

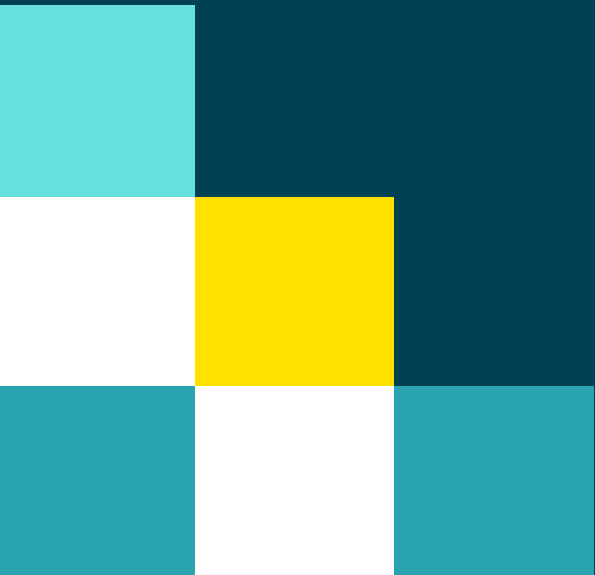


Wales Centre for Public Policy
Canolfan Polisi Cyhoeddus Cymru

Easy Read: Lived experience evidence in disability policy making

Kathryn Williams

March 2023



Our Mission

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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Core Funders



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Economic and Social Research Council (ESRC) is part of UK Research and Innovation, a new organisation that brings together the UK's seven research councils, Innovate UK and Research England to maximise the contribution of each council and create the best environment for research and innovation to flourish.



Llywodraeth Cymru
Welsh Government

Welsh Government is the devolved government of Wales, responsible for key areas of public life, including health, education, local government, and the environment.

Contents

| | |
|--|-----------|
| How to use this report | 4 |
| What this report is about | 5 |
| How we did the research | 8 |
| Findings | 9 |
| Meaning of words | 9 |
| What evidence matters? | 13 |
| Including lived experience evidence and co-production | 17 |
| What could be done? | 21 |
| Hard words | 23 |
| Author Details | 24 |

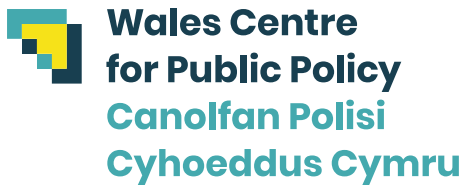
How to use this report



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

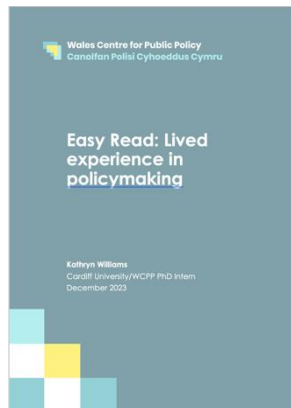


Words in **bold green writing** may be hard to understand. You can see what these words mean on page 23.



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.



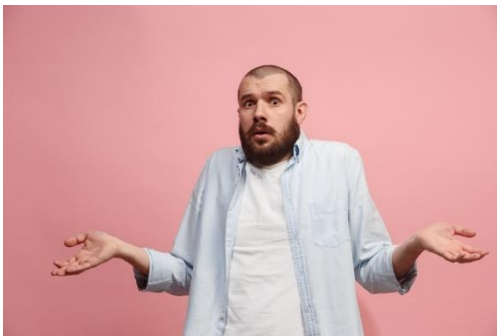
We asked them questions about how they do **co-production**.



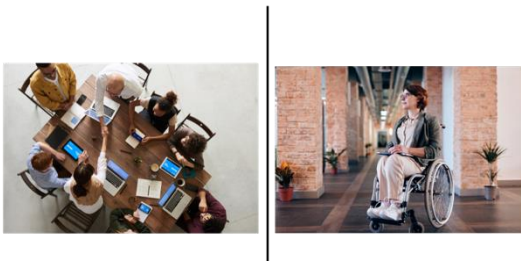
We read documents about lived experience and **co-production**. These were written by Welsh Government, **grassroots organisations** and **knowledge brokers**. These documents were found on the internet.

Findings

Meaning of words



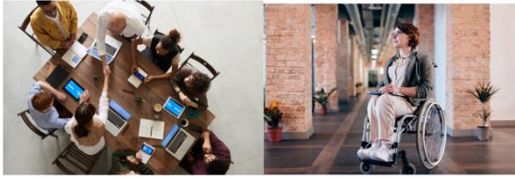
Some words do not have fixed meanings. For example, disability **policy making** might be about **policy** just for disabled people. Disability **policy making** might also be about how regular **policy** affects disabled people.



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**.



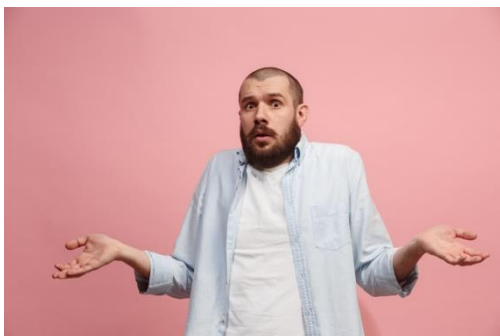
Co-production is very important for good **policy making**. **Co-production** makes **evidence** for **policy** stronger.



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.

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