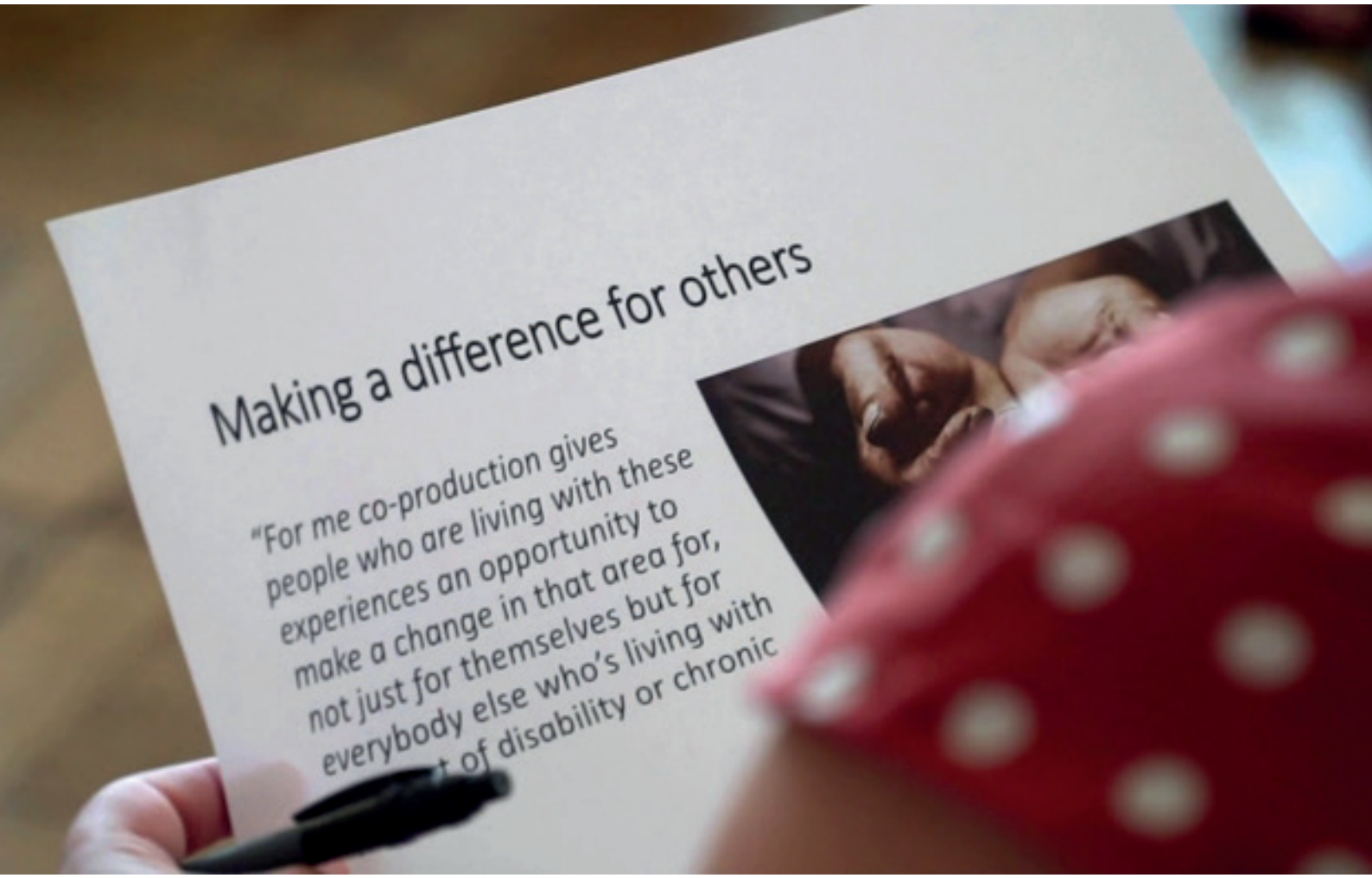
Disability Wales
Anabledd Cymru

Working with Peer Researchers
Developing Future Strategies



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Disability Research on Independent Living & Learning
Ymchwil Anabledd ar Fyw'n Annibynnol a Dysgu

CRONFA GYMUNEDOL COMMUNITY FUND

Disability Wales
Brydon House
Block B
Caerphilly Business Park
Van Road
Caerphilly
CF83 3ED

T: 029 2088 7325
F: 029 2088 8702
E: info@disabilitywales.org
www.disabilitywales.org

Charity Number: 517391
Company Number: 1998621

Disability Wales received funding from the Welsh Government

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Flickr.com/Disability Wales

Contents

Acknowledgements 4

Executive Summary 5

Future Strategies 7

Introduction 8

Policy Context 15

Methodology 20

Research Findings 24

Conclusion 40

References 44

Lead Researcher: Ruth Nortey, Disability Wales, 2019

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Finally, we would like to thank the DRILL funded projects who gave their time to share their experiences.

Executive Summary

This report describes the findings from a series of interviews and focus groups with coproduced research teams who have worked on DRILL funded projects, with a specific focus on the experiences of peer researchers. The research has been coproduced by Disability Wales in partnership with members of Wales School for Social Care Research, HOLI Coproduction Research in Wales, the Wales DRILL National Advisory Group, as well as members from the research teams who participated in the research.

The research provides insights into the benefits of coproduction as well as some of the challenges of this.

Key findings

- In most teams, peer researchers were involved in all aspects of the research process. However, the inclusion of peer researchers during the funding application stage was particularly limited because teams did not usually have access to necessary funds to enable this. Seed corn funding could enable peer researcher involvement in the initial stages of an idea.

- There were mixed feelings about the term 'peer researcher'. This phrase is easily understandable to funding bodies, disabled people and policy makers. However it may reify existing unequal hierarchies between academic researchers and those with lived experience. Consensus was not reached about a suitable alternative term.

- Research coproduction in disability studies is crucial to including the contributions of disabled people. Peer researchers played a particularly important role in recruitment, fieldwork and research dissemination.

- Participation in coproduced research improves peer researchers' wellbeing, raises confidence levels, extends networks and broadens future aims.

- A number of barriers to successful research coproduction were highlighted. These challenges include:
  - the difficulties of arranging payment for those peer researchers who receive welfare benefits. Given these challenges are widespread and complex, we recommend further research and action on this area.
  - poor planning of the provision of in-depth training and support for research team members.
  - University ‘red tape’ within universities can make it difficult for peer researcher involvement.
  - The need for flexibility from all parties was considered key to overcoming such challenges.

