it. Most people (77%) who had used the service were happy with the support they had received.

About half of the people (52%) said that they had received some help when they were looking for a job. Figure 28 shows where people had got help from.

This Figure shows that people were most likely to get help from their parents or support workers.



*new deal*★



*connexions*



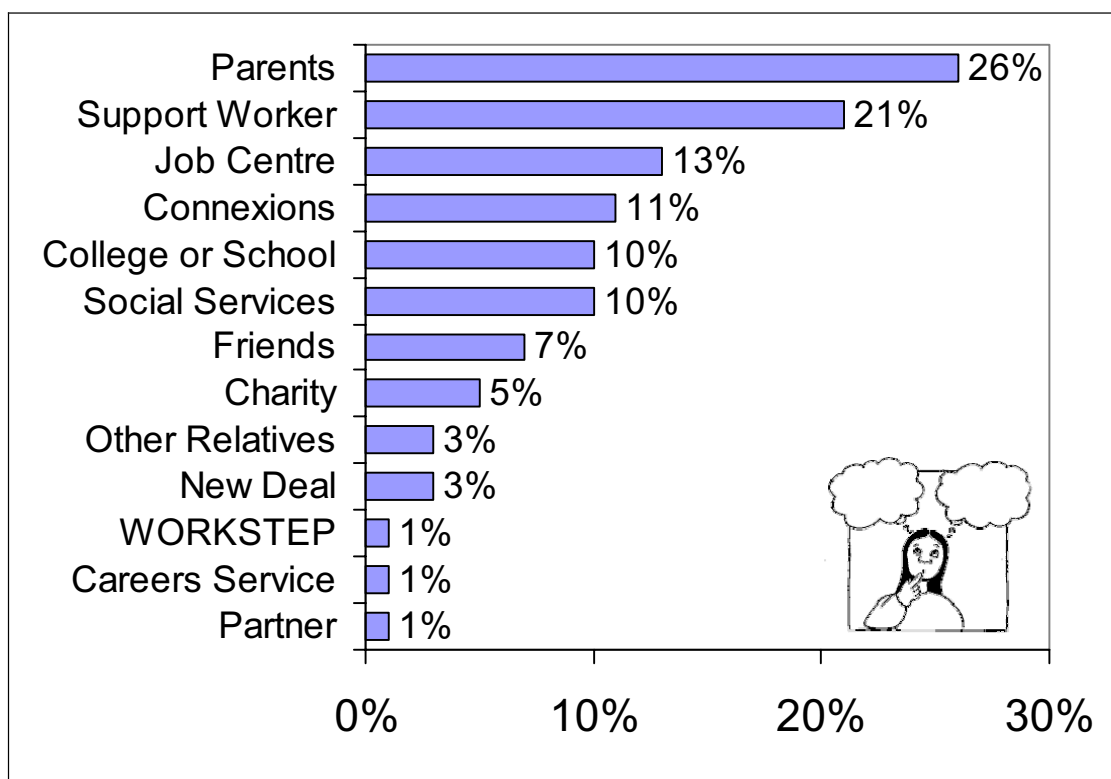
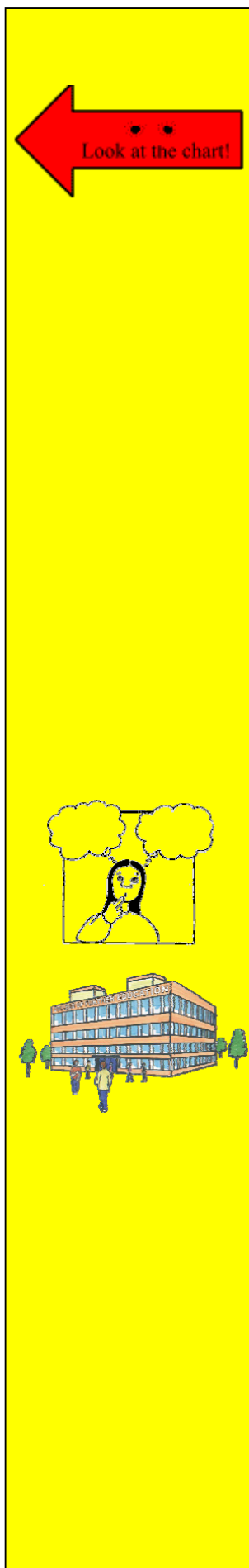


Figure 28: Who People Would Turn to For Help Finding a Job

Finally we asked everyone who they would ask if they wanted to find out about taking a course. Figure 29 shows who people would ask for support.





