



Easy
read

Supported decision making - experiences, approaches and preferences

June 2018



drill
Disability Research on
Independent Living & Learning



**QUEEN'S
UNIVERSITY
BELFAST**



a charity at the centre of caring

Contents

1. Background to the research	
2. Introduction to the research	
a. Why is decision making important?	Page 6
b. Why did we do the research?.....	Page 7
3. How did we do the research?	
a. Literature review.....	Pages 8-10
b. Peer researchers	Pages 11-12
c. Data collection (interviews)	Pages 13-14
d. Data analysis	Page 15
4. What did we find out from the research?	
a. Experiences of making decisions.....	Page 16
b. Feelings about making decisions on your own.....	Page 17
c. Things that make decision making harder	Page 18
d. Feelings about support.....	Page 19
e. What makes someone a good supporter?	Page 20
f. Types of support people want	Page 21
5. Why was this research important?	
a. Summary of the main things we found out.....	Page 22
b. What we think should happen now	Page 23
6. Hard words and what they mean	
Other things to know about	Page 27-28
Notes.....	Pages 29-31

This document is an Easy Read summary of the ‘Supported decision making – experiences, approaches and preferences’ research report.

This Easy Read summary was developed by Rosalie Edge, Community Support Officer at Mencap NI with support from Mencap Peer Researchers Barbara Norris and Aine Owens.

To request a copy of the full report, or for more information about the project please contact



Rosalie Edge
Mencap NI
02890691351
rosalie.edge@mencap.org.uk

or



Paul Webb
Praxis Care
02890727193
paulwebb@praxiscare.org.uk

Praxis Care, Mencap NI and Queen’s University Belfast would like to thank all the research participants from Praxis Care and Mencap for sharing their experiences and opinions.

Thank you also to the DRILL national and international advisory groups for their input and support.

1. Background to the research



Research is collecting information to find out things.



This research was funded as part of the **Disability Research on Independent Living and Learning (DRILL) Programme.**



This research project was led by **Praxis Care** and was done in partnership with



Mencap NI

and



Queens University Belfast.

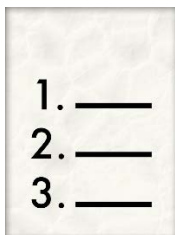


The research report is all about how people have made decisions, and what types of support they like.

It is called '**Supported decision making - experiences, approaches and preferences.**'



Supported decision making is when someone gets support to help them make their own decision.



This report will help you understand

- Why we did this research
- How we did this research
- Why this research is important
- What we want to happen now

2. Introduction to the research

a. Why is decision making important?



Everyone should be allowed to make decisions about their own life.

Making decisions about your own life is called **autonomy**.

This is a key part of **independence, freedom and human rights**.



Some people might not be able to make decisions on their own.

This is ok, because everyone needs help sometimes.



Sometimes, people are not allowed to make decisions.

This includes people with a **learning disability** or **mental ill health**.

This is **discrimination** and it is wrong.



The **Mental Capacity Act (Northern Ireland) 2016** is a law. It says that it is wrong to think that people cannot make decisions.



It also says that people should be supported to make decisions if this is what they want or need.

b. Why did we do the research?



The United Nations Handbook on the Convention on Rights of Persons with Disabilities (Article 12) says that disabled people have the same right to make their own decisions about important things as everyone else.



Disabled people should have the proper support they need when making decisions. If a person really does need someone else to speak for them there should be rules to make sure this is done properly.



Although we know that disabled people should have the support they need when making decisions, we don't know what that support should be.



We did this research to help us find out what that support should be.

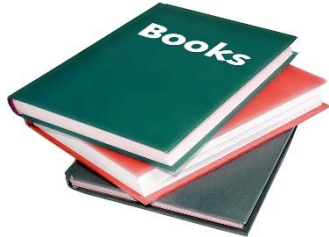
This will help create some guidance for how the **Mental Capacity Act (Northern Ireland) 2016** can make sure people are supported in the right ways.



This is really important to help people make good decisions and live independent lives.

3. How did we do the research?

a. Literature review



We looked at all the research that was already done about how people make decisions. This is called a **literature review**.



The **literature review** helped us understand what is meant by **supported decision making**. It helped us understand the different ways people make decisions.



We looked at different **laws, policy** and **guidelines** about decision making. For example, the **Mental Capacity Act (Northern Ireland) 2016**.



It helped us understand other options, for example, **substitute decision making**.



Substitute decision making is when someone else makes a decision for you.



It helped us understand that people might need different **types of support** for different **types of decisions**.



We make lots of different types of decisions. **Supported decision making** can be **formal** or **informal**.



Formal supported decision making is for big decisions, like when a social worker helps you decide where to live.



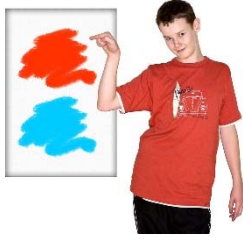
Informal supported decision making is for small decisions, like when someone helps you decide what to have for lunch.