Future Strategies for Working With **Peer Researchers**

Define Co-Production

The term 'co-production' is not understood in the same way by all. This may lead to power imbalances and conflict during the research process. It is useful to discuss and create mutual understanding of co-production at the start.

Build Research Capacity Within DPOs

Disabled People's Organisations (DPOs) and individual disabled people require sustainable access to finding and practical support to continue to build their capacity to lead on disability research projects. Opportunities for training and networking would help to build capacity.

Make Co-Production Mandatory for Funded Research

DRILL has shown that research co-production delivers high-quality research and can have wide-reaching outcomes for policy and practice. We would like to see funding bodies make co-production an essential requirement for all disability research projects.

Value Lived Experience

Our findings indicate that disabled people's lived experiences are often under-valued in universities, leading disabled researchers to feel their involvement is tokenistic. We must create a culture which ensures peer researchers have equal roles within research projects.

Institutional Change

University 'red tape' can obstruct disabled people's involvement in research projects. We must review policies and practices to ensure that these meet the requirements of all involved.

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Introduction

The DRILL Programme, which stands for Disability Research in Independent Living and Learning, is led by disabled people, for disabled people. DRILL is a five year, four nations coproduced research programme funded by the National Lottery Community Fund. DRILL delivers the world's first major research programme led by disabled people. Each of the four national Disabled People's Organisations in the UK are partners in the programme.

The programme has distributed £3.5m to fund 32 research projects across the UK. At the heart of the DRILL Programme is the promotion of research coproduction between disabled people, disabled people's organisations (DPOs), academia, research bodies and policy makers. Through DRILL, disabled people have been empowered to influence decisions that impact on their independent living, particularly in relation to policies, legislation and services.

Nothing About Us Without Us

The slogan 'Nothing about us without us' became a rallying call for disabled activists during the 1990s (Charlton, 2000). The slogan supported the disability rights movement which sought the direct participation of disabled people in decision-making processes. Disabled people were rejecting the traditional form of paternalistic support and wanted an active role in deciding how they live their lives.

Disabled people in Wales are more likely to experience poverty and to have fewer opportunities than non-disabled people (Davies and Parken 2017). There are two main theories used to explain why disabled people are disadvantaged. These are the Medical Model of Disability and the Social Model of Disability.

The Medical Model of Disability focuses on the individual's impairment as the root cause of societal disadvantage. From this standpoint, people living with impairments are either 'fixed' by medical interventions or segregated from society. Historically, the Medical Model of Disability views disabled people as passive recipients of care, dependent on others for support (Oliver, 1983, Finklestein, 1993).

The Social Model of Disability derived from the disability rights movement of the 1980s, where disabled people rejected the disempowering approach of the Medical Model. The Social Model focuses on the attitudinal, organisational and environmental aspects of society that prevent disabled people from living the lives they want to (Roulstone, 2004). The Social Model of Disability removes the blame from the individual disabled person and focuses on how society can be adapted to be more inclusive.

Traditionally, public services have not provided disabled people with opportunities to make decisions about or evaluate the services they receive. The values of coproduction – sharing power and decisions with citizens, the involvement of people with lived experience and a promotion of a culture in which people's experiences are valued and respected – are closely linked to the principles of the Social Model of Disability. The true

sense of coproduction includes disabled people on an equal footing with academic or professional researchers.

What is Coproduction?

The framework of coproduction has featured heavily in health and social care and seeks to engage members of the public in how the services and facilities they use are delivered.

There are various definitions of coproduction. Dineen (2012) defines coproduction as a democratic and effective method of commissioning, designing, delivering and evaluating public services. Löffler (2009) suggests that devising a set of principles and values for coproduction is more effective than using one single definition. Advocates for coproduction largely follow the following principles and values:

- **Equality** – Value all participants and build on their strengths. All participants share equal power and responsibility
- **Reciprocity** – Develop networks of mutual support, where people get something back for what they have contributed
- **Diversity** – Coproduction should be as diverse and inclusive as possible, with under-represented groups being encouraged to participate
- **Accessibility** – Making practices and processes accessible will reduce barriers and allow more people to participate fully

Coproduction and Peer Research Methodology

Traditionally, research on disability has been developed and led by non-disabled people, excluding the voices and lived experiences of disabled people. In contrast, peer research approaches seek the involvement of community members in the design and delivery of the research.

For many years, researchers in the social sciences have been using terms such as 'action research', 'feminist research methods', 'participatory action research' and 'emancipatory research'. These terms stem from very different historical and political contexts and precise definitions of these concepts vary between and within academic disciplines. However, these terms all share two important elements.

First, they involve people with lived experience of the research area. Second, they aim for research to lead to change. 'Coproduction' and 'peer research' are relatively new terms but in essence, this emerging body of work builds on the collective wisdom offered by this canon.

The focus of this research project is to explore the benefits and challenges of research coproduction. The term peer researcher has often been used to refer to people who are recruited and given basic research training and then asked to interview other people in the target population (Elliot et al, 2012). For example, people with learning difficulties would be trained to interview others with learning difficulties. This approach is attractive to research teams who may find it difficult to gain trust and engage participants from the target population. In contrast, however, we have sought to broaden research coproduction in this project by enabling disabled people to take the lead in the research process at all levels, not only during fieldwork.

In this research project we define 'peer researchers' as disabled people with previous experience of research (whether currently working as a researcher or not) and also disabled people with no prior research experience, who have been recruited and trained specifically to co-produce DRILL funded research projects.

Why Explore Experiences of Coproduction in Disability Research?

DRILL is a four nation research project which delivers the world's first major research programme led by disabled people. In total, DRILL has funded 32 research projects plus two commissioned research projects. All projects have been co-produced with disabled people in the lead.

