

# Experts by Experience: Continuing the journey

Good practice from homelessness, housing and support services in Wales and beyond

January 2025



# **Foreword**

There is growing recognition that people with lived experience have unique insights and invaluable expertise that can help to deliver better policy and practice. Across Wales, homelessness, housing and support providers are continuing to explore ways to embed lived experience in service design and evaluation, while government and the third sector are incorporating these perspectives in policy making and legislative reform.

Although the involvement of experts by experience has been established as good practice for some time, the extent and impact of lived experience engagement can vary and continues to evolve through co-production, trial and error. However, there appears to be a real commitment from many organisations, and we are seeing some really effective and impactful approaches, as well as efforts to widen involvement to people from a variety of backgrounds and experiences.

There is a strong desire to ensure that engagement opportunities are meaningful and have real influence and impact. Organisations are acutely aware of the benefits of gaining insight and expertise from experts by experience, but also feel a responsibility to do so with care and to avoid re-traumatisation. They understand that people have often experienced significant trauma, adversity and system failure, so there is a fine line between encouraging people to tell their story and overwhelming someone by revisiting painful experiences.

This report aims to share good practice examples that demonstrate how experts by experience can be encouraged and supported to make their voices heard. We spoke to several organisations as part of our research for this report, all of whom spoke candidly about their experiences, keen to celebrate success but honest about the challenges they have faced.

We are grateful to the Oak Foundation and the Welsh Government, who have supported us to explore, promote and embed lived experience over the last few years. A huge thank you to all of the organisations who took the time to speak to us, and every person with lived experience who has given their time and energy to one of these projects. Your voices are being heard and your impact is being felt.

Jordan

Jordan Brewer
Policy and External Affairs Manager

Steph

Stephanie Whitehead Policy and Research Officer

Thank you to the following organisations for sharing their experiences with us:

Adullam, Cadwyn, Carmarthenshire Council, Cardiff and Vale Drug and Alcohol Service, Crisis, Drive, Housing Justice Cymru, Llamau, Melin Homes, Mirus, Merthyr Tydfil County Borough Council, New Pathways, Pobl, Practice Solutions, Revolving Doors, Shelter Cymru, The Wallich, Walsingham Support, Welsh Refugee Council.

# Introduction

Cymorth Cymru is the representative body for providers of homelessness, housing and support services in Wales. We act as the voice of the sector, influencing the development and implementation of policy, legislation and practice that affects our members and the people they support.

At Cymorth we really value the views of people with lived experience and we are passionate about giving them a platform to make their voices heard. In 2020 we met 80 people with lived experience and asked them how they thought we should end homelessness in Wales. The resulting report was submitted to the Welsh Government's Homelessness Action Group, influencing recommendations to the Minister for Housing and Local Government. In 2021, the Welsh Government's Ending Homelessness Action Plan made a commitment to empower people with lived experience to continue to influence policy and practice.

Over the past three years, Cymorth has been leading an Experts by Experience project, with support from the Oak Foundation and the Welsh Government. It was established to empower people with lived experience of homelessness and housing support services to influence policy and practice across Wales. One of our proudest achievements has been working with people with lived experience to shape a new Homelessness Bill, which is due to be tabled before the Senedd in 2025. We engaged with over 300 people and they have had a huge impact on the legislative proposals.

As part of this project, we are also publishing this good practice report, featuring examples from the homelessness, housing and support sector in Wales. We have heard from a range of organisations across Wales about their experiences of engaging with people using their services, including the successes, challenges and key learning.

# Overview of existing research

There are several pieces of research about involving people with lived experience in the design and delivery of services, on a UK and global scale, as well as learning from different sectors in Wales. This existing research is a valuable resource for any service or project looking to design their own forms of engagement.

Research suggests that there are many benefits to working alongside people with lived experience of homelessness<sup>1</sup>, for both the people experiencing homelessness and services<sup>2</sup>. Naturally, there are differing approaches and views about the most effective ways of doing this. However, as with the organisations we spoke to in drafting this report, there are some common themes which seem key to delivering positive results. These include:

- Strengths-based approaches: People with lived experience of homelessness have unique experiences which gives the ability to see things in different and creative ways<sup>34</sup>. Creating opportunities which play to people's strengths lead to the best outcomes for both the person and the organisation<sup>5</sup>.
- Shared experiences: Approaches such as peer support<sup>6</sup>, understanding a person's history<sup>7</sup> or a person sharing their experiences on their terms<sup>89</sup>, can make a person's experience with engagement meaningful and as though they've truly been heard<sup>10</sup>.
- Wellbeing impacts: Empowering people to make decisions which have an impact on their day to day environment or support can have positive outcomes related to physical and mental health; strengthening social bonds; and improved sense of empowerment and hope<sup>11</sup>.

#### Who we talked to

We are privileged to represent a broad range of organisations who provide homelessness, housing and support services in Wales. We put out an open call to our membership and the wider sector for organisations who were willing to speak to us about their experiences of engaging with experts by experience. The organisations we spoke to varied in nature, size and capacity, but all were open about their successes and challenges.

People contributed through the following methods:

- · Completing a questionnaire
- · One to one meetings / conversations
- · Submitting case studies
- · Inviting us to attend shadow boards, engagement groups etc.

## Structure of the report

We gathered a vast amount of information from the organisations who spoke to us, and we are immensely grateful for this. We have structured the report around the following areas:

- Service Design
- Recruitment
- Governance
- · Peer Research
- · Influencing national policy

At the end of the report we have reflected on the overarching themes arising from the good practice examples and challenges, as well as making some recommendations.



