

Does it matter?

Decision-making

by people with learning disabilities.



Easy read
summary



People First
(Scotland)



Contents

Introduction.....3

Our research.....5

What we did.....6

How we did it.....8

What people said.....10

What we learned from reading.....17

What we found out.....21

Steering group members said..... 23

Introduction



My name is Fiona Wallace and I am the Chairperson of People First (Scotland).

I am delighted to present this report and I hope you find it interesting.



**People First
(Scotland)**

People First has campaigned for the rights of people with a learning disability in Scotland for 27 years.



We are the only Disabled Persons User-Led Organisation of people with a learning disability in Scotland.

People First is run by and for us, the members. We hire the staff and we democratically elect our Directors through our local advocacy groups.



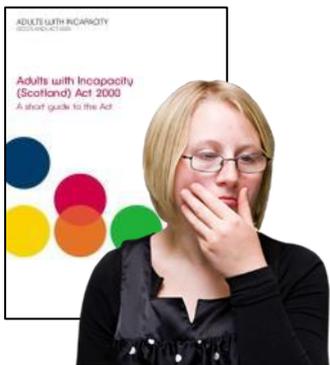
LOTTERY FUNDED



At People First (Scotland) we have always thought it is wrong that people with learning disabilities are denied their right to make decisions, to choose.



In our experience, we are often treated like children and others often make decisions for us.



The law in Scotland can take away our right to make decisions only because of our learning disability.

Many people think it is not a problem that decisions are made by others for us.



This is why we campaign to improve laws in Scotland and to make sure that our human rights are recognised and protected.

Our research



This easy read report is about the research we did on decisions and decision-making by adults with learning disabilities.



Research is when you ask people questions and then you look at the answers they gave. This helps to understand how people think.



We did this research because it is important to find out how people with learning disabilities feel about making decisions or not making them.



The research was funded by the Big Lottery and is called DRILL – Disability Research on Independent Living and Learning.



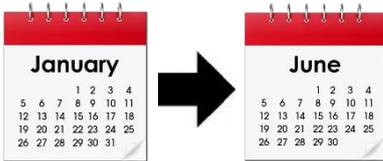
LOTTERY FUNDED



LOTTERY FUNDED



To do the research, People First (Scotland) worked with a company called Animate Consulting. It is their job to do research.



The research lasted from January until June 2017.

What we did



We wanted to find out what works for people with learning disabilities. Especially the differences between being supported to make our own decisions and having other people make decisions for us.



We asked:

Does it matter to people with learning disabilities whether they are supported to make their own decisions or have others make decisions for them in their lives?

We also asked:

- if substitute decision-making will always be needed for some people.
- who could best support decision-making and how



We asked about:

1. Decisions that you make by yourself without support or help from anyone



2. Decisions that people help you to make



3. Decisions that people make about you without asking you



All the people who took part and answered the questions were adults with a learning disability.

How we did it



The research was led by people with learning disabilities.

A 'Steering Group' made decisions about how we do the research.

This was a group of adults with learning disabilities who are members of the People First 'Law and Human Rights Group', funded by Comic Relief.



The Steering Group and Animate Consulting wrote the questions.



A group of People First members called the 'Pilot group' helped us make the questions better by trying them out.



Members of People First (Scotland) called 'Peer-researchers' were trained to ask the questions.



We spoke to more than 120 people with learning disabilities.



We met with groups around Scotland.



We also spoke to some people on their own.



This easy read report is a summary of the answers people gave to our questions.



All the people who took part agreed for their answers to be included in the report.

What people said



Decisions you make by yourself without support or help from anyone

People who took part spoke about the kinds of decisions they make by themselves and how they feel about making them.



Some people said:

“I don’t get other people to decide for me. I’ve got a voice.”



“It empowers me to speak up, speak my mind.”

“I feel it’s better if I decide where I spend my money. If somebody else does my shopping, they might get something I don’t want or don’t like.”



“If you have your own independence, you can choose what time you’re going to things, for example going to church or the theatre, and how you’re going to get there. It’s good if you have your own choices.”



Most people said that making their own decisions helped them feel confident and in control.



People also said that sometimes they find it challenging to make decisions on their own.



Some people said that they sometimes feel nervous. Maybe they are not making the right choice. Often people appreciate some advice or help from others.

Some people said:



“Sometimes it’s hard because I need time to think about things and to choose what I want to do.”



“I feel nervous when I’ve got to decide things for myself but I still do it. It makes me feel good to still go ahead with it.”



“Some people need advice and help to understand but then it is important to get the final choice, go away and decide for yourself.”



Some people said that they don’t always get the chance to make their own choices.





One person said:

“Sometimes I don’t decide, the workers decide. They don’t ask and help me – they tell me what I am doing. Sometimes I want something different and they say no.”



Decisions that people help you to make



Many people said that they sometimes get help to make decisions.

People get help from their family, friends, support workers or social workers.



Most people said they had a positive experience of being helped to make a decision.



People we asked, said that this worked best when they knew the ‘supporter’ well and had built a relationship with them.



People felt that trust and being listened to were really important for this to work.

Most people said it helps to have the right information and advice. They said it was helpful to have support to understand information.