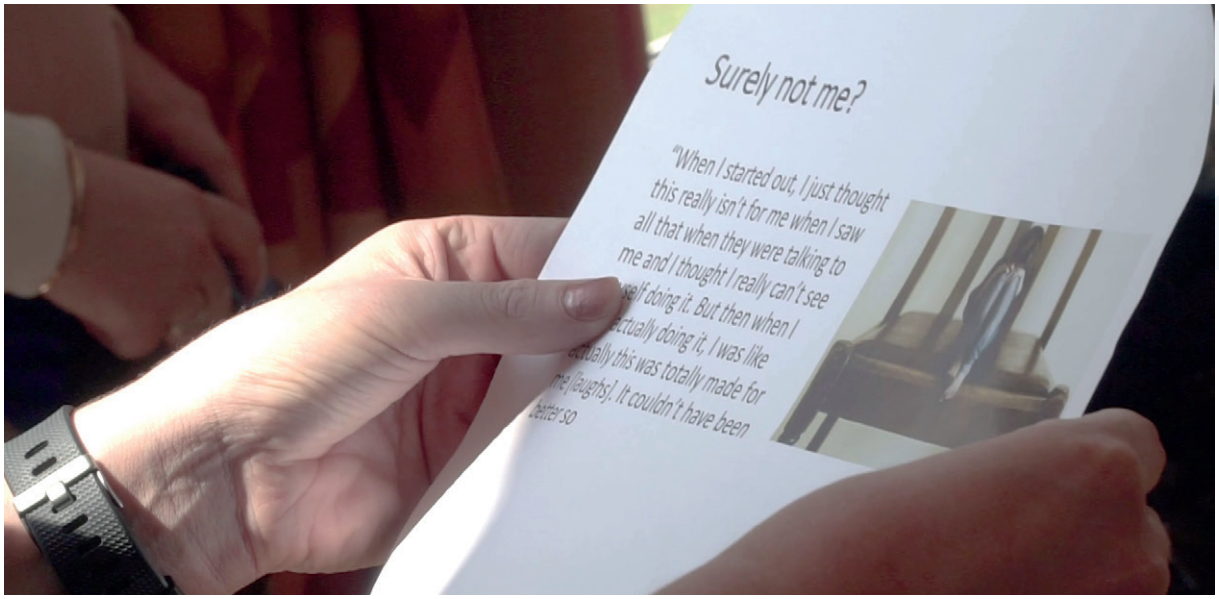
In supporting and monitoring DRILL funded projects, Disability Wales saw that the research projects were developing an array of innovative and accessible approaches to coproduction throughout the research process. The many challenges to research coproduction also became apparent. For instance, DRILL Programme Officers were told about the difficulties projects faced when seeking ethical approval from university research ethics committees. As small third sector organisations, the DRILL Team also became aware of bureaucratic inefficiencies common to very large organisations such as universities.

At Disability Wales it is important to us that disabled people are actively involved in producing research that will lead to positive change. We want to see more disabled people designing, delivering and leading on disability research. With crucial learning about coproduction emerging as part of DRILL funded projects, and driven by a concern that attitudinal and institutional barriers could discourage academic researchers from collaborating with disabled people or DPOs in the future, we sought to highlight the advantages of research coproduction, and some solutions to the barriers encountered.

Our Research Team

This research project has been co-produced by Disability Wales and a project reference group. The reference group included representatives from the DRILL funded projects that participated in this research, as well as representatives from HOLI, DRILL Wales National Advisory Group (NAG), and the Wales School for Social Care Research. The Wales NAG co-wrote the application form for funding, and in partnership with Disability Wales' researcher – Ruth Nortey – the reference group:

- Decided which DRILL funded projects were invited to participate
- Developed the list of questions for the interviews and focus groups
- One member facilitated a data analysis session, and the rest of the group contributed to the analysis of the data
- Provided feedback on the final report and dissemination methods
- Contributed to the project dissemination video
- Are planning to write a peer reviewed journal article based on this research



Our Research Question

This research sets out to answer the following research question:
"What has DRILL learnt about working with peer researchers through the work of the DRILL funded projects?"

More specifically, this report explores five key issues:

1. How have DRILL funded projects utilised the skills of peer researchers?
2. What are the barriers in working with peer researchers and how can these be tackled?
3. In which ways has participating in DRILL-funded projects changed things for the peer researchers?
4. How has collaboration with peer researchers impacted on the outcomes of the project?
5. What alternative language could be used instead of 'peer researcher' to reflect the non-hierarchical philosophy of coproduction?

Policy Context

This section sets out the context of coproduction and its development. The first section of this review outlines the policy context at international, UK and Welsh Government levels. This includes legislation and guidance issued by intra-government, national and devolved governments and third sector organisations involved in increasing levels of coproduction within academia and within communities.

Coproduction in Health and Social Care

International and national legislation provides a framework that encourages coproduction in decision making across various sectors including research, health and social care services.

Outside of academia, coproduction is mostly practiced within the health and social care sector. Recent legislative developments across the devolved nations have seen an increased emphasis within Health and Social Care legislation on the importance of co-producing policy developments with members of the public, particularly those that may be directly affected by policy changes.

The United Nation's Convention on the Rights of Disabled People (UNCRDP) does not explicitly mention coproduction, however it does call for disabled people to be involved within their local community and decisions that affect their lives.

Coproduction in Wales

DRILL is a four nation research project which delivers the world's first major research programme led by disabled people. In total, DRILL has funded 32 research projects plus two commissioned research projects. All projects have been co-produced with disabled people in the lead.

The principles of coproduction feature widely across Welsh legislation and policies. In relation to public service delivery the Welsh Government defines coproduction as:

> *"the concept of genuinely involving people and communities in the design and delivery of public services, appreciating their strengths and tailoring approaches accordingly. As set out in its vision, co-production is fundamentally about doing things 'with' rather than 'to' people" (Auditor General for Wales, 2015:87)*

This definition sets out a clear vision for coproduction in Wales. **The Social Services and Wellbeing (Wales) Act 2014** is a ground-breaking legislative framework that aims to transform the way social care support is delivered in Wales. Coproduction is an overarching principle of the Act which places the public at the heart of care and support packages. In practice, the public have equal decision-making powers in commissioning social care services, evaluation and assessments for social care packages.

However, recent findings from the Measuring the Mountain project, which evaluated the impact of the Social Services and Wellbeing (Wales) Act 2014, found that the values of coproduction have not been widely adopted within social care in Wales. The findings indicate that more work is needed to ensure the principles of coproduction are embedded within social care practices (Cooke et al, 2019).

The **Wellbeing of Future Generations (Wales) Act 2015** embeds public involvement as part of its sustainable development principles. In addition, one of the principles of prudent healthcare in Wales is to "Achieve health and well-being with the public, patients and professionals as equal partners through coproduction" (NHS Wales, no date: 3). The Act places a duty on

public bodies to involve people that reflect the diversity of the communities that they service within their working practices.