# Service Design

People with lived experience are having a growing impact on the development, design, delivery and evaluation of services. Increasing opportunities for involvement not only illustrates an organisation's commitment to a client-centred approach, but can create a sense of value, purpose and ownership among people using services. Meaningful engagement can result in services developing an increasingly effective approach to supporting people, based around their real time needs and experiences.

## **Ongoing involvement**

Some services have established dedicated groups that involve the people they support on a regular basis in the development and improvement of service design and delivery. These range from weekly resident meetings and surveys, where people contribute to the day-to-day running and decisions within housing and support services, to dedicated groups which are established to influence strategy, delivery and property design.

Melin Homes has established two groups, a Communities Group and Customer Service Group, which focus on community activities, reviewing documents, policies and procedures, undertaking service reviews, and making recommendations for improvements. The organisation has told us that these groups give staff and residents a great opportunity to work alongside each other to directly influence service delivery.

"They are the first point of contact for staff who wish to have a resident's perspective on the services that Melin provides. They have an opportunity to influence the way we do things."

Cadwyn's Nightingale House has involved residents in the physical design of properties, including the development of a mural for the garden area and the installation of air conditioning in flats. This sits alongside weekly meetings, and resident engagement is facilitated through 1-to-1 meetings and feedback forms. Another mode of engagement is the opportunity to complete a questionnaire six weeks after move-in, to identify any unmet needs or gaps in the service. They are also setting up a resident panel specifically for their temporary and supported housing schemes.

"We complete a move-in questionnaire (after 6 weeks) with new tenants. We then analyse these on an individual and group basis to identify any trends and gaps in service, and identify ways in which residents may want to get more involved."

"Residents raised concerns about some visitors in Nightingale House. [A] group of residents and staff got together to look at visitors, what checks we do, what consent we have to do checks, and how we manage visitors' behaviours."

The Citadel Project, run by Housing Justice Cymru, actively uses a strengths-based approach to match volunteers 1-to-1 with clients, conjoining the attributes of the volunteer to the strengths and needs of the person using the service. During their time at their time at the project, service users are able to work flexibly with their paired volunteer on a range of aspects of their lives based on what matters to them and what they would like to achieve from the support. Support across the project is shaped by the ongoing conversations and relationships between service users and volunteers, as well as those employed to oversee the Citadel project. Service users are actively involved in discussions about how the project is functioning, including what works well and what doesn't. Consequently, having these conversations also means that the project has been able to put together plans for activities and skills building exercises (i.e. cooking, food budgeting) based on commonly mentioned issues during these conversations, therefore directly targeting the needs of service users based on their influence.

# Consultations, reviews and pilots

In some cases, organisations involve people in large scale consultations and evaluations of services, either in place of, or alongside ongoing opportunities for engagement. Services have found that actively engaging the people they support can prevent problems from arising in service design that could affect a person's engagement and progression within a service, and help clients to get the most out of the support they receive. The extent to which people with lived experience were involved varied across organisations, but engagement had a positive impact on clients, staff and services.

Through their dedicated Involvement and Engagement (I&E) team, Llamau runs a policy of 'Voice, Choice and Control', which directly involves their residents in accessible involvement and consultation opportunities. The I&E team work alongside the support team to promote these opportunities to people using services, and empower them to directly influence the decisions that affect them. The dedicated team is given flexibility to offer a range of ways to engage. In some cases, services will actively involve people throughout the process of reviewing services. Pobl regularly involve people they support in their care audits. For the experts by experience, the process includes supporting the Responsible Individual (RI) in undertaking visits to services and observing what they find, see and feel, therefore taking account of the perspective of someone using services.

"Having people with lived experience bring a different perspective to 'what good looks like' and what is important to those with lived experiences. On the day, those with lived experience are supported with a colleague from the quality team or inclusion officer and they are encouraged to have their own conversations with individuals and staff. Sometimes they just like to listen and watch, feeding back later on."

Pobl has also involved its clients in a variety of other consultation opportunities, most notably the digitalisation of its services, to ensure that people using services felt confident and capable using the technology.

"Being able to move and adapt how services and support is provided in an ever increasing digital world cannot be done alone. Digitalisation and words like technology can be scary. It is important that we work to remove this fear."

During a recent pilot of the analogue to digital switch-over for a warden call system, people using services were involved in the self-evaluation of the pilot service overseen by the inclusion officer. Similar to the RI evaluation, service users were consulted on a basis that worked for them, including the offer of 1-to-1 discussions with the inclusion officer about the evaluation, flexible participation, and accessible materials in written and audio format. Providing this level of accessibility across the evaluation was paramount for getting clear understanding of the impact of the switch-over across the client population.

"In-person demonstrations were the key to this project, with different companies being questioned by the end users. If it wasn't simple to use, it was a no!"



#### **Active involvement in evaluations**

Evaluations can be an important way of ensuring that services are running in the most effective way. Some services actively involve their clients on an ongoing basis to evaluate the performance of the service in meeting their needs. Shelter Cymru's Take Notice Project aims to improve housing and homelessness services across Wales through service evaluations led by people with lived experience. Evaluations offered by the project vary considerably, depending on the needs of the client. Ranging from 'Light Touch', which offers flexible outputs based on the perspective of Take Notice members, to 'Targeted' and 'Deep Dive' evaluations.

As well as offering external evaluations, Take Notice also plays a role in reviewing Shelter Cymru's internal services to ensure that people experiencing housing insecurity are being supported as effectively as possible. Internal evaluations take place quarterly by conducting focus groups and 1-to-1 interviews with clients whose cases have been closed. Qualitative and quantitative information is gathered from this feedback and used to refine services, including identifying good practice and areas for improvement as part of longer-term operational action plans.