We found out that sometimes, everyone needs some support to make decisions, whether or not they have a disability.



We found out that there needs to be more research done about **supported decision making**.



New research needs to look at people's own experiences about making decisions.



We also found out some **types of support** that are recommended by the **United Nations Handbook on the Convention on Rights for People with Disabilities**:



- Support from someone you trust
- **Peer support**
- **Advocacy**
- Help to communicate
- **Assistive technology**
- Time to plan in advance.

b. Peer researchers



Peer researchers are people who do research and have something important in common with the people in the research study.



Mencap NI employed 2 people with a learning disability to interview other people with a learning disability.



Praxis Care employed 2 people with experience of **mental ill health** to interview other people with experience of **mental ill health**.



The peer researchers had to do all of these things:

- Training about research
- Writing interview questions
- **Data collection** (interviews)
- **Data analysis** (making sense of the information)
- Help write the report.



41 people were interviewed by peer researchers.
They are called the research **participants**.



The research **participants** were all people who have experience of living with a learning disability and/or **mental ill health**.

c. Data collection (interviews)

The peer researchers asked participants questions about



- **Everyday decisions**, like what clothes to wear.



- **Major decisions**, like where to live.



- **Important recent decisions**, like where to go on holiday.



The peer researchers asked participants to tell them

- What **information** or **support** they needed to make the decisions.



- If **other people** were involved in making the decisions.



- **How they feel** about making decisions.

The peer researchers also asked participants



- If **someone else** had ever made decisions for them.



- If they think people should **always** be given support to make decisions.



- If there are times when people **should not be allowed** to make their own decisions.

d. Data analysis



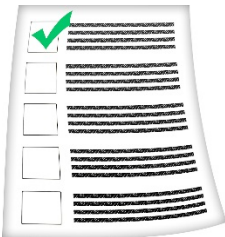
The research team completed **data analysis** after all the participants had been interviewed.



Data analysis helped us make sense of the research findings.



Data analysis is done by using a computer application called **data software**.



Data analysis shows what patterns and themes are in the data. This means what similar things **participants** said during the interviews.



Participants were also given a copy of the findings and asked what they thought before the report was written.

4. What did we find out from the research?

a. Experiences of making decisions



Everyone has different experiences of decision making.
Everyone makes lots of different types of decisions.



Some people said in the past they weren't allowed to make decisions. Other people made decisions for them.



Some people said they make their own decisions all the time. Some people said they have always made their own decisions.



Some people said they find it hard to make decisions on their own.



Some people said they put off making decisions because they find it hard.

b. Feelings about making decisions on your own



Everyone has different feelings about making decisions on their own.



Some people said making their own decisions made them feel happy.



Some people said making decisions on their own made them feel nervous.



Some people find it hard to tell others when they are struggling to make a decision.



Some people get confused if they have to make a decision quickly.



Some people get confused if the information they need to make a decision is given to them in a way they are not used to.

c. Things that make decision making harder



Some people told us about things that sometimes make decision making harder for them.



Sometimes your feelings can make decision making harder, like if you feel sad.



Some people said the type of decision can make it harder. For example, it can be much harder to decide where to live than it is to decide what to have for lunch.



Some people said other people can make decision making harder

- What other people think
- If the decision will affect other people.



Some people said it is harder to make a decision if they feel rushed or do not have enough time to think about the decision.



Some people said it is harder to make a decision if they do not know what things might happen after the decision is made.

d. Feelings about support



Everyone has different feelings about the support they have when making decisions.



Some people said they feel angry if other people are trying to make decisions for them, or if people made decisions for them in the past.



Some people said that they liked it when someone helped them make decisions.



Some people said that they sometimes liked help to make decisions, depending on what happened after the decision was made.



Some people said they liked having support from their family, and some said they think families should always be involved in making decisions.

e. What makes someone a good supporter?



People talked about what made someone a good supporter to help them make decisions.



Lots of words and phrases were used to describe the type of person people wanted to help them make decisions.

Some of the words and phrases were



- A good listener
- Someone you can talk to
- Someone who understands you.



- Someone you know well
- Someone kind and caring
- Someone trustworthy.



There are lots of different people who can be a good supporter, such as

- Family member
- Friend
- Social worker
- Support worker.

f. Types of support people want



There are lots of different types of support people want when making decisions.



Types of support can be **practical**

- Reminders to take medicine
- Support for job searching
- Help filling in forms.



Types of support can be **informational**

- Advice on spending money
- Reading and explaining
- **Accessible information**



Types of support can be **emotional**

- Peer support
- Someone to talk to
- Someone to cheer you on



People said they liked support when making decisions because it helped to give them **independence.**

5. Why was this research important?

a. Summary of the main things we found out



Decision making is important for **independence**.

There are lots of different types of decisions

- **Everyday decisions**
- **Major decisions**
- **Important recent decisions.**



There are things that can make decision making harder

- How you feel
- How much time you have
- What information you have.