The Coproduction Network for Wales was launched in 2012 as a voluntary endeavour. It is now a member led network that advocates for coproduction of public services in Wales through campaigning, influencing legislation and training.

Coproduction in England

The incorporation of coproduction within English health and social care legislation is somewhat inconsistent. The **Care Act 2014** is the legal framework for social care in England. The Act includes coproduction within its statutory guidance. However, the definition of coproduction in the Act only mentions individuals influencing service delivery. This does not reflect the spirit of coproduction where members of the public and professionals have an equal say in the way services are developed and run.

The NHS England: Five Years Forward plan does not explicitly discuss coproduction. However, it does include many of the values of coproduction including community engagement and patient empowerment.

The **Health and Social Care Act 2012** does include duties on public bodies to ensure coproduction, participation and involvement of the public within decision-making. This is a positive measure and ensures that citizens have a greater voice within all levels of decision making within NHS England.

Getting Things Changed (University of Bristol, 2018) was a large multi-centre research project focused on coproduction and disabled people. The research was led by the University of Bristol and explored the barriers to and opportunities of coproduction between disabled people and statutory services and the impact on disabled people's health and independent living. It also focused upon the attitudes of managers and frontline staff. The research highlighted that in some instances coproduction was simply a tick box exercise that lacked meaningful engagement with disabled people.

The research also found that disabled people were often viewed as the 'lay' person with little value given to their knowledge or experience. These findings highlight institutional cultures where power is held almost entirely by managers and senior professionals. Nevertheless, the findings indicate some signs of improvement and a shift towards the implementation of coproduction within statutory bodies.

Coproduction in Northern Ireland

There are few policies and legislation relating to coproduction in Northern Ireland. This could be attributed to the lack of devolved government in Northern Ireland since January 2017. However, guidance relating to social care from the Department of Health, Social Services and Public Safety and the Health and Social Services (Ireland) Act 2009 does include duties for public participation and involvement (PPI) within health and social care delivery.

Coproduction in Scotland

Over the past decade the Scottish Government has adopted the values of coproduction within its policy development, particularly within the design and delivery of health and social care services. The Scottish Coproduction Network was created as an informal network in 2010, co-facilitated and chaired by the Scottish Community Development Centre and NHS Tayside on a voluntary basis. The Network is supported by the Sottish Government and aims to facilitate the sharing and exchange learning of coproduction practices.

The principles of coproduction feature within Scottish health and social care legislation. The **Community Empowerment (Scotland) Act 2015** embraces the spirit of coproduction by calling for communities to have a greater say in decisions that affect their lives. The Act seeks mutual responsibility between the citizens and public bodies in creating communities that work for all.

The **Public Bodies (Joint Working) (Scotland) Act 2014** integrates adult health and social care services in Scotland. The Act contains a duty for people who use the services – as well as careers, service providers and professionals – to be included in the strategic planning and commissioning of services.

Additionally, the **Social Care (Self-directed Support) (Scotland) Act 2013** alters the balance of power and gives people greater choice, voice and control over the way the services they receive are delivered.

Methodology

This research took an inductive approach using qualitative research methods – interviews and focus groups – which we believed offered the most effective way to explore the complex and nuanced experiences of research coproduction as experienced by research teams in DRILL funded projects.

The Project Participants

Initially, 12 DRILL funded projects were invited to participate in this research project. We invited projects running concurrently with our own fieldwork timeline as well as those projects that had already finished, in order to collect a range of viewpoints. In addition to the inclusion of all four nations in this research, we sought projects that represented a diversity in relation to gender, ethnicity, social class and age as well as including people living with a range of impairments or health conditions.

In the end, six projects participated, including at least one project from each nation. We found recruitment to be relatively straightforward. Perhaps this was because projects saw the benefits of having a space to reflect upon their experiences of either being a peer researcher or working alongside peer researchers.

Given that we aimed to collect a diversity of experiences of coproduced research represented in the DRILL Programme, we spoke to

- Peer Researchers with prior research experience
- Peer Researchers with no prior research experience
- Academic researchers
- Independent researchers[1]
- Disabled people involved in project steering groups

[1] Defined as self-employed researchers or those who are between research jobs.

Interviews and Focus Groups

Each project was invited to take part in a focus group – involving the whole project team – or individual interviews. As this project included participants from across the four nations, we tried to be as flexible and accessible as possible in our approach to the fieldwork. As a result, a number of individual interviews were conducted via telephone where this method was accessible to the individual. The other interviews and focus groups were conducted in a location chosen by the participants. In total, four focus groups and ten individual interviews were conducted by researcher Ruth Nortey, who identifies as a disabled person.

Both the focus groups and interviews were based on questions designed by the Project Reference Group. On average, the interviews lasted around half an hour, and the focus groups around one hour. With the participants' consent, the interviews and focus groups were digitally recorded and then transcribed.

Data Analysis

Community of Inquiry Session

A photo taken during the Community of Inquiry Session; 10 group members can be seen sat in a circle in the middle of a Community Hall.

A Community of Inquiry session provided an accessible way for the Project Reference Group to analyse the data. The Community of Inquiry session was held with the Project Reference Group, staff, trustees and volunteers from Disability Wales and other disabled people interested in coproduction. In total, 15 people attended the data analysis session, which was facilitated by Nick Andrews, of Wales School for Social Care Research.

In brief, a Community of Inquiry is a 10-step approach to generating questions and facilitating discussion in response to a stimulus. The stimulus in our session included short, varying excerpts from the data, which were chosen by the researcher. Group members then work together to generate a question based on themes from the stimulus material. This question then forms the basis of a longer discussion. During the discussion group members can only build on what the last person has said and only one person can speak at a time, which allows for a highly reflexive discussion.

In using the excerpts from the data as stimulus, the Community of Inquiry session helped the group to identify the main themes from the project findings.

The researcher and the Project Reference Group used these themes to structure the research findings into a cohesive story, and guided by the initial research questions drawn up by the Wales NAG.

Ethical Considerations

This research project was approved by the DRILL Ethics Committee. Our application to the Committee addressed power relationship between the Disability Wales researcher and the participants, who were being asked to reflect on experiences relating to DRILL-funded projects they have led or otherwise participated in. One of our concerns was the potential conflict of interest between this research and Disability Wales' role in monitoring DRILL-funded projects, which might have impacted on the data produced. To reduce this conflict of interest the role of DRILL Wales Programme Officer and Researcher were staffed by different people. In order to limit the power differences between the participating projects and our partnership and the wider DRILL team, we set up a Project Reference Group, made up of individuals who have not been part of DRILL processes of assessing grant applications. We invited a representative from each of the funded projects as well as representatives from HOLI and the Wales School for Social Care Research.