More formally, the Citadel project is reviewed every twelve months with service users at the heart of the evaluation. For example, a recent evaluation carried out by Dr Helen Taylor at Cardiff Metropolitan University sought to speak directly to service users. Service users were empowered to meet the consultant on their terms and build up a relationship of trust. Equally, it was important that the project made service users aware of the conditions of the evaluation so that they could share their experiences authentically. Being able to discuss the impact of the project on them this way was also facilitated by the approach of the researcher to not ask questions about the service based on their own assumptions<sup>12</sup>.

"Because the evaluation was external, there was no pressure to be positive — the service users could say what they wanted. We made sure that service users were aware of this and that what they said wouldn't impact their support."



#### **Direct involvement in services**

Some services have mechanisms which involve people in the central day-to-day functioning of a service; this includes some on a voluntary basis to develop, design and run activities or support sessions within a service. This can utilise people's strengths to shape the service in a way that can help people to engage effectively, while also having someone that other clients can relate to.

Cardiff and Vale Drug and Alcohol Service (CAVDAS) has recently partnered the lived experience group Voice, Action, Change to further develop parts of their services. Voice, Action, Change is a co-produced lived experience volunteer group developed by Recovery Cymru and Kaleidoscope. A key part of the design process was building rapport with the lived experience volunteers through regular meetings to ensure they felt comfortable and therefore were able to contribute in the best way they could.

"To ensure they were supported and comfortable, we did have many meetings before the first session to build a good working relationship for them to become familiar with the hostel. [Volunteer 1] had volunteered at Northlands for a while now and so was eager to help with these sessions. I believe having two VAC members as opposed to one helped with feeling supported as it brought familiarity."

The ability to build strong relationships between clients and those supporting them is integral to having an embedded approach. Additionally, in some cases having volunteers with lived experience themselves added to the ease of building a trusting relationship between volunteer and client. By having the support of someone with lived experience of homelessness, clients felt they had someone with whom to identify.

"The flexibility to adapt to individuals' needs . . . hopefully fights the 'institutionalised' approach where supportees feel like 'tasks' being 'processed'."



# Key enablers

Across the examples given, accessibility was a key factor for enabling the participation of people with lived experience. Consideration was made for participants' physical and mental health access needs, ensuring that participants could not only be involved but felt comfortable doing so. This was done in a variety of ways, including providing transport, considering the setting where meetings are held, having a range of options for age, learning needs and engagement preferences, and providing specific material to give people the information they need.

In some cases, people can find engagement overwhelming, or do not trust that their input will be listened to. This often follows significant experience of not being listened to by services or systems. Building trust and relationships is therefore central to ensuring people feel comfortable and supported during any engagement process and ensuring that involvement will genuinely have an impact on service design and delivery.

By providing a diverse range of opportunities for people to be involved, organisations are able to gain a variety of perspectives across the full spectrum of the people they support. Consequently, in terms of service design, the most authentic and effective approach can be chosen and implemented based on what works for the majority.

Across the examples highlighted, not only were multiple meetings offered to participants of projects, but also opportunities to speak 1-to-1 with staff about their ideas and thoughts; this demonstrated that their thoughts mattered, regardless of how they wished to share them, while also providing a gateway to participation for less confident and reserved service users.

#### **Impact**

Creating a bank of meaningful options where service design is influenced by people receiving a service has many positive effects. Adding the perspective of service users into the design stage prevents gaps in service design and support, by helping services better understand the broader needs of the service users beyond their perceived needs. Beyond the evaluation being carried out, it can also open doors to revealing further opportunities for client engagement in service design.

"It has also enabled us to learn about what the needs are for those with lived experiences, where we can learn together. Whether that be from introducing devices to promote independence for longer to the reduction of social isolation."

For people using services, the impact is that there is a better service for them to access which is more fitting to their needs, and can also empower ownership of services and improved overall wellbeing. For example, in the case of Cadwyn, involvement of service users in the development of service design resulted in a greater sense of community within the service and consequently fewer incidents among residents.

Organisations report that the processes of engaging experts by experience in service design can result in building stronger relationships across staff and residents and can also give opportunities for people to learn and gain skills.

"Seeing the difference that I can make, makes it all worthwhile."

There can also be benefits to people's health, wellbeing and recovery, through the sense of value and purpose they gained from their involvement.

"A resident approached me outside of the hostel. He said he interacted with us quite a while ago. He says, since then he has completely stopped his cannabis use and reduced his tobacco use over the past several weeks."

# Staff recruitment

For a number of services, involving people who use services in the recruitment of new members of staff has become an important element in ensuring that services are personcentred. Involving clients on recruitment panels, and in the development of questions and scenarios, can help services to seek out the most authentic candidates who are best suited to working with their client group. Including people with lived experience on recruitment panels was a common theme among services that we spoke to. However, there was a variety in how clients were involved not just on panels but throughout the hiring process.

#### Pre-recruitment

Some services involve people with lived experience earlier in the recruitment process, such as the development of job adverts or shortlisting of candidates. By encompassing clients and individuals with lived experience in the development of the advertising stage of the recruitment process, services can find candidates that align with what their clients feel is most important.

Pobl gave the example of a project which involves people using services in the initial stages of recruitment. Pobl seeks to co-produce adverts with their clients to target the exact needs of the service, so that candidates are aware of what the role entails within a specific service. Equally, they view involving people with lived experience as vital, as they will be the ones receiving the support.

"Each service is different due to the make-up of those in the service. When advertising, it is important to know what those with lived experience see as important, what makes them different. When a position needs to be filled, the manager and recruitment advisor will work on developing an advert with input from individuals from that service. A lot of brainstorming and word-cloud gathering is completed so that the language used is reflective of those with lived experience. Once that has been completed, draft adverts are created and these are reviewed by those with lived experience to check that the advert has captured what they felt was important."