There are different **types of support** available to help make decisions

- Family and friends
- Social workers and other professionals
- Information
- Encouragement.



Everyone has different experiences of decision making and everyone likes different types of support when making decisions.

b. What do we think should happen now?



With the new laws, for example **Mental Capacity Act (Northern Ireland) 2016**, people with or without a disability should be given the chance to make their own decisions.



If someone needs support to make a decision, it is important to remember that everyone is different. This means everyone should be allowed different types of support to help them make decisions.



There needs to be more research about what types of support work best for supported decision making.



We think that more research should use peer researchers. The participants said this helped them feel at ease when being interviewed.



We want more people who are involved in making laws to listen to us and use the experiences of people with a disability to help make good laws.

6. Hard words and what they mean

A

Accessible Information – information that is easy to understand, for example, Easy Read

Advocacy – when you get support to have your say

Approaches - the different ways people said they make decisions

Assistive technology – any equipment that makes it easier for someone with a disability to be more independent.

Autonomy – the ability to make a decision on your own.

D

Data – information collected during the research.

Data analysis - making sense of the research findings.

Data collection – how information is collected, for example interviews or questionnaires.

Data software – computer applications to help understand the data.

Discrimination – When someone is treated unfairly because of things like • their disability • their religion.

DRILL – a research project in Britain and Ireland, it is the world's first major research programme led by people with a disability.

E

Experiences – what people have said about times they have made decisions.

F

Formal decision making – decisions that might involve laws and professionals, for example where to live or what health treatment to have.

Freedom – the power to do, say, or think as you want.

G

Guidelines – advice for how something should be done.

H

Human rights - The rights that everyone has, like the right to go to school and the right to start a family.

I

Independence – Doing things on your own. Making your own choices.

Informal decision making – small, everyday decisions, for example what to have for lunch or what TV show to watch.

L

Laws – The rules that everyone in the country has to follow.

Literature review - looking at what research was already done on a topic.

M

Mencap NI – A Northern Ireland organisation that works to make life better for people with a learning disability and their families.

Mental health – how you feel and think about life.

Mental ill health – when you have a long-term and/or serious problem with your mental health.

P

Participants – the people who were interviewed in the research study.

Peer – a person of the same age, status or ability as you.

Peer researcher – people who carry out research who share ability or disability with the participants.

Policy - guidance from the government about how things should be done.

Praxis Care – A group that works to make life better for people with mental health problems.

Preferences - the types of support people like when making decisions.

Q

Queens University Belfast – a place for high-level education, where teaching and research is done, in Belfast.

R

Research is collecting information to find out things.

S

Substitute decision making – when someone makes a decision for someone else.

Supported decision making – when someone gets support to help them make a decision.

Others things to know about

Types of decision

Everyday decision – a decision you make everyday, like what to eat or what clothes to wear.

Major decision – a decision that makes a big difference to your life, like getting married or deciding where to live.

Important recent decision – a decision that involves lots of time or money like deciding where to go on holiday.

Types of support

Emotional – support for your feelings.

Informational – telling you what you need to know to make a decision.

Practical - anything else that helps decision making.

Mental Capacity Act (Northern Ireland) 2016

The Mental Capacity Act is a law that says no one should assume a person cannot make decisions for themselves.

It says people should have support to make their own decisions about their lives.

The Mental Capacity Act says people are allowed to make **unwise** decisions.

There might be times when a person cannot make some decisions for themselves. This is called **lacking capacity**.

Someone might **lack capacity** if they have a learning disability, dementia or a physical health problem, for example,

If someone **lacks capacity**, other people have a duty to make the decision for them in the person's **best interests**.

The person should still be involved as much as possible in making the decision and the decision must be the **less restrictive** option.

United Nations Handbook on the Convention on Rights of Persons with Disabilities

This is an agreement that sets out what countries have to do to make sure that disabled people have the same rights as everybody else.

(Article 12) is all about being treated equally by the law. Disabled people have the same right to make their own decisions about important things as everyone else. Disabled people should have the support they need when making decisions. If a person really does need someone else to speak for them there should be rules to make sure this is done properly.

Notes

Notes

Notes

Praxis Care

25 – 31 Lisburn Road
Belfast
BT9 7AA

T: 028 9023 4555

E: info@praxiscare.org.uk

W: www.praxisprovides.com/

Twitter: twitter.com/praxiscare

Facebook: facebook.com/praxiscare/

Mencap NI

Mencap Centre
5 School Road
Newtownbreda
Belfast
BT8 6BT

T: 02890691351

E: helpline.ni@mencap.org.uk

W: northernireland.mencap.org.uk

Twitter: twitter.com/Mencap_NI

Facebook: facebook.com/MencapNI

Queen's University Belfast

University Road
Belfast
BT7 1NN

T: 028 9097 3151

E: g.davidson@qub.ac.uk

W: www.qub.ac.uk

Twitter: twitter.com/QUBelfast

Facebook: www.facebook.com/QUBelfast/