People we asked said these things made a good difference when they make decisions:

- **Support to go through their options.**

Options are the different things you can choose when making a decision.



- **Support to understand the consequences of the choices they could make.**

Consequences are what will happen after you make one choice or another.

Some people said:



“I find it helpful because they might come up with something I’ve not thought about. I’ll start thinking about it and might do it. I know I’m getting the right advice. It comes down to trust – who you can trust



“If I’m doing something, I need all the information to make my choice. Other people can help me get the information and make sure it is accessible to me.”



“I need to do some things for myself but sometimes it’s difficult with choices that involved a lot of things. Sometimes I know what choice I want to make but I double-check with other people I trust.”



A few people said they sometimes felt pressured to make decisions that please other people and found it hard to say ‘no’ if they disagreed.



Decisions that people make about you without asking you



Most people said that they had experienced other people making decisions for them without asking them.

Some people said:



“I don’t get much chance to decide anything. I get decisions made for me and I don’t like it. I’m 47 years old not 12. I want to be able to decide what I do and where I go.”



“Some people don’t get a choice when to leave the night club. Support staff decide when to leave, when their shifts are finished.”



“I feel angry – the reason is because they never consult with me when decisions are being made. They make decisions they think are right for me but they never ask.”



“People say 'go and do this and that'. Like holidays – we stayed in a big house but we did not get to make that decision. Every year is the same. Maybe we don't want to go to Blackpool!”



“I am on Option 3 of Self-Directed Support. I wanted to go on Direct Payments. I wanted to employ my own staff. I had a couple of people I wanted as Personal Assistants. The Council wouldn't let me do it. They said I couldn't sort money out. I felt heartbroken.”



“It makes me feel unhappy, upset, vulnerable - like life is not really your own.”

What we learned from reading



As well as us talking to people, Animate Consulting read a lot about decision-making and the law.

This part of the report talks about what is happening in Scotland at the moment.

Challenges we face



We can be treated like children. Carers and services often have more control over our lives than we do.



The law in Scotland can take away our right to make our own decisions if a judge says we do not have capacity because we have a learning disability. This can be for big decisions and for small decisions too.



The law in Scotland also says that because we have a learning disability we have a 'mental disorder'.



Protecting us should not mean taking away our human rights and dignity.



The focus should be on our ability to make each individual decision and not on being able to make all choices and decisions.

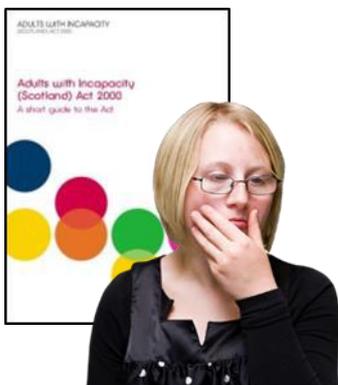


Successful support to make decisions, depends not only on our understanding but also on the skills of the supporter.



Guardianship

Guardianship is when the law takes away our right to make our own decisions and says someone else should make decisions for us. This is sometimes called substitute decision-making.



Guardianships are being granted without trying hard to find out how someone could be supported to make decisions



Making Guardianships happen is expensive and takes a lot of time.



The law says a Guardianship should only happen if all other support has been tried and not worked. This is not happening.

If we have a Guardianship for life, we are not supported to develop skills to make decisions.



Our wishes and feelings may not be taken into account when decisions are made on our behalf; only what other people decide is in our 'best interest'.



The law says Guardians are supposed to be supervised to make sure they are doing a good job. We know that this does not happen for many Guardians.

Once Guardianship is in place the system makes it very difficult for us to challenge it.

What we found out



We found out that making our own decisions does matter to people with learning disabilities, very much.



We also found that in Scotland there are some places where people are supported well to make their own decisions.

We found out that no country in the world has completely moved away from substitute decision-making (like Guardianship) yet.



We found out that there is more research to do and that trying out or “piloting” supported decision-making would help answer the questions people have.



We found out that no one with power in Scotland has decided who should set the rules about how supporters for decision-making work.



We found out that in Sweden supporters for decision-making are skilled and that money is spent to back up the system there.



We found out that in Scotland Guardians are not trained to be skilled in supporting decision-making.



We found evidence that supported decision-making is likely to work for people with learning disabilities but that a big change in attitude is needed to make it happen.

We found that those in power need to think differently about the rights of people with learning disabilities and the risks people with learning disabilities face.



Supported decision-making could work if it is accepted and the money and time is spent to make it happen well.

Steering Group members said:



“This kind of research makes people think differently about us. People can see that we have a voice.”



“I feel the research opened the eyes of people with learning disabilities about their human rights...We also learnt that some people had never thought about how much choice they actually have in their life until they took part in the research. What they used to think was choice, was in fact not a real choice.”



“It was a ‘safe space’ for people...I reminded people who took part in interviews and focus groups all the time that there was no right or wrong answer and that no one would judge them for what they said.”



“Some of us didn’t know what research was before we started. Many people didn’t know what decision-making was. The research has been a way for a lot of people to learn more and understand different things.”



A list of the materials we looked at is attached to the main report. It is on our website;

<http://peoplefirstscotland.org/news/>



People First (Scotland) thanks Photosymbols for their support in our work.