In addition to recruiting candidates through adverts, Pobl regularly offers the opportunity for clients to attend job fairs alongside recruitment colleagues and managers. Providing face-to-face opportunities to recruit candidates such as this seeks to demonstrate the authenticity of the service and allow clients to gain confidence.

"Having a diverse and inclusive stand enables both those with lived experience, us, and the candidate to have a true picture of how we value co-production and inclusion in what we do."

# **Developing interview materials**

Cadwyn's Nightingale House shared that they give residents from across the service the opportunity to be involved in the recruitment process before, during and after interviews had taken place, including the opportunity to submit questions to be used during the interview and offer feedback.

"[We] always have someone with lived experience on the panel. We ask residents in advance for any questions they want included in the interview process. In addition, we always try to include a tour of the projects as part of the interview process where candidates meet residents and have an opportunity to ask any questions. Following interviews, the hiring lead meets with residents to get their feedback on candidates"

Carmarthenshire's 16-25 Floating Support Service involve the people they support in the hiring process through the production of scenario-based questions, ahead of the interview. During the interview, candidates are given two scenario-based questions. The first of the two questions is written by a service user not in attendance and given to the candidate to answer before entering the interview; it is used to test the amount of knowledge a candidate has, therefore allowing the depth of knowledge to shine through. The second scenario question is written and delivered by a client present on the interview panel and aims to test how the candidate would support a young person in a genuine setting. By having a client provide a scenario-based question on the spot, not only can the authenticity and values of the candidate can be demonstrated, but also the way in which a candidate interacts with the young person present. As the panel is looking for someone that can help clients effectively, the panel pays attention to who the candidate interacts with most (i.e. the panel or the young person) when answering the question, including how they work with the client in real time and how they support the client to develop their own problem-solving skills.

#### During and after the interview

Several of the services we spoke to shared how having someone with lived experience as an active panel member brought fresh perspective to the recruitment process and changed the dynamic of the interview room. People shared a variety of ways to engage as a panel member in a capacity which suits the person, from simply observing the interview to asking questions from their perspective and scoring candidate responses. Clients are also consulted following the interview to hear their thoughts on candidates, therefore involving them in the shortlisting process. Other services shared various points in the recruitment process where they encouraged and enabled people with lived experience to input their knowledge and expertise in a way that is best suited to that person.

#### Key enablers

Across all the examples provided to us, ensuring that the recruitment process was made as accessible as possible was central to ensuring service users could be involved. For many services, this meant allowing clients to be involved as little or as much as they'd like and holding interviews in a safe space for the client.

For example, during interviews for Carmarthenshire's 16-25 Floating Support Service, clients are encouraged to be involved in whichever way they feel comfortable, from simply observing to asking questions to candidates independently. Equally, the young person is allowed to wear whatever they feel the most comfortable in with the interview being held in youth clubs – an environment familiar to the young person, which also reflects the reality of youth work to the candidate. Similarly, in addition to the training and preparation given to clients, Pobl's involvement of clients at job fairs takes a similar approach:

"Those with lived experience are throughout given the opportunity to have support from the inclusion officer, and will have met the recruitment lead so that on the day, they have familiar faces around them should the experience become overwhelming. The lengths of attendance on the day is also open, there is no expectation to attend the whole day, but what is appropriate for the person with lived experience."

Additionally, one of the key considerations across many areas of involving people with lived experience is the payment of expenses, remuneration or incentives. In the case of involving service users in recruitment many services cover expenses for food and travel where financial remuneration might not be possible. For example, in the case of Carmarthenshire's 16-25 Floating Support Service, lifts were offered to the young people involved to and from the interview venue, therefore opening up the opportunity to clients that may not have access to transportation, while also putting them in the presence of someone they trust ahead of the interview.

Equally, it was seen as important across many of the examples given to offer remuneration as an incentive to encourage service users to take part and feel they were getting something out of the process. In most circumstances, this involved the offer of a voucher for a store of the client's choice.

"We've had really good success with including tenants on interview panels. We'll pay travel expenses if needed, provide lunch and will provide a voucher following interviews also. We tend to offer incentives initially to try to get residents interested [and] engaged."

#### **Impact**

Services reported a number of positive outcomes from involving their clients in the recruitment process, both on the service user and the service itself. The examples provided to us pointed to examples of self-development, skills building and a greater awareness of the recruitment process and what to expect when applying for jobs themselves. For example, when asked about their experience of partaking in interviews, young people from Carmarthenshire's 16–25 Floating Support service reported a sense of pride for taking part, and increased confidence following the interviews, which they have carried forward in their own lives.

"It was an honour to be a part of the interviews, and the interviews were to help young people. It had made me more confident in myself."

Similarly, Pobl touched on how involving those with lived experience provided clients with the opportunity to shape the service and offered them a level of responsibility.

"For those with lived experience, being able to help design job adverts offers them a chance to shape the service and who is recruited into the service. Being included in the recruitment [process] offers a level of responsibility that can be beneficial when personalities sometimes clash."

"Attending job fairs offers an opportunity to develop communication skills, learn about the recruitment process, and understand why it can take a while for positions to be filled."

Across the examples provided, it was also reported that involving clients in the recruitment process had a positive effect on the service, including a better sense of community and a service that better reflects the needs of the service and helps to build a truly person-centred approach to support.

"Having those with lived experience help create the job advert enables us to target the right candidates for the role. Knowing what the role entails from the start helps reduce time on unnecessary applicants."

"Having those with lived experience attend job fairs again can reduce the time spent on candidates that are not really interested in the role, but on the reverse can offer the potential candidate a more comprehensive insight into the role."



# Governance

Many of the organisations who participated had mechanisms which gave opportunity for people to influence the governance of organisations. There are many different ways in which organisations facilitate this, including people with lived experience being inducted as board members, dedicated lived experience groups, or shadow boards. These approaches varied in intensity and commitment, from flexible approaches where groups meet ad-hoc to discuss time-sensitive issues, through to formal board roles with fixed terms.