Each participant was given a Project Informant Sheet and Consent Form before the interview or focus group. Participants were given the opportunity to ask the researcher questions about the research before participating.

Research Findings

The word cloud below represents the frequency of the top count words used in the interviews and focus groups. The most frequently used words were; People, Research, Project, Researchers and Peer.

Section 1: What Does Coproduction Mean

In this section we explore participants' understandings of the term 'coproduction', and then focus on terminology, in particular the phrase 'peer researcher'.

The meaning of the term 'coproduction' generated a mixture of responses. Some participants had not heard of the term before, whereas other participants with some previous research experience were able to offer definitions that included:

> "It means working together"
> *Peer Researcher*

> "It's bringing people together with different experiences and different viewpoints under shared values to achieve change"
> *Peer Researcher*

> "The service users and the academics work together to investigate a topic, to produce the resources, to present the findings so that as much as possible it's joint working together"
> *Academic Researcher*

All those to whom we spoke – both disabled people and non-disabled people – pointed to the importance of disabled people playing an active role in disability research. Participants said that coproduction in disability research gave disabled people a chance to have their voices heard:

> "We are the ones who need to be telling the story really, we're the ones who should be using our voices, to go and find the research and to contribute to what the policies are"
> *Peer Researcher*

Whilst many responses incorporated the principles of coproduction in keeping with the definitions proposed by Löffler (2009) and Dineen (2012), some respondents told us that there was not always agreement about the definition of research coproduction within their research teams:

> "[colleague] got all of us to write down what we thought coproduction meant. And when we compared our answers it was kind of 'oh, we should have done this before we started'. Because we did all have different ideas about what coproduction meant"
> *Project Researcher*

As this respondent indicates, it is important that all team members have a shared understanding of the principles of coproduction. This may serve to establish equal working practices at the start of the project and ensure that all parties are working towards similar goals in keeping with the spirit of coproduction.

Nevertheless, our respondents pointed out that even when research teams have shared understandings of research coproduction and had wholeheartedly aimed to share power and responsibility on an equal basis at the outset of the project, various barriers could work to prevent this. These various barriers are discussed in more detail in section four.

What terminology should we use?

Our Project Reference Group wanted to explore research teams' language preferences, especially in relation to the term 'peer researcher'. This is because some members of our Project Reference Group were concerned that the term 'peer researcher' is not in keeping with coproduction because it may perpetuate traditional hierarchies between academic researchers and those with lived experiences.

We asked our participants about the term 'peer researcher' and what this signified to them. For some, the term peer researcher identified that the researcher had a shared identity with the research participants:

> "For me a peer is somebody who is part of the group in a way but also they are also a researcher"
> *Peer Researcher*

Other participants suggested that the term placed researchers with lived experience on a lower status than researcher with formal academic qualifications. For some the term perpetuates the assumption that researchers with lived experience do not have academic qualifications and academic researchers do not have relevant lived experience:

> "Quite often it just means 'other'. It means lesser. If it's going to mean anything it should mean better"
> *Peer Researcher*

> "I think it puts the academic researchers in a different box where they don't get to be peers"
> *Peer Researcher*

Moreover, some peer researchers did not want to be identified as a peer researcher because this would identify them as having a particular impairment when they were psychologically not ready to 'come out' in the public domain:

> "it might be a hindrance if you have peer or lived experience in your title"
> *Project Partner*

To avoid the issues of hierarchy, one DRILL funded project used the term 'co-researchers' for the whole research team. The team told us that in their opinion this terminology was successful in signifying equal power within the team.

In discussing the advantages and disadvantages of the term 'peer researcher', most of those used the term 'peer researcher' because this term was easily understood by disabled people, funding bodies and policy makers. Most research teams had some misgivings about the term 'peer researcher', yet their use of the term did not mean they subscribed to unequal hierarchies within research coproduction, only that there seemed to be no other alternative phrase that could be used.

Our participants agreed that if the term 'peer researcher' is used by those practicing research coproduction, it needs to have a clear definition that does not undermine the expertise and knowledge carried by all team members. Within this research report, in line with the participants' preferences, we have opted to use the term 'peer researcher'. Nonetheless we remain mindful of problems with this term and would encourage further attention and research on this terminology.

Section 2: The Benefits of Research Coproduction

In this section we discuss the advantages that research coproduction brings, paying attention to the individual benefits gained by the peer researchers as well as the ways that coproduction may improve aspects of the research process, including recruitment, data collection and the impact of the research.

Benefits of research production on the research process

One important contribution of peer researchers was to help produce information sheets in plain English, which often served to increase recruitment by making documents much more accessible. Peer researchers described their participation in the research as being reassuring to the participants, as one peer researcher told us:

> "Having an actual true peer researcher within the project increased participation, because participants would actually have somebody who they can in some way relate to"

This finding is consistent with previous research studies that suggest that involving those with lived experience in research encourages people from the target audience to participate in the research (Purcal et al 2018; Elliott et al, 2002; Durose et al 2011).

There is now a rich body of literature which explores the diverse ways that a researcher's identity as an insider or outsider can impact on the data that is collected in qualitative research studies (Mellor et al, 2014). Burns and Schbotz (2009) noted that the shared experiences and language between researcher and participants may encourage participants to give responses which are more detailed, due to a stronger rapport during fieldwork. Commenting on the advantages that this perceived disability 'insider' status brings to data collection, a peer researcher told us:

> "I have had people say to me at the end of an interview, 'I've told you things I've never told anyone before'"
> *Peer Researcher*

> "We were able to empathise I think on a level that a professional researcher wouldn't"
> *Peer Researcher*

Smith et al (2008) suggest that peer research involvement during the dissemination stage of a research project can increase the impact and credibility of the research findings, due to the insights that lived experience brings. Increasing diversity within research teams enriches discussions and brings new ideas and perspectives (Biziewska and Johnston, 2015). Some participants we spoke to highlighted the importance that played by peer researchers during research dissemination activities, as we were told by one university researcher:

> "The peer researchers introduced a level of emotion and a communication of the importance of what the research was about which I probably wouldn't have been able to"
> *Academic Researcher*

All academic researchers that we spoke to noted that peer researcher involvement had a positive impact on the whole process. Among the benefits of coproduced research, peer involvement was thought to bring innovation with teams becoming more dynamic as compared to traditional types of research:

> "[The meetings] were a bit more relaxed, a bit more open and a bit more flexible, there was much more laughter and engagement as a team than on other projects"
> *Academic Researcher*

Section 3: Individual advantages gained by peer researchers

Much literature has reported the benefits that research coproduction has on peer researchers in relation to raising confidence and the opening of future opportunities (Durose et al, 2011; Guta et al, 2013). One advantage of research coproduction is that it builds capacity within communities, by empowering those involved (Purcal et al, 2019) and enhancing peer researchers' skills and opening opportunities for contributing to making changes within their communities (Zimmerman, 1995).

