



Voices from the Frontline policy influencing guide

Part two: Involving experts by experience

February 2016





Introduction

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Voices from the Frontline workshop in Nottingham (photo: Kate Lowe)

Why influence policy?

Changes to policy at a national and local level affect all of us, but are most acutely felt by people with multiple needs, who are in contact with a range of services yet often do not receive the support they require. This group of people experience several problems at the same time such as mental ill health, homelessness, drug and alcohol misuse, contact with the Criminal Justice System and family breakdown.

They are some of the most vulnerable people in our society and often suffer stigma and discrimination. One way to change this is by working with people with direct experience of multiple needs, who are experts by experience, to influence policy.

People facing multiple needs are policy experts in their own right: from their experiences they know what has worked to support them and what needs to improve. They can give a unique perspective on the impact (intended or otherwise) of current or future policy, and help decision makers understand how they can implement change.

"It is important to include people with lived experience, as it ensures policy makers hear first hand from those whom the policy will impact upon. How can policy makers implement change without actually having spoken to those with lived experience in a particular area?"

Maxine, Beneficiary Ambassador, Opportunity Nottingham

How our guides can help you

If you work directly with people experiencing multiple needs, or are an expert by experience yourself, then our guides on influencing policy are for you!

This is the second of two guides we have produced. The first part, *Influencing local policy*, describes the range of organisations and individuals who make local decisions that affect people with multiple needs, and gives advice on how to engage effectively with them to influence those decisions.

In this second part, we provide further advice and suggestions on involving experts by experience in that process. It has been informed by experts by experience from Opportunity Nottingham (part of the Big Lottery Fund's Fulfilling Lives programme). It also develops ideas raised in a workshop at the National Multiple Needs Summit in April 2015, where representatives from the MEAM coalition and Opportunity Nottingham discussed working with experts by experience to influence policy.



Section one

Ways to involve experts by experience in policy influencing

Experts by experience can contribute to policy work in a range of different ways. The first section of this guide looks at the different opportunities available, while the second explores a range of good practice behaviours.

Working to influence policy can empower people experiencing multiple needs, and help ensure policy work is grounded in their experience, rather than based on assumptions about their views and perspectives which may not be accurate.

Getting