Some set-ups, such as Drive's Advisory Group and The Wallich's Shadow Board, examine organisational matters such as upcoming policy changes, appointment of a new CEO, and service design. The groups are seen as an integral part of the organisation's scrutiny process. One group facilitated by New Pathways consistently consults with survivors on planning and co-production of services whilst also facilitating meetings with commissioners and key partners.

"I recently attended a Police meeting, as they asked New Pathways to hear survivor voices. It was challenging as I previously had a bad experience with the Police. I was very nervous and couldn't remember their names. I decided to just concentrate on what I wanted to say, and it was amazing — I found it very freeing to tell my story and have a group of people listen and be willing to change. It was really powerful and it has rebuilt some trust with the Police. I was very proud of myself and would recommend others to do the same if they get the opportunity."

"I find this group very, very helpful. I didn't have a voice for so long, and this group gives me great inspiration. I am very grateful to be involved."

"I feel like I am listened to."

"I like being involved in making decisions, it feels important."

# Key enablers

A key theme arising from the organisations we spoke to was a good recruitment and induction process – one which is accessible and gives people the support and information they need to fully contribute. Organisations also highlighted how much easier it was to engage people and run these groups in a meaningful way when they were able to source funding for a dedicated job role or team. Although participants advocated for a cross-organisational approach to embedding lived experience, they also noted how work was much more meaningful and quicker to grow when investing in someone to lead and oversee this work.

# **Impact**

Organisations shared that these governance boards, groups and mechanisms have had no end of positive impacts on both organisations and the people the support. They reported benefits such as getting an honest and sometimes unexpected perspective on various aspects of their (and their partner) services, influencing the design and accessibility of services, moving services towards working in a truly strengths-based way,

Individuals involved have reported feeling listened to, being heard and raising awareness, a sense of giving back by helping services develop and improve, getting opportunities to put into practice skills and influence things they are passionate about.

## Peer Research

As the involvement of experts by experience grows across the sector, so also has the development of peer researcher roles in key pieces of homelessness research. Across organisations, the impact of people's personal expertise and experience has expanded its influence, with people with lived experience being increasingly involved in the co-production of research and influencing policy change. Across organisations, varying approaches are taken to the development of peer researcher roles and their involvement in various projects, from the beginning to the end stages.

Approaches and practices that people have found successful include the following:

## Creating a non-prescriptive approach to recruitment

For the majority of organisations that actively involve recruitment researchers, the initial stages of the role, including recruitment and training of peer researchers, is vital for ensuring effective and inclusive engagement. Taking a non-prescriptive approach to recruitment was a central theme among the organisations we talked to. By applying a degree of flexibility to recruitment, services found that people were more open and receptive as well as creating greater diversity of experience across the project.

An example was given by respondents to End Youth Homelessness Cymru's (EYHC) approach to their most recent research project exploring the experiences of neurodivergent young people. They purposefully kept criteria for recruitment vague around the type of homelessness people had experienced, in order to be inclusive of all experiences of homelessness. They have since expanded on this approach by including the criteria as being 'a young person living in Wales' that is 'passionate about ending youth homelessness'. By taking an approach that is less prescriptive in their recruitment of peer researchers, EYHC found they avoided questions from young people about whether they were 'homeless enough' to share their experiences and therefore widened the diversity of experience. It also welcomes the voice of those who may not have experienced homelessness but may have been at risk, an experience which can better help organisations understand the issues from a preventative perspective.

Across organisations, the non-prescriptive approach also included flexibility of participation, while framing being a peer researcher as an opportunity for growth and development, ensuring the opportunities meet people's strengths and interest. For example, alongside research opportunities, these roles also have the chance to explore blog writing, participating in podcasts and more. This flexibility comes with things to bear in mind, however, with some organisations stressing the importance of clarifying that work is casual and not always regular during the recruitment process to ensure people's expectations are managed.

# Providing adequate training

Beyond recruitment, it was also seen as important across organisations that peer researchers were adequately prepared to take part in projects, both practically and emotionally. In many of the examples provided, training on research methods, research ethics, and personal safeguarding and wellbeing was standard practice.

For example, Shelter Cymru's peer research project puts great emphasis on the need to offer training to their peer researchers to feel confident in contributing to research projects. In conversations with their peer researchers, many of them stated that training around safeguarding and trauma-informed practice was essential, and – although not mandatory to their role – training on the legal aspects was 'interesting and valuable' to their role with many speaking highly of Shelter Cymru's 'Homelessness and the Law' module.

Equally, the design and approach of training sessions was also a key element of the ensuring inclusivity and flexibility for peer researchers. For example, EYHC shared that following learning from a previous project, they have altered their requirement for peer researchers to attend a certain number of in-person training sessions; they have now have incorporated that degree of flexibility into the training stage through the production of a pre-recorded pack that would allow people to take part in training at their own pace. They have found this approach offers more control over people's own learning preferences and removes many of the practical limitations, such as geographical barriers and creating flexibility around educational and work commitments. It is important to note that this degree of flexibility remained a central part of involvement beyond the training stage, to protect the emotional wellbeing of peer researchers.

#### **Building relationships with peer researchers**

The focus on flexibility to protect the emotional wellbeing of researchers forms an element of a wider commitment to relationship building. Across organisations where peer researchers are regularly involved, building a strong relationship of trust and inclusion was central to having a positive experience as a peer researcher. For many peer researchers, feeling valued for the work they put in was important; however, creating an established relationship with an organisation was key for building those relationships effectively.