Our research found similar advantages. All members of the research teams we spoke to benefitted on an individual level by engaging in coproduced research. We do not want to suggest that it is only peer researchers who gained from coproduction. In fact, some discussions pointed to the ways that professionals and academic researchers also experienced valuable formal and informal learning which may increase their future career opportunities. However, we focus upon the ways that individual peer researchers benefit from participating in research coproduction, given that this topic was discussed in much greater detail.

All the peer researchers to whom we spoke had received in-depth training and support to carry out their research role. This training included, for instance, training in data analysis or presentation skills to ensure that peer researchers had an equal role in the research as well as receiving transferable skills for the future. Similar to the training that peer researchers received in the research of Logie et al (2012), Lushey and Munro (2014) and Smith et al (2008), many of the teams we interviewed discussed the indepth methods training for peer researchers. Unusually, in one project, this training was a formal, accredited qualification in research methods. For some peer researchers, involvement in DRILL funded research projects has opened up the possibility of returning to university to continue learning, or to pursue greater involvement in disability research in the future.

Out of the 15 peer researchers interviewed for this project, at least five have progressed on to paid employment as a direct result of their research work.

> "The [Lead Partner] sent me a thing saying 'I think you'd be great for this job' and I applied for it and I got the job!"
> *Peer Researcher*

> "Doing this research has given us skills that we can use, possibly, in different jobs"
> *Peer Researcher*

Given that disabled people are much more likely to unemployed, or underemployed, the opportunities associated with becoming involved in research coproduction are significant.

Some peer researchers we spoke to noted that as a result of their research work, they had developed a better understanding of their own health conditions as well as a greater awareness of the lives of other people with the same condition. This knowledge was considered to be empowering and opened up valuable networks. This phenomenon has been reported by Devine (2004), who found that participation in qualitative research can open up valuable networks and lead to greater understanding of key issues.

> "It made me appreciate as an individual how fortunate I am with my situation. It makes you appreciate what you do have"
> *Peer Researcher*

Involvement in the research projects also helped some peer researchers to develop their own independent living skills, including their confidence in using public transport alone. Many peer researchers described how their confidence had increased through the course of the research, particularly those who had never had the chance to take the lead in this way before. As one peer researcher told us,

> "There is such a sense of feeling valued and feeling heard being able to be part of research like this"
> *Peer Researcher*

A strong sense of achievement arose from the opportunity to make a difference to the lives of other disabled people, as one peer researcher told us:

> "I can't change the fact that this has happened but what I can do is my part in ensuring that hopefully this doesn't happen again."
> *Peer Researcher*

Section 4: Challenges

In this section, we discuss a number of challenges as experienced by research teams practicing research coproduction within disability studies.

Ongoing support and training

The diverse support needs of disabled people working as peer researchers is a topic which has not received a great deal of attention within the academic literature (Logie et al, 2012). By paying attention to the complexity of positions that disabled peer researchers may inhabit, the process of research coproduction raises a diversity of experiences and training or support needs.

Our research has highlighted a number of practical challenges associated with research coproduction. Similar to the findings of others (Elliott et al, 2002; Lushey et al, 2014), we also found that coproduced research teams required ongoing, intensive training. This was crucial to ensuring all team members have an equal role in – and responsibility for – the research. This may present a challenge to projects that have not adequately planned for this level of support. However, such support is often difficult to deliver. Within the literature there is agreement that research coproduction takes longer and may incur additional costs, as compared to research that is not coproduced (Roche, Guta and Flicker, 2010; Elliot et al, 2012).

The type of support offered by the teams we spoke to varied a great deal. Some of the teams, for instance, provided peer researchers with independent living support to ensure the safety of peer researchers conducting fieldwork, as one respondent told us:

> "We always got help on what buses we needed. I got given directions on what buses to get on and they picked me up at one place and took me to the other place"
> *Peer Researcher*

Given that many coproduced research teams we spoke to were asking all members of the team to step out of their 'comfort zone' and to practice a type of research they might not have done before, the teams that were most successful were the ones who provided in-depth support and mentoring to all who needed this. This is what we were told by two respondents:

> "Some were already experienced researchers, but some had no experience, really, of conducting research. So that was a challenge"
> *Academic Researcher*

> "When it came to completing a particular task I'm sure many of us here to begin with had never done this sort of primary research before, so we were able to ask [Lead Partners] as many questions as we wanted to, just to know how best to complete this particular task"
> *Peer Researcher*

Some academic researchers we spoke to regarded coproduced research as carrying greater risks than other types of research, as this respondent told us:

> "There is a risk in adopting this model that, for us was around letting go of power, letting go of control. The uncertainty, what happens if you don't produce? This is our academic reputation or our organisational reputation. And not having that control in reality is scary for organisations"
> *Project Partner*

Coproduction involves equal sharing of power across all partners. This may be difficult for academic researchers who have been used to controlling all elements of the research process. It is important that the culture and mind-set of academic researchers and other organisations used to having sole control over projects. In order to practice research coproduction effectively, academics need to relinquish some of their power and universities need to create a working environment where decisions are made jointly and new perspectives are welcomed. In this new culture, academics and other lead organisations need to be encouraged to take risks, experiment with new ways of working and be open to learning from when things go wrong.

