Giving people with learning difficulties power through research

Disabled people, older people and people with learning difficulties say that they want to be involved in research about their lives. Research is when you find things out. The Toronto Group is a group of people who talk about giving power to people with learning difficulties and other service users through research.

The Toronto group includes people who do research, people with learning difficulties and other service users as well as people who pay for research. The group had 4 special meetings. This is what they found out:





There are some good ways of involving people with learning difficulties and other service users in research.



Some researchers do not involve people with learning difficulties properly.



People with learning difficulties need to be involved right at the start of research about their lives. They can be involved at all the stages of the project.



People with learning difficulties and other service users need to have a say in **all** the decisions about their lives.



Finding out about the lives of people with learning difficulties

Everyone who does work about people with learning difficulties should involve people with learning difficulties. Sometimes researchers are good at involving people with learning difficulties. Others don't include people with learning difficulties at all.

Some researchers don't include people with learning difficulties in a good way.



People with learning difficulties should be involved right from the start of the project. People with learning difficulties can be involved in all stages of the project.

People with learning difficulties and other service users need to be involved in deciding which projects are good.

Researchers need to tell people with learning difficulties what they found out. They need to check with people with learning difficulties to make sure they have got it right.

The people who give money for research need to make sure that there is enough money to involve people with learning difficulties.



Research and projects by people with learning difficulties

People with learning difficulties can do research. There should be more projects run by people with learning difficulties. Projects run by people with learning difficulties should also involve people with learning difficulties.

These projects also need to show how they would make lives better for people with learning difficulties.



People from Black and minority ethnic communities

Many people said that too much research had been done to people from Black and minority ethnic communities. People from Black and minority ethnic communities have not been involved in doing the projects.

It is important for researchers to get to know people before they do research. Researchers need to know about the communities' language, customs and food. For example, researchers working with Chinese people need to speak Chinese and know about their way of life.

Many people from Black and minority ethnic communities said that they wanted to know how research would make a difference. They want to know this before they decide whether they will take part in research.



Things to do

- You can ask researchers these questions about research projects. The questions will help you find out how well research projects involve people with learning difficulties.
 - What is the project for?
 - How will the project make a difference to peoples' lives?
 - Is there money for people with learning difficulties to have a say in the project?
 - How will people with learning difficulties have a say in what the project will do?
 - How will the project make sure that people with learning difficulties have a say in what the project finds out.
- You can look at Plain Facts 41 and 42. It is called Our Lives, Our Research. You can look at the CDRom. A CDRom works in a computer.

About the Project

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You can get a copy of Research as Empowerment: Report of a series of seminars organised by the Toronto Group from: www.jrf.org.uk/bookshop, using your credit or debit card. The report costs £13.95.

It is also available as a free PDF download from the Joseph Rowntree website. Please contact info@jrf.org.uk or 0 1904 615 905 for more details.

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