Some organisations used the approach of inviting peer researchers to sign organisational policies which allow them to attend whole staff meetings, as well as recreational activities such as Christmas parties, creating an environment where people feel authentically part of the organisation and involved at a meaningful level.

Other ways of building trust and relationship include an understanding that just because a peer researcher has lived experience does not mean they have to share these experiences.

"Some of the team had in the past been put under pressure to share the stories of their experiences in spaces they didn't feel comfortable in and through a lens that they hadn't chosen. The team shared openly about the impact this had on their mental wellbeing."

Similarly, some organisations ensured that their peer researchers were involved only in the areas of the research they felt most suited to, while putting emphasis on providing an environment where peer researchers could share their experiences without judgement.

"The meetings provided us with a space where we were able to share our own experiences without judgement or hierarchy. We were given the freedom to undertake sections of the research we were more suited to while not feeling any pressure to do anything that might make us feel uncomfortable."

Creating clear pathways for peer researchers to communicate their needs throughout their period of involvement served as a key factor for developing positive relationships within organisations. Some shared that having a single point of contact or lead contact dedicated to supporting peer researchers was helpful. This could also include regular opportunities to debrief at routine intervals during and following projects on a 1-to-1 basis with their point of contact as a way of maintaining that relationship and allow the peer researcher to be heard while making the most of the opportunity to develop.

# Key enablers

Across organisations, it was raised that the element of building relationships was one of the most important elements of people feeling supported and thriving in their role. Some organisations shared that it is regular for people come to the opportunities with low confidence or negative belief systems, and that allowing time and support is crucial for people to get the most out of their experience and achieve the things they are passionate about.

#### **Impact**

Having peer researcher roles as part of an organisation or project can create a more authentic approach to finding solutions. Experts by experience will have their own perspectives shaped by their experiences, which allow for more creative and inclusive thinking. Peer researchers can also give other people with lived experience a greater confidence to share their experiences.

Peer research roles can also create employment pathways or access to education or training for the people taking part. Examples we were given demonstrated the importance of allowing peer researchers to gain in a professional capacity from their recruitment and training. For example, Shelter's training is accredited and can therefore be taken across to other organisations where their research training can be used in separate peer researcher role, or other capacities. Similarly, when advertising peer research roles, EYHC frame the opportunity as a way to develop skills and expand their CV, while also offering references for future work opportunities.



# Influencing national policy

There are a number of examples of experts by experience being involved in the development of national policy and legislation, in Wales and other parts of the UK.

## **Expert Review Panel (Wales)**

In 2022 the Minister for Climate Change, Julie James MS, established an Expert Review Panel<sup>13</sup> (ERP) to make recommendations for legislative reform to improve how Wales prevents and responds to homelessness. Cymorth Cymru was a member of the ERP and took on an additional role in facilitating involvement with experts by experience. Over the course of the Panel's work, Cymorth engaged with over 300 people with lived experience, gathering their views and experiences through online surveys, in-person events, conversations on the streets, and visits to temporary accommodation, supported accommodation, prison and probation services. Additional work was undertaken by Tai Pawb to engage with specific diverse groups.

This engagement resulted in six reports<sup>14</sup> being submitted to the ERP, each focused on a different element of the proposed reforms. Each paper was introduced and summarised in advance of the relevant discussion and the feedback from experts by experience was considered carefully by ERP members before decisions were taken on recommendations for legislative reform. Both the ERP's report<sup>15</sup> to the Minister, and the Welsh Government's subsequent White Paper<sup>16</sup>, were heavily influenced by the contributions from people with lived experience, and included proposals for earlier prevention, removal of barriers, and new duties on public services. The resulting legislation will be tabled in 2025.

#### The Prevention Commission (Scotland)

The Scotland Homelessness Prevention Review Group (PRG) was established in 2019 by the Scottish Government to develop recommendations for legal duties on Scottish local authorities and wider public bodies to prevent homelessness, and how these might be best implemented. The PRG wanted to engage with people with lived experience of homelessness and frontline staff to make sure that its recommendations were realistic and would make the difference that they wanted. As a result, Homeless Network Scotland established the Prevention Commission<sup>17</sup>, which held regular meetings and producing reports that summarised their discussions and put forward key considerations for the PRG. It also held shared meetings with the PRG at key stages of the process.

The PRG's final report, Preventing Homelessness in Scotland<sup>18</sup>, was published in early 2021, providing the framework for a government consultation on new homelessness prevention duties. In March 2024, the Scottish Government published the Housing (Scotland) Bill, which seeks to introduce an 'ask and act' duty on social landlords and public bodies, such as health boards and the police, to ask about a person's housing situation and act to avoid them becoming homeless wherever possible. It also reforms provision for people threatened with homelessness up to six months ahead and includes provisions for tenants experiencing domestic abuse.

# **National Expert Citizens Group (England)**

The National Expert Citizens Group (NECG) is a group made up of people from across England with lived experience of multiple disadvantage. The NECG works with central and local government, statutory bodies and frontline services to ensure that people who have lived with multiple disadvantage can shape the services and policies that impact them, ultimately making them more accessible and effective. Revolving Doors, who run the NECG, do this by providing equal, trauma-informed spaces, bringing together key decision-makers and those with first-hand experience of multiple disadvantage to co-produce innovative solutions for systems change.

The reach and the influence of the NECG is wide-ranging<sup>19</sup>, including advising the Dame Carol Black Independent Review of Drugs where they brought the issue of dual diagnosis to the table and focused on highlighting the gaps in provision and the needs of those people struggling with addiction and other multiple disadvantages. In addition, one of the NECG Members sat on the House of Lords Panel on drug policy change. The influence of NECG has stretched to the Ministry of Housing, Communities and Local Government rough sleeping response team and the Housing Committee on responses to the pandemic. The NECG is now working with the Office for Health Improvement and Disparities (OHID) on a new initiative<sup>20</sup>, the 'Lived experience voices' project, which will bring more diverse lived experience insight into OHID's projects and plans.