Coproduced research may raise ethical considerations that are not usually encountered by university research ethics committees. For example, a greater emphasis may be placed on safeguarding the wellbeing of peer researchers, particularly those with limited research experience (Wilson et al, 2017). Fieldwork which taps into sensitive and upsetting accounts may create emotional distress for those experiencing similar (Lushey and Munro, 2014). Many of our research participants were involved in DRILL projects that involved highly sensitive and emotional discussions, which often negatively impacted on individual members. One way to support peer researchers through this was by writing reflective diaries, which could then be discussed with the wider team:

> "We were doing reflective diaries throughout and that meant that there were points where we did stop and reflect on where we were with that, where our heads were with those relationships as well and what was working and what we needed to think about"
> *Peer Researcher*

Financial Challenges

Our research has highlighted the complexity of organising payments for peer researchers, especially those who receive welfare benefits. Some peer researchers we interviewed chose not to accept payment so their benefit payments would not be jeopardised once the research was complete, as this respondent told us:

> "I didn't want to take payment because it would affect my employment support allowance. It just isn't worth taking a risk"
> *Peer Researcher*

In addition, fearful of the impact volunteering may have on benefit entitlements, some peer researchers requested to work anonymously in fear that their benefits may be stopped if authorities found out they were volunteering:

> "if the DWP find out I am volunteering well, are they going to then come in and say, 'well if you're volunteering you could be working'!"
> *Peer Researcher*

All participants voiced opinions that the policies surrounding payments for peer researchers receiving welfare benefits need to be rethought, with one participant suggesting that universities ought to create permanent roles for peer researchers.

Another financial challenge highlighted through our research was related to reimbursement of peer researchers' expenses. Many peer researchers had to complete extensive expenses forms and experienced long delays in having expenses reimbursed. This 'red tape' was particularly an issue within universities.

> "the university had very slow procedures. It could take – if you were lucky a month! Or it could take longer to get your expenses put through"
> *Research Assistant*

For those peer researchers reliant on welfare benefits and already on the 'bread line', delays in payment may discourage participation, leading one academic researcher to comment that universities:

> "do not easily lend themselves to [research coproduction] and that can become very very frustrating for any type of peer involvement"
> *Academic Researcher*

Whilst some peer researchers were paid for their involvement, often university payment rates for peer researchers were set at minimum wage limits. This was guided by an assumption that peer researchers are unskilled and easily replaced, as one academic told us:

The challenges of working with peer researchers was evident in the levels of pay peer researchers received in comparison to academic or more established researchers.

> "Peer researchers were obviously paid for their time appropriately as well, but the rate of pay was not high. They are bringing in a form of expertise which we're not currently acknowledging in their pay"
> *Academic Researcher*

Vastly unequal rates of pay at universities between peer researchers and academic members of staff may undermine the ethos of coproduction even when individual research teams practice equality.

It is clear that responsibility for successful research coproduction cannot rest solely with research teams. Many to whom we interviewed pointed to the difficulties relating seed corn funding, or a lack of money to enable peer researchers to come on board right from the start of an idea.

Traditionally the process would be that a lead organisation would apply for funding to do some coproduced research. Once funding has been awarded, the organisation would then go out and seek a group of partners – usually with lived experience – who would then work on this pre-defined project. Many respondents spoke negatively about this style of coproduction:

> "we were only getting people involved as peer researchers after the project had already been funded."
> *Academic Researcher*

Inequality within research teams, such as limited involvement in the whole research process, can lead to feelings of frustration and disempowerment (Guta et al, 2013). If communities become mistrustful of academic researchers they may be unwilling to engage with research in the future (Willyard et al, 2018).

It is clear that funding application processes need to be made more accessible to enable people all disabled people – especially those with learning difficulties – to be involved in the application process. The lack of involvement of disabled people at the start of the project led some participants to feel that their research project was not truly co-produced:

> "It takes huge amounts of time to do coproduction properly, but if you don't co-produce at the first stage of writing the grant application then, I don't think you can actually say that you've done coproduction."
> *Project Researcher*

Conclusions

This research project has focused upon the benefits and challenges of coproduced research within disability studies. Exploring the complex and nuanced experiences of several research teams who carried out DRILL funded projects between 2017 and 2019, we draw the following conclusions.

1. How have projects utilised the skills of peer researchers in DRILL funded projects?

Our findings suggest that for most teams, peer researchers were involved in all aspects of the research process, including developing the research idea and research methods, conducting fieldwork, analysing data, writing the report and disseminating the research findings. However, the inclusion of peer researchers during the funding application stage was particularly limited. Research coproduction can be costly and teams may not have access to necessary funds to enable this. One possible solution to this barrier is for funding bodies to offer seed corn funding to be used to develop coproduced research proposals.

2. What are the barriers to working with peer researchers and how can these be tackled?

Our research identified a number of barriers. First, there are practical challenges in relation to the ongoing training and support of peer researchers. Poor planning could lead to inefficient use of resources and unethical practices that are incompatible with the values of coproduction. The need for flexibility from all parties was considered to be key in overcoming such challenges.

Secondly, our research identified financial barriers to research coproduction including difficulties relating to payment for those receiving welfare benefits. Many teams to whom we spoke were able to give helpful information and advice to peer researchers in this situation and work around many problems. However, given these challenges were so widespread and complex, we recommend further research and action on this area.

Finally, we indicated that 'red tape' within universities can make it difficult for peer researcher involvement. These institutional barriers were most apparent in the processes relating to the reimbursement of expenses to peer researchers, with some experiencing very long delays. One solution adopted by some of the teams to whom we spoke has been to task the smaller partner organisations with the administration of expenses payments.

3. In which ways has participating in DRILL-funded projects changed things for the peer researchers?

Involvement in the DRILL funded research projects has had many positive impacts for the peer researchers. All the peer researchers we spoke to noted that their participation improved their wellbeing, raised confidence levels, extended their networks and broadened future aims. For some, research coproduction has led to further employment or a desire to gain formal research qualifications with the hope of continuing disability research in the future.

4. How has collaboration with peer researchers impacted on the research outcomes?

Everyone we spoke to agreed that research coproduction in disability studies is crucial. We were told by all teams that working together on an equal basis with those with lived experience improves the research process, especially in relation to enabling more successful recruitment, dissemination and impact on policy and practice.

5. What alternative language could be used instead of 'peer researcher' to reflect the non-hierarchical philosophy of coproduction?

Our research findings showed mixed feelings about the term 'peer researcher'. Many agreed that the advantage to this phrase was that it was easily understandable to funding bodies, disabled people and policy makers. Nevertheless, many respondents also considered the term 'peer researcher' to be problematic because of the danger of reifying existing hierarchies between academic researchers and those with lived experience. Consensus was not reached on an alternative term which could be used instead of 'peer researcher'. In this report we have opted to use 'peer researcher' but nonetheless we remain mindful of problems with this term and would encourage further attention and research on this terminology.

