Easy Read: Lived experience evidence in disability policy making

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The Wales Centre for Public Policy helps to improve policy making and public services by supporting ministers and public service leaders to access and apply rigorous independent evidence about what works. It works in partnership with leading researchers and policy experts to synthesise and mobilise existing evidence and identify gaps where there is a need to generate new knowledge.

The Centre is independent of government but works closely with policy makers and practitioners to develop fresh thinking about how to address strategic challenges in health and social care, education, housing, the economy and other devolved responsibilities. It:

- Supports Welsh Government Ministers to identify, access and use authoritative evidence and independent expertise that can help inform and improve policy;
- Works with public services to access, generate, evaluate and apply evidence about what works in addressing key economic and societal challenges; and
- Draws on its work with Ministers and public services, to advance understanding of how evidence can inform and improve policy making and public services and contribute to theories of policy making and implementation.

Through secondments, PhD placements and its Research Apprenticeship programme, the Centre also helps to build capacity among researchers to engage in policy relevant research which has impact.

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**Welsh Government** is the devolved government of Wales, responsible for key areas of public life, including health, education, local government, and the environment.
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How to use this report

This is an Easy Read document. But you may still need help to read it. Ask someone you know to help you.

Words in **bold green writing** may be hard to understand. You can see what these words mean on page 23.

Where the report says we, this means the Wales Centre for Public Policy.
What this report is about

This is a report. It is about lived experience evidence and co-production for disability policy making in Wales.

Policy makers want to include people with lived experience.

Evidence is information that can be used to prove something.

Co-production is where different people work together as equals.

Policy making is the job of creating a policy.

A policy is a list of what needs to be done and how it should be done.

Policy makers are people who create policy.
We did research to answer three questions:

1. What is the role of lived experience evidence in policy making?
2. What do people say about lived experience?
3. How do people include lived experience evidence co-productively?

Co-productively means working in co-production.

This report looks at how different organisations include people with lived experience. These include grassroots organisations, knowledge brokers and Welsh Government.

Grassroots organisations are people in the community who work together to solve problems and help people.

Knowledge brokers are people who find evidence for policy makers.
Not everybody uses words in the same way. This report looks at how people use words like lived experience and **co-production**.

Some people think that other **evidence** is more important than lived experience **evidence**. This report looks at how important people think lived experience **evidence** is.

This report looks at who is included in **co-production**. The report also looks at who is left out of **co-production**.
How we did the research

We interviewed seven people. We asked them to talk about lived experience and co-production.

We asked them questions about what they think of lived experience.

We asked them questions about how they do co-production.

We read documents about lived experience and co-production. These were written by Welsh Government, grassroots organisations and knowledge brokers. These documents were found on the internet.
Findings

Meaning of words

Some words do not have fixed meanings. For example, disability policy making might be about policy just for disabled people. Disability policy making might also be about how regular policy affects disabled people.

Co-production and lived experience evidence are usually understood as two separate things.

Lived experience evidence is usually described as including information from people who have experience of a topic. In disability policy making, this would be disabled people. Some people would say it is also disabled people's parents or carers.
Sometimes co-production and lived experience evidence were talked about like they were the same thing. Other times co-production and lived experience evidence were talked about like they had to be combined.

This shows that people are using the same words but have different meanings. This might mean it is harder for people with lived experience to understand what is being talked about.

Knowledge brokers and grassroots organisations are usually understood as doing different work.

Grassroots organisations often act like knowledge brokers. They do background research to give evidence to policy makers.
Knowledge brokers can describe their work using grassroots organisation words like advocacy. This is when they use evidence to say what policy is needed.

Research already written talks about people with lived experience, policy makers, knowledge brokers, and grassroots organisations as different groups of people.

Sometimes policy makers and grassroots organisations are also people with lived experience.