## **Wales Mental Health and Wellbeing Forum**

The Wales Mental Health and Wellbeing Forum<sup>21</sup> is a group of people with lived experience of mental health issues, and their friends and families. The Forum was established in 2013 by the Welsh Government following the development of the Together for Mental Health Strategy. Practice Solutions supports the Forum using a co-production approach to develop national guidance and facilitates conversations between individuals, carers, partner organisations and Welsh Government to influence and inform policy activity. The Forum is made up of a minimum of four members from each of the seven health board areas in Wales and a minimum of ten independent members, who are recruited nationally to ensure that the Forum reflects the diversity of the people of Wales and the range of their experiences.

Representatives of the Forum also sit on the Welsh Government's Mental Health National Partnership Board, which oversees the delivery and implementation of the mental health strategy and its delivery plan. The Forum regularly submits discussion papers to the Board, prompting important discussions that feed into national policy development. Since the Forum's inception in 2013, they have co-produced several papers on a broad range of topics, addressing issues such as Care and Treatment Planning, Suicide prevention, Stigma and discrimination and ending Coercive Practice and ECT. Over the last two years it has also contributed to the development of a new Welsh Government mental health and wellbeing strategy.



# Key enablers

A range of enablers emerged from these examples. The commitment from decisions makers (particularly government) to listen to, respect, and respond to lived experience is critical in ensuring that people's contributions have a meaningful impact. Organisations facilitating this engagement also have a responsibility to advocate strongly on behalf of people who have shared their views, but be mindful not to sanitise, reword or alter the message from people with lived experience.

On a practical level, providing multiple and varied ways for people to share their views is also important, whether this be online or in-person, as well as going to meet people where they are located, not just expecting people to come to you. Being able to cover people's expenses or reward people's involvement can also help to encourage involvement, but it is important to be mindful of how any remuneration could impact someone's welfare entitlements.

Being able to articulate why people's views and experiences are being gathered, as well as how it will have a real impact on people's lives, can be key in encouraging people to contribute. However, policy and legislation can take a while to change, so it is also important to be honest about timescales. Closing the feedback loop can be challenging, especially where engagement has been anonymous or the process has been lengthy, but trying to articulate the impact of people's input is really valuable.

As highlighted elsewhere in this report, being mindful of people's experiences of trauma or adversity is especially important, as well as taking care to ensure that people do not feel pressured to share more than they feel comfortable, and can take time out if they need to. Some people may want to be supported by a key worker while they share their stories; however, some people may also want to do so without fear of repercussions if they have any negative feedback about systems or services.

## **Impact**

Involving people with lived experience can give the government greater confidence that their policies and legislation reflect the reality of people's experiences, and will therefore be more effective. The benefits for people involved in contributing to policy development include feeling valued and respected for their expertise, having a positive impact on services and systems, and helping to improve other people's experiences and outcomes in the future.

"I want to thank each of the individuals who shared their personal experiences of homelessness with us. Our proposals are rooted in your insight and your expertise. I hope you see your contribution and I hope that our proposals lead to the meaningful change that you have asked of us."

Julie James MS, Minister for Climate Change, Welsh Government

"Strongly influenced by the Prevention Commission, a group of people with lived and frontline experience of homelessness, [...] the recommendations in this report hold the potential to radically change the face of the homelessness system in Scotland."

Professor Suzanne Fitzpatrick, Chair, Prevention Review Group

"Being a member of the NECG gives me a chance to put my opinion across to improve services nationally and locally. It also gives me a voice [and] a feeling of being heard, as well as the opportunity to make services better for those who will need them in the future."

National Expert Citizens Group member

# Report reflections: Good practice and challenges

Across the different examples highlighted in this report, providers often expressed a range of strengths and challenges they had encountered when involving people with lived experience. Regardless of the nature or extent to which people with lived experience were involved, it was clear that common strengths and challenges were in occurrence across projects.

# **Good practice**

## **Building strong relationships and communication**

All the projects and organisations we spoke to pointed to consistent communication and developing strong relationships as central to successful engagement. Making sure that people with lived experience felt comfortable and listened to throughout their involvement was essential not only for the success of the project, but also made the experience meaningful for the person giving their time and expertise. Some approaches to foster relationships and communication include:

- Maintaining a consistent point of contact: Organisations found people were more
  confident and engaged when there was a consistent member of staff who was a key point
  of contact. Having a variety of ways in which people felt they could get in touch such as
  regular 1-to-1 and group meetings, a direct phone number or email, and the opportunity
  to meet online or in person can give people the confidence to fully engage and share
  concerns and ideas.
- Mentoring: Alongside having a consistent point of contact, having a dedicated member of staff who takes the role of a mentor can allow people to make the most of their experience and achieve personal goals.
- **Demonstrating impact**: For many people, communicating how their involvement has a real impact is important for maintaining trust and developing self-belief. Being able to demonstrate the difference people have made through follow-up evaluations or physical outcomes, such as reviews, reports or guides, can be an important for building people's confidence and creating meaningful opportunities.

# Accessibility of participation, flexibility and support

All the organisations spoke about the importance of ensuring that people with a broad range of experiences have the opportunity to participate in projects and want to continually improve this aspect of engagement. One way of doing this is offering a variety of ways for people to share their expertise, whether online or in-person, holding open events, 1-to-1 meetings, and visiting a variety of services and locations. Some organisations found consulting or co-designing with the people they support not only helps to design a service representative of their client's needs, but also develops the range of ongoing opportunities for involvement, impact and influence.



