

Our lives, our communities: Promoting independence and inclusion for people with learning difficulties

Findings
Informing change

August 2007

This study examines the issue of independence and inclusion for people with learning difficulties. Rather than being led by university researchers, people with learning difficulties research the lives of other people with learning difficulties.

Key points

- Research by people with learning difficulties is often seen as not serious or reliable.
- The more choices were available to people with learning difficulties, the more likely they were to be included in their local communities.
- Some people interviewed did not receive enough support to manage their lives and were left to struggle by themselves.
- Parents were usually the most important people in the lives of those with learning difficulties, but they did not always allow them freedom to make their own decisions.
- People who lived in community-based homes had the most choice and freedom but there were still difficulties, such as only going out when staff and transport were available.
- People who lived in residential homes and those who lived with their parents found it harder to be independent and to make decisions in their lives.
- Most people with learning difficulties who were interviewed did not have full control of their money, but they also thought it important that there was support for people. There were conflicting views about what sort of support this should be.

The research

By Fresh Start, a team of people with learning difficulties from Central England People First.

Background

There is a lot of research about people with learning difficulties and, increasingly, some of it is being done by people with learning difficulties. Much of this research is very good but often projects are taken over by academic researchers. A group of people with learning difficulties from Northampton (the Fresh Start team at Central England People First) wanted to look at what life was like for people with learning difficulties. They felt that the way research is done makes a big difference to what is discovered.

The project used a research support person to give advice on different stages of the research project. Staff members from Central England People First gave support in arranging interviews and collecting information. As this was the first research project that the team had undertaken, and was unusual since people with learning difficulties were in control of the whole process, there was a lot of preparation to work out how the project could be put into practice.

The research

The team worked with 15 people and their friends, families and networks in eleven case studies. They developed ways of presenting information about links between these networks and relationships. The team talked to those with learning difficulties and the people in their networks in a total of 50 interviews and discussed different aspects of their lives including relationships, money, work and housing. The Fresh Start team shared out the interviewing work between them.

The team used diagrams to represent the stories, as well as using interviews and observations. They presented the story about each of the people with learning difficulties and then compared it with other stories by looking at similarities and differences. This involved a great deal of discussion within the team to make sure that the group agreed on the findings.

Sometimes it was difficult for people with learning difficulties to get permission from families and services to do the interview work.

The findings

Money

Money is important in allowing people to make choices. This means having money, but also being in control of it.

- Only one couple interviewed actually controlled their own bank account.
- The people who lived with their parents had the least control.
- Those who lived in residential homes had less control than the people who lived in some of the community-based homes.

The research team and the people interviewed did not always agree on the best way of controlling money. Some felt that people with learning difficulties did need some support. But it seemed that people with learning difficulties had little control of their money or of other decisions in their lives.

Activities

During the day most people either worked or had organised day activities. In some areas, people also had time to themselves to do what they wanted. People who lived at Smith Homes (a village community) could not simply pop out to the shops or just have a break. In the evening, people who lived in Smith Homes and people who lived independently could go out and do things, although often transport was a problem for people who lived out of town. People who lived with their parents had much less choice and control.

Choices

People who used support services sometimes did not seem to mind having limited choices. Fresh Start team members felt that often they had little experience of anything better. Others with learning difficulties decided to live independently and were happy in their lives and relationships, but sometimes their parents did not approve. This made the people with learning difficulties feel let down. The Fresh Start team saw some things happening in support services which they didn't like but felt that people didn't have enough information to be able to see the problems.

Meeting people

Family, friends and people who use services overlap. Families are important to people with learning difficulties, but sometimes this means that choices are limited for them. It was very difficult to find out about those who lived with their parents.

Most people interviewed listed their friends as being people they had lived with or who had used the same services. The people who used outside services seemed to know very few people. They had met some members of the public who were friendly, but some people knew that they had been labelled and did not get respect. The Fresh Start team also saw treatment of people with learning difficulties which they saw as disrespectful.

Conclusions

- People with learning difficulties are not taken seriously as researchers.
- Research by people with learning difficulties can be very important in discovering what happens to people with learning difficulties from their point of view. It is very valuable but it takes time.
- In this study, the more choices that people with learning difficulties had, the more they were included in their local community. The more independently they lived, the more people they knew. People who lived at home with their parents knew the fewest people and had the least choice.
- Some communities of people with learning difficulties offer a range of choices. People were treated more like equals and could do more of what they wanted. However, people who lived in residential places had less choice. Sometimes this was because of the attitude in the home, because a staff member wasn't available to help, or because of transport problems.
- The project did try to look at the lives of people from black or ethnic minority backgrounds. However there were only three such people in the study and it was difficult to find out about their lives.
- Most people had only limited control of their money, but it was unclear what an ideal approach might be. Many seemed happy to have their money controlled and there were different views in the Fresh Start team about the nature of good support.
- Most people had limited control over what to do during the day.

For more information

The full report, **Our lives, our communities: Promoting independence and inclusion for people with learning difficulties** by Craig Hart, Chris Shane, Karen Spencer and Angela Still, is published by the Joseph Rowntree Foundation.

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