

Getting Things Changed

Final report Summary

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'Getting Things Changed' was a **research** project. It took place from 2015-2018. It was about the problems faced by disabled people in the UK and how things can be changed.



We sometimes have good laws and policies. That includes the Equality Act. But disabled people still face problems in practice.



The research was about lots of different parts of people's lives. For instance we did research with people who have a personal assistant (PA).



Another part of the research looked at how students learn new ways of making music in school.



Part of the research was about parents with 'learning difficulties'. They were not labelled as 'people with learning disabilities' but they still needed support when they had a baby.



There was research about actors with learning disabilities on TV.



There were other parts of the research that were about all disabled people, not just people with learning disabilities. For instance, disabled people may need hospitals to adapt to their needs.

How did we do the research?



Disability Rights UK was a partner in the research.



There were also lots of disabled people doing the research. That included a drama group of people with learning disabilities.



One person with learning disabilities was employed as a researcher on the project. Several other people in the staff team were also disabled.



We did the research in lots of different ways. For instance, we made videos of what was happening in people's lives.



We went and asked people questions and ran surveys. Lots of different people took part over all the parts of the research.

What did we find out?



In lots of places, people thought about disability as a problem inside the person. They did not understand the **social model of disability**.



We found that people always do things in the same way. The 'experts' had power, and they made the rules for how to do things. That even happened in the TV channels, but also in hospitals and in social care.



We found that there are still lots of problems for disabled people. For instance, people did not always get information that was easy to understand when they went into hospital.



People did not always like to talk about themselves as 'disabled'. That meant it was hard to know who was disabled and who was not.



We found people often talked about doing '**co-production**'. But disabled people sometimes did not have power to make the changes they wanted.



But when they shared the same goal and had a task to get done together, it was more successful. Disabled people also need to get more confident.



Groups of disabled people supported each other and made changes happen.

That was also true for people with dementia in this project.



There were many places where disabled people could only be the client, or the patient, or the student. But disabled people want to have good jobs, and to be more powerful.

Conversations



Disabled people want to make their own decisions. We looked at how that can happen in conversations with another person.

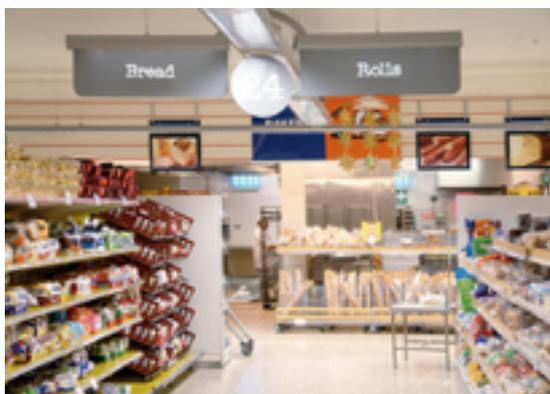


If the conversation did not work well, it sometimes meant that the disabled person did not get what they wanted, like a role on TV.



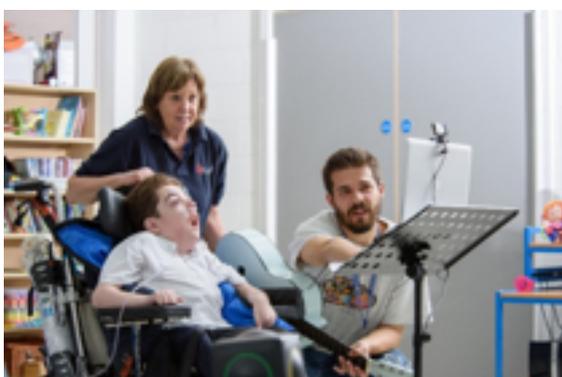
Sometimes the way things get done is difficult for disabled people. It's also difficult when other people are bossy, or do not listen.

Social Practices: another way of looking at things



Social practices are the things we all do, like shopping or cooking. Some people think of social practices being made of:

- 1) Things
- 2) Values
- 3) What people can do



Things

Practices can be changed. We saw how that could happen with music. Disabled people can make music with new types of instruments, using computers.



Values

Support for parents changed for the better, when supporters believed that people with learning difficulties could be good parents.



Disabled people trained staff to do things differently. Sometimes they did this by making videos.

The good things



In our project we found lots of places where people were starting to do things differently. PAs gave good support.



Support services for parents with learning difficulties were thinking more positively about how these parents can do well. And they were making sure they kept in touch, to support them when they needed.



Some people had changed the whole way something can be done. This was happening with *Open Orchestras*, who were changing what it means to make music.



More people with learning disabilities and other disabled actors were getting roles on TV.



Lots of great staff in hospitals were doing things differently, so that disabled people had a better time in hospital.



Creative managers in local authorities were really working with disabled people's groups and listening to them.



And the University was consulting disabled staff and students about its new buildings.

What did we learn about how to make changes to include disabled people?



Changes happened in services when there was a lead person who tried out new things.



That was good, until that person went away. It was important to make changes in the basic way things are done, so that people learn how to do things better for the future. For instance, a disabled person could be in charge.



We need to understand better how things fit together. One thing is linked with another. For instance, when you go to hospital, you need to have transport. Disabled people get stuck, because things do not always fit well.

What needs to happen now?



Disabled people can challenge local authority staff, hospitals or universities by working with them and getting them to change the way they do things.



Disabled people can train staff, especially when they have their own PA. In our project, people with dementia made videos to train staff in lots of different groups.



But we also need other people to make changes, like senior managers in hospitals, universities or in TV.



Managers in hospitals or in social services or universities all need to make sure that they are following the Equality Act. That means they have to change the way things are done to include disabled people, and to check how well they are doing.



Disabled people should feel welcome, and that they are valued. There should be more disabled people in top jobs.



The people at the top should ask disabled people to run training for them, to think about what the social model of disability really means.



Disabled people's organisations should help people use the law to get their rights.



Disabled people need to be confident to do things in their own way, to talk about disability, and change the world.

Glossary

Co-production:

Disabled people work with the managers to change things.

The Equality Act:

a law that says disabled people must have equal rights, and that others need to make changes in order to include them.

Research:

Finding things out, understanding them and changing them.

Social Model of Disability:

the ideas of disabled people about how their problems are caused by the world around them.

Social practices:

the things that we all do, like shopping or cooking.

**Thank you to everyone who
took part in this research.**

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Norah Fry Centre for Disability Studies
8 Priors Road
Bristol
BS8 1TZ

Contact details:
GTC-SPS@bristol.ac.uk

bristol.ac.uk/sps/gettingthingschanged

In memory of Dr. Sue Porter, 1953-2017.