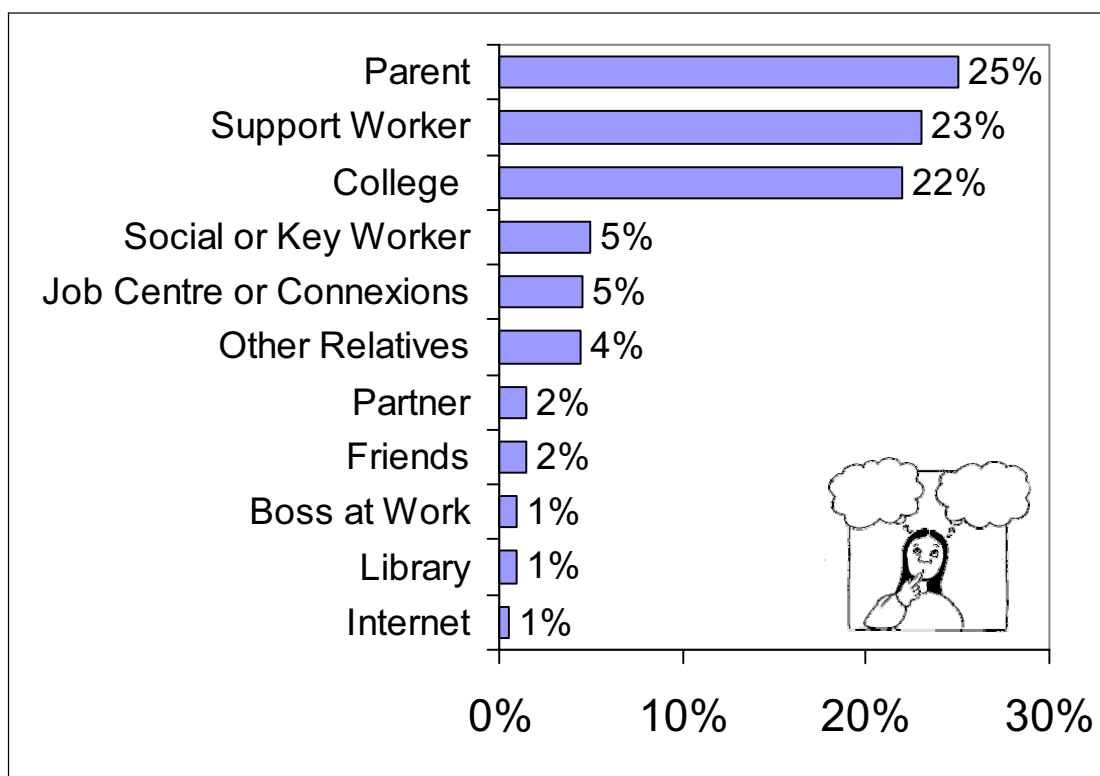


Figure 29: Where People Would Go for Help About Doing a Course

This Figure shows that people were most likely to ask for help from their parents or support workers, or they would ask at a college.



# Appendix 1: Membership of the Advisory Group

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Karen.Spencer (Central England People First)  
Ian Davies (Central England People First)  
Nigel Lott (Central England People First)  
Liz Harkness (National Forum)  
Simon Cramp Formerly of National Forum now independent  
Consultant  
Ian Berry (Department of Health)  
Richard Bond (Department of Health)  
Catherine Baines (Consultant for the Department of Health)  
Zoe Porter (Department of Health)  
Sheila Hollins (Department of Health)  
John O'Shea (Department of Health)  
Michael Sweetland (Department of Health)  
Kathleen Kelly (Office of the Deputy Prime Minister)  
Andrew Holman (Community Living Welfare)  
Michelle Chinery (Learning difficulties Task Force)  
Penny Mendonca (Support worker)  
Justin Wilson (Learning difficulties Consultant)  
Martin Routledge (Valuing People Support Team)  
Eric Emerson (University of Lancaster)  
Sue Brooker (BMRB Ltd)  
Sally Malam (BMRB Ltd)  
Lucy Joyce (BMRB Ltd)  
Penny Tapp (BMRB Ltd)

## **Appendix 2 – “Thank You”**



The research team would like to thank some of the people who helped on the project. Many other people also helped who are not named here.