Flexibility with participation is a key part of this. The approach of Llamau's 'Voice, Choice and Control' aims to create opportunities for people to decide where, when and how they're involved, ensuring people can have impact on a piece of work whilst acknowledging their capacity or ability to engage at that time.

#### Examples given include:

- Providing reasonable transport to venues
- Conducting meetings in a space that is accessible and comfortable
- · Producing alternatives to written materials, such as audio files or pictorial versions
- Offering opportunities in a variety of languages
- Holding meetings both online and in person
- Co-designing the timeline of a project

## Using a strengths-based approach

Strengths-based (or asset-based) approaches focus on individuals' strengths (including personal strengths and social and community networks) and not on their deficits. This is increasingly viewed as an important approach in the context of support services, but is also key to how we view the involvement of people with lived experience in service design and policy making. It recognises that people with lived experience have invaluable expertise that can be beneficial for their recovery as well as strengthening services. Understanding someone's strengths, their goals and how they would like to explore these, are important considerations and should shape how people are supported to use this expertise. This is demonstrated in a number of the examples shared in this report, including the different ways that people can be involved in service design, recruitment processes and peer research, depending on their interests and strengths.

# Challenges

# **Avoiding tokenism**

A universal challenge is creating meaningful experiences where people feel recognised for the work they do. There is a risk that people feel they were being 'wheeled out' to talk about their experiences, which can leave people feeling disenfranchised with the experience at best and re-traumatised or impacting their mental health at worst. Some of the ways that organisations have tried to avoid this include:

- Clear purpose: Being clear with people about why the engagement is taking place, the timescales and likely impact.
- Being included as a full team member: If the work is taking place sporadically or over a longer period of time, there can be a risk that people do not feel like an active team member. Some organisations offer wider opportunities for involvement, such as staff training opportunities, meetings or social events. Offering access to a programme of internal activities in this way can also be useful for maintaining engagement with experts by experience when there are fewer formal opportunities for involvement.
- Remuneration: Some organisations provide remuneration for people's time and expertise; however, this can also present challenges. Remuneration is good practice where there are systems set up to handle the process correctly and can recognise people's expertise and the burden on their time. However, organisations should consider the potential impact on people's benefits and look to offer choice if offering vouchers or paying expenses.

# Safeguarding, wellbeing and being trauma-informed

Organisations highlighted several factors indicating a need to remain conscious of people's wellbeing when being involved in projects. Some of the factors highlighted included:

- Re-traumatisation: In some of the projects showcased in this report, the risk of re-traumatisation was often a consideration where a person with lived experience may be sharing their story, or where someone offers to volunteer with a project connected to a place related to their trauma. Further challenges may occur when individuals are sharing their experiences in small groups or with people they have not formed a sufficient relationship with. Organisations should seek to understand someone's past experiences, avoid scenarios that could re-traumatise, and provide support to people if they want or need it.
- Decentralisation of involvement: Although beneficial in terms of ensuring diversity and regional variation, it can be challenging where a project takes a pan-Wales, decentralised approach. Where volunteers are spread across Wales, without a central 'hub' it can be difficult to provide consistent and adequate support. It can also be difficult to find opportunities for volunteers to benefit from peer-peer support when geographical barriers apply.
- Flexibility and capacity: People's capacity to be involved can vary considerably depending
  on their circumstances. It can often be difficult for projects to find a balance between
  ensuring sufficient involvement without this impacting on someone's wellbeing. In many
  projects they stressed not wanting to make people feel obligated to be involved or share
  their experiences, to protect their wellbeing.

#### Resourcing and funding

As lived experience involvement increases, organisations will need to provide enough resources to ensure that people with lived experience are fully supported during their involvement. Aside from remuneration and safeguarding, several other areas were highlighted as being impacted by the resources available. One area that was mentioned was learning and development. Being able to provide training and support learning has been a key aim of many of the projects mentioned. The level of training provided across projects varies considerably; however, resources are still required to allow projects to provide opportunities for skill development where the opportunity arises. One example noted that the lack of funding for IT equipment was a huge barrier in supporting people's digital literacy, and limited the potential of the project to fully upskill volunteers. Overall, it is important that projects have the capacity to provide additional training and development opportunities, particularly where lived experience involvement aims to aid service users' growth and recovery out of homelessness.



# Recommendations

For any organisations looking to get started or further develop their experts by experience opportunities, people may want to consider the following:

- Bring people in at the earliest opportunity: Think about the type of engagement you're
  wanting to do, and involve people from the earliest point possible. People's sense of
  ownership and buy-in will be greater and it will help to identify any potential problems or
  opportunities.
- Think about the purpose of the work: When trying to avoid tokenism, it should be really clear why you are asking someone to be involved in the piece of work; be as clear as possible with the time frame and what someone's involvement will change or achieve.
- Be clear with expectations: Is this a paid opportunity? Will people receive a certificate of participation or a voucher? Is this an opportunity for people to improve skills and gain confidence in an area they're passionate about? Have answers to these questions before the piece of work starts so that people are aware of the situation before agreeing.
- Close the 'feedback loop': Think about what the end result of the work was, and share this with the people who contributed. Whether this is a report, a presentation to your board of directors, or a change to a service, people want to know the result of their work and expertise.
- Work in a trauma-informed way: Think about situations which may be overwhelming or upsetting for the people taking part, ensure there is time to reflect on any contributions, and that support is available if needed.
- Consider your resources: It is always better to do something on a smaller scale which is
  meaningful and well executed than stretch capacity too thinly and have a bad experience.
  Think about the strengths of your organisation and the people you're working with, and go
  from there.
- **Keep learning, stay curious:** Things are rarely perfect the first time, but the most important thing is to take lessons on board and adapt going forward. Listen to the people who are taking part, and form relationships with other services to inspire and support one another.



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