This sometimes meant that people from grassroots organisations were seen as the lived experience voice. Some people think it is easier to have people from grassroots organisations. People from grassroots organisations know how policy works.
Grassroots organisations were seen as being able to give lived experience evidence and as having policy knowledge. This meant that they were seen as being super experts. It also means that other people with lived experience are not seen as experts and can be left out.
What evidence matters?

Lived experience is sometimes called extremely important. One document wrote about the statutory duty to include lived experience. This shows how important lived experience is for disability policy making.

A statutory duty is something the law says must be done.

Lived experience might not say what is needed for all disabled people.

Lived experience was not always talked about as evidence. Some people said that lived experience was separate from traditional evidence and not as true as research using numbers.
This might mean that some people still think some evidence is more important than lived experience. Some people said that traditional forms of evidence are gold standard which means the best. Other people were worried about being biased.

**Biased** means listening to one side more than the other.

Not everyone agreed with this. Some people said they need to ensure that lived experience is treated the same as other evidence. Some people said that they don’t think research with numbers is less biased.

Some people said that policy makers get to choose what lived experience they listen to. Policy makers still have power over people with lived experience because they can choose not to listen to them.
Some people said that people with lived experience should not have equal power.

Policy makers also have some power in choosing who gets to give their lived experience. They tell people about projects by sending emails.

This means that a lot of the time the same people who are already talking to Welsh Government give lived experience.
Some people are left out from giving lived experience, even though this is not on purpose. These people are often from minoritised ethnicities or people with a learning disability.

**Minoritised ethnicities** are people who are not White British.

Some people are left out because they do not trust researchers and policy makers.
Including lived experience evidence and co-production

Lived experience evidence is important. But other types of evidence are also important for good policy making.

People do not always say how they include different types of evidence. Some people said that it is hard to do.

Some people said that they look for repeated patterns in the evidence.
Co-production is very important for good policy making. Co-production makes evidence for policy stronger.

Co-production should be at every stage of the policy making process.

But some people said that some parts of policy making are too difficult for people with lived experience. This shows that not everyone agrees that co-production should be at every stage.

It is also not clear what people mean when they talk about co-production. Some people give lots of detail explaining what they mean.
Most documents did not say what **co-production** means. Some people said that the word **co-production** made them feel nervous because it is hard to say what it means.

True **co-production** is involving people with lived experience. This **co-production** shares power. True **co-production** means people with lived experience are equal partners.

But some people said that it was hard for people with lived experience to be equal partners. Sometimes, this is because Ministers make the final **policy** decision.

**Co-production** also means that everyone involved must agree to work that way. Sometimes, people do not do this, meaning people with lived experience feel left out. The people who do not do this are usually other people invited to **co-production** and not Welsh Government.
Co-production means policy making takes a longer time. This sometimes means that people cannot work in co-production.

But some people said that co-production saves money. This is because people with lived experience can see where things are going wrong at the beginning of policy making.
What could be done?

Welsh Government and other organisations can make changes to help include lived experience through co-production.

People need to agree the meaning of words used in a project. This is so people with lived experience know what is being talked about.

People with lived experience should have training when they join projects. This is so they know more about policy making.
Lived experience evidence needs to be seen as just as important as other evidence.

Welsh Government and other organisations need to work harder to include people from minoritised ethnicities and people with a learning disability. This is so people are not left out.

Welsh Government and other organisations should include different types of evidence.
Hard words

**Biased** means listening to one side more than the other.

**Co-production** is where different people work together as equals.

**Co-productively** means working in co-production.

**Evidence** is information that can be used to prove something.

**Grassroots organisations** are people in the community who work together to solve problems and help people.

**Knowledge brokers** are people who find evidence for policy makers.

**Minoritised ethnicities** are people who are not White British.

**Policy** is a list of what needs to be done and how it should be done.

**Policy makers** are people who create policy.

**Policy making** is the job of creating a policy.

**Statutory duty** is something the law says must be done.
Author Details

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