Learning from the Research

Define Coproduction

The term 'coproduction' is not understood in the same way by all. This may lead to power imbalances and conflict during the research process. It is useful to discuss and create mutual understanding of coproduction at the start.

Build Research Capacity within DPOs

Disabled People's Organisations (DPOs) and individual disabled people require sustainable access to funding and practical support to continue to build their capacity to lead on disability research projects. Opportunities for training and networking would help to build capacity.

Make Coproduction Mandatory for Funded Research

DRILL has shown that research coproduction delivers high-quality research and can have wide-reaching outcomes for policy and practice. We would like to see funding bodies make coproduction an essential requirement for all disability research projects.

Value Lived Experience

Our findings indicate that disabled people's lived experiences are often under-valued in universities, leading disabled researchers to feel their involvement is tokenistic. We must create a culture which ensures peer researchers have equal roles within research projects.

Institutional Change

University 'red tape' can obstruct disabled people's involvement in research projects. We must review policies and practices to ensure that these meet the requirements of all involved.

References

- Auditor General for Wales 2015, A Picture of Public Services
- Biziewska, D. Johnston, G. 2015, *Peer Research*, https://www.seemescotland.org/media/7368/peer-research-in-mental-health-paper.pdf
- Burns, S. Schubotz, D, 2009, *Demonstrating the Merits of the Peer Research Process: A Northern Ireland Case Study*, Field Methods,
- Cook, K. Iredale, R. Williams, R. Wooding, N. 2019, *Measuring the Mountain: What Really Matters in Social Care to Individuals in Wales*, University of South Wales
- Davies, R. and Parken, A. (2017), 'Devolution, Recession and the Alleviation of Inequality in Wales', Fée, D. and Kober-Smith, A. (Ed.) Inequalities in the UK, Emerald Publishing Limited, pp. 323-340.
- Dineen, R, 2012, *The Who, What and Why of Co-Pro*, https://info.copronet.wales/the-what-why-and-who-of-co-pro/
- Durose, C. Beebeejaun, Y. Reed, J. Richardson, J, Richardson, L. 2011, *Towards Coproduction in Research with Communities*, Connected Communities
- Di Lorito, C., Birt, L., Poland F., Csipke E., Gove D., Diaz-Ponce A. and Orrell, M. (2017), 'A synthesis of the evidence on peer research with potentially vulnerable adults: how this relates to dementia', International Journal of Geriatric Psychiatry, 32: 1.
- Elliott, E. Watson, A, J. Harries, U. 2002, *Harnessing the Expertise: Involving Peer Interviewers to Qualitative Research with Hard-to-Reach Populations*, Health Expectations, Volume 5 (2), pp 172-178
- Greer, A.M., Amlani, A., Pauly, B., Burmeister, C. and Buxton, J. (2018), 'Participant, peer and PEEP: considerations and strategies for involving people who have used illicit substances as assistants and advisors in research', BMC Public Health, 18: 834.

- Guta, A. Flicker, S. Roche, B. 2013, Governing Through *Community Allegiance: Qualitative Examination of Peer Research in Community-based Participatory Research*, Critical Public Health, 23 (4), pp 432-451

- Löffler, E. 2009, *A Future Research Agenda for Co-production: Overview Paper*, in Local Authorities & Research Councils' Initiative, 2010, *Co-production: A series of commissioned reports*, Swindon: Research Councils UK.

- Logie, C. James, L. Tharao, W. Loutfy, M. (2012). *Opportunities, Ethical Challenges, and Lessons Learned from Working with Peer Research Assistants in a Multi-method HIV Community-Based Research Study in Ontario*, Canada. Journal of Empirical Research on Human Research Ethics: An International Journal. 7 (4). Pp 10-19.

- Lushey, Clare. Munro, Emily, 2014, *Participatory Peer Research Methodology: An Effective Method for Obtaining Young People's Perspectives on Transitions from Care to Adulthood?* Qualitative Social Work, 14, (4), pp 522-537

- Mellor, J., Ingram, N., Abrahams, J. and Beedell, P. (2014) 'Class matters in the interview setting? Positionality, situatedness and class', British Educational Research Journal, 40: 1.

- NHS Wales, no date, *Prudent Healthcare: Securing Health and Wellbeing for Future Generations*, http://www.prudenthealthcare.org.uk/wp-content/uploads/2016/02/Securing-Health-and-Wellbeing-for-Future-Generations1.pdf

- Purcal, C. Fisher, K, R. Robinson, S. Meltzer, A. Bevan, N. 2018. *Co-production in Peer Support Group Research with Disabled People*, Royal Geographical Society

- Roulstone, A, 2004, Disability Employment and the Social Model, in, Barnes, C. Mercer, G, *Disability Policy and Practice: Applying the Social Model*, The Disability Press, Leeds

- Roche, B. Guta, A. Flicker, S, 2010, *Peer Research in Action I: Models of Practice*, The Wellsley Institute, Toronto

- Smith, E., Ross, F., Donovan, S., Manthorpe, J., Brearley, S., Sitzia, J.& Beresford, P. 2008, *Service user involvement in nursing, midwifery and health visiting research: a review of evidence and practice*. International Journal of Nursing Studies, 45, pp 298–315, Willyard, C. Scudellari, M. Nordling, L. 2018, *How Three Research Groups Are Tearing Down the Ivory Tower*, Nature, https://www.nature.com/articles/d41586-018-06858-4

- University of Bristol, 2018, *Getting Things Changed*, http://www.bristol.ac.uk/media-library/sites/sps/images/gettingthingschanged/Final%20GTC%20report_web.pdf

- Wilson, E., Kenny, A. and Dickson-Swift, V. (2018), 'Ethical Challenges in Community-Based Participatory Research: A Scoping Review', Qualitative Health Research, 28: 2.

- Zimmerman, M, A. 1995, *Psychological Empowerment Issues and Illustrations*, The American Journal of Community Psychology, Volume 23 (5)

Disability Wales
Brydon House
Block B
Caerphilly Business Park
Van Road
Caerphilly
CF83 3ED

T: 029 2088 7325
F: 029 2088 8702
E: info@disabilitywales.org
www.disabilitywales.org