At Central England People First (CEPF):

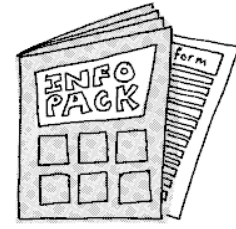
- Nigel Lott who was part of the team when the project started;
- For their support:
  - Neil Morris, Joan Walker at Central England People First;
  - Ian Buchanan of the Open University.

At the University of Lancaster:

- Professor Chris Hatton.

At BMRB

- The research team, especially Sue Brooker, Jim Muir, Christine Carey, Kathryn Warrener, Ruth Gosling, Jonathan Pickup and Tracy Mackey;
- The operations team, especially Caroline Evans and Jo Knott.



## Appendix 3: Getting More Information

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You can see (and download) a copy of the questionnaire we used from

[http://www.dh.gov.uk/PublicationsAndStatistics/PublishedSurvey/ListOfSurveySince1990/GeneralSurveys/GeneralSurveysArticle/fs/en?CONTENT\\_ID=4081207&chk=u%2Bd5fv](http://www.dh.gov.uk/PublicationsAndStatistics/PublishedSurvey/ListOfSurveySince1990/GeneralSurveys/GeneralSurveysArticle/fs/en?CONTENT_ID=4081207&chk=u%2Bd5fv)

You can get a copy of our raw data from the *UK Data Archive* ([www.data-archive.ac.uk](http://www.data-archive.ac.uk)).

There are also a number of detailed technical reports you can see (and download) from

[http://www.dh.gov.uk/PublicationsAndStatistics/PublishedSurvey/ListOfSurveySince1990/GeneralSurveys/GeneralSurveysArticle/fs/en?CONTENT\\_ID=4081207&chk=u%2Bd5fv](http://www.dh.gov.uk/PublicationsAndStatistics/PublishedSurvey/ListOfSurveySince1990/GeneralSurveys/GeneralSurveysArticle/fs/en?CONTENT_ID=4081207&chk=u%2Bd5fv)

These include reports on:

- The full 'Dress Rehearsal' that we did for the survey
- The response rates for the final sample
- The way we weighted the data to make it as representative as possible

## Appendix 4: Working Out Why Good and Bad Things Were More Likely to Happen to Some People Rather Than Others

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We wanted to find out why good or bad things were more likely to happen to some people rather than others. For example, we wanted to find out why some people were more likely to have a paid job, and why other people were less likely to have a paid job.

One way of doing this would be to see whether people in some groups were more likely to have a job than people in other groups. So, for example, we could compare young and old people. Then we could also compare people with low support needs and people with high support needs, and so on.

If we did this we would find that

- younger people are more likely to have jobs than older people
- **and**
- people with lower support needs are more likely to have jobs than people with higher support needs.

This causes us a big problem because we also know that younger people have lower support needs. So, we then need to ask ...

- Are younger people more likely to have jobs because they are younger or because they have lower support needs than older people?

- OR
- Are people with lower support needs more likely to have jobs because they are more able or because they are younger?

To help us work out the answers to these kinds of questions we used a statistical procedure called logistic regression.<sup>38</sup> We used a programme called SPSS v12.01.

This way we can work out which things are independently related to getting a job. This means that a particular thing (e.g., age) is related to the chances of someone getting a job even when we take into account the possible impact of all the other things we are looking at (e.g., support needs, ethnicity, how poor people are).

We did these kinds of sums for each of the good or bad things that we were interested in (e.g., having a job, being a victim of crime). Each time we did this we looked at many things that might be important.

In most of the analyses, the things we looked at were:

- The person's age, gender, ethnicity and level of support needs
- Whether they had a long standing illness or disability and whether they had good or poor general health
- How poor they were
- How deprived the neighbourhood was in which they were living
- Whether they were living in supported accommodation or not and, if so, the type of supported accommodation they were living in (Supporting People, Registered Residential Care Home, NHS provision)
- Whether they had a paid job



- How many people they were sharing their home with
- How often they saw friends (with and without Learning difficulties) and family
- How many different leisure activities they did in the last month

In some of the analyses (who gets placed in supported accommodation, peoples' experiences of their schooldays) we just looked at:

- The person's age, gender, ethnicity and level of support needs
- Whether they had a long standing illness or disability and whether they had good or poor general health
- How poor they were
- How deprived the neighbourhood was in which they were living

# Notes



- <sup>1</sup> Department of Health (2001). *Valuing People: A New Strategy for Learning Disability for the 21<sup>st</sup> Century*. London: Department of Health.  
<http://www.dh.gov.uk/PolicyAndGuidance/HealthAndSocialCareTopics/LearningDisabilities/fs/en>
- <sup>2</sup> Cabinet Office (2005). *Improving the Life Chances of Disabled People: Final Report*. London: Prime Minister's Strategy Unit, Cabinet Office.  
[http://www.strategy.gov.uk/work\\_areas/disability/index.asp](http://www.strategy.gov.uk/work_areas/disability/index.asp)
- <sup>3</sup> Emerson, E., & Hatton, C. (2005). *The Socio-Economic Circumstances of Families Supporting a Child at Risk of Disability in Britain in 2002*. Lancaster, Institute for Health Research, Lancaster University.  
<http://www.lancs.ac.uk/fss/ihr/publications.htm> Also see note 2.
- <sup>4</sup> Since our survey was done, NCSC has been replaced by the Commission for Social Care Inspection (CSCI)
- <sup>5</sup> In the BMRB Household Sample we asked people whether they themselves had 'Learning difficulties' or whether someone they lived with or supported had 'Learning difficulties'. Because we just asked people, we realised that we might end up interviewing some people who did not have Learning difficulties as such, but who may have other difficulties (e.g., dyslexia). We decided to exclude people if they had been awarded a GCSE at grade C or above, an O level, an A level, a degree or HND qualification. This led to us excluding 76 people. Of these, 58 were from the BMRB Household Sample, 8 from the Supporting People sample, 6 from the National Care Standards Commission sample, three from the Social Services sample and one from the NHS sample.

- 6 Emerson, E., Hatton, C., Felce, D., & Murphy, G.  
(2001). *Learning Disabilities: The Fundamental Facts*.  
London: The Foundation for People with Learning  
Disabilities. <http://www.learningdisabilities.org.uk/>
- 7 Emerson, E & Hatton, C. (2005). *Estimating the Current  
Need/Demand for Supports for People with Learning  
Disabilities in England*. Lancaster: Institute for Health  
Research, Lancaster University.  
<http://www.lancs.ac.uk/fss/ihr/publications.htm>
- 8 Summerfield, C, & Gill, B. (2005). *Social Trends 35*.  
London: National Statistics.  
<http://www.statistics.gov.uk/StatBase/Product.asp?vlnk=13675>
- 9 See Appendix 3 for more information about how we did  
this.
- 10 See note 7.
- 11 Similar results were found in an analysis of the 1991  
Census: Emerson, E & Hatton, C. (1996). *Residential  
Provision for People with Learning Disabilities: An  
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Health Research, Lancaster University.  
<http://www.lancs.ac.uk/fss/ihr/publications.htm>
- 12 See Section 6 (Money) to see how we measured how  
poor people were.
- 13 See Section 8 (Being Part of the Community) to see  
how we measured how poor the areas were in which  
people were living.
- 14 See Section 9 (Health & Well-Being) to see how we  
measured people's general health.
- 15 We used the definition of 'working age' used by the  
Department of Work and Pensions: men aged 16-64;  
women aged 16-59.
- 16 Data extracted from *Social Trends 35* (Note 8).
- 17 Data extracted from *Social Trends 35* (Note 8).
- 18 See Appendix 3 for more information about how we did  
this.

See Section 7 (Families, Friends & Relationships) to see how we measured how often people saw friends. See Appendix 3 for more information about how we did this.

Selected items (slightly modified) from the *Millennium Poverty and Social Exclusion Survey*. Gordon, D., et al., (2000). *Poverty and Social Exclusion in Britain*. York: Joseph Rowntree Foundation.

<http://www.jrf.org.uk/bookshop/>

See note 21.

See Appendix 3 for more information about how we did this.

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See note 21.

<http://www.caci.co.uk/acorn/>

Noble, M., Wright, G., Dibben, C., Smith, G., McLennan, D., Anttila, C., et al. (2004). *Indices of Deprivation 2004. Report to the Office of the Deputy Prime Minister*. London: Neighbourhood Renewal Unit. [http://www.odpm.gov.uk/stellent/groups/odpm\\_urbanpolicy/documents/page/odpm\\_urbpol\\_028470.hcsp](http://www.odpm.gov.uk/stellent/groups/odpm_urbanpolicy/documents/page/odpm_urbpol_028470.hcsp)

See note 28.

<http://www.statistics.gov.uk/timeuse/default.asp>

See Appendix 3 for more information about how we did this.

Home Office (2004). *2003 Home Office Citizenship Survey: People, Families and Communities*. London: Home Office.

<http://www.homeoffice.gov.uk/rds/citizensurvey.html>

See note 21.

Dodd, T., Nicholas, S., Povey, D., & Walker, A. (2004). *Crime in England and Wales 2003/2004*. London: Home Office.

<http://www.homeoffice.gov.uk/rds/bcs1.html>

35 See Appendix 3 for more information about how we did  
this.  
36 Data extracted from *Social Trends* 35 (Note 8).  
37 See Appendix 3 for more information about how we did  
this.  
38 Forward stepwise conditional variable entry (p entry  
<0.05; p exit p >0.1).

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1 Department of Health (2001). *Valuing People: A New  
Strategy for Learning Disability for the 21<sup>st</sup> Century*.  
London: Department of Health.  
[http://www.dh.gov.uk/PolicyAndGuidance/HealthAndSo  
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2 Cabinet Office (2005). *Improving the Life Chances of  
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3 Emerson, E., & Hatton, C. (2005). *The Socio-Economic  
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- 7 Emerson, E & Hatton, C. (2005). *Estimating the Current Need/Demand for Supports for People with Learning Disabilities in England*. Lancaster: Institute for Health Research, Lancaster University. <http://www.lancs.ac.uk/fss/ihr/publications.htm>
- 8 Summerfield, C, & Gill, B. (2005). *Social Trends 35*. London: National Statistics. <http://www.statistics.gov.uk/StatBase/Product.asp?vlnk=13675>
- 9 See Appendix 4 for more information about how we did this.
- 10 See note 7.
- 11 Similar results were found in an analysis of the 1991 Census: Emerson, E & Hatton, C. (1996). *Residential Provision for People with Learning Disabilities: An Analysis of the 1991 Census*. Lancaster: Institute for Health Research, Lancaster University. <http://www.lancs.ac.uk/fss/ihr/publications.htm>
- 12 See Section 6 (Money) to see how we measured how poor people were.
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<http://www.caci.co.uk/acorn/>

Noble, M., Wright, G., Dibben, C., Smith, G., McLennan, D., Anttila, C., et al. (2004). *Indices of Deprivation 2004. Report to the Office of the Deputy Prime Minister*. London: Neighbourhood Renewal Unit.  
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See note 28.

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See Appendix 4 for more information about how we did this.

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- 35 See Appendix 4 for more information about how we did this.
- 36 Data extracted from *Social Trends* 35 (Note 8).
- 37 See Appendix 4 for more information about how we did this.
- 38 Forward stepwise conditional variable entry (p entry <0.05; p exit p >0.1).



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This booklet was designed by Sally Ferguson from Speakup Self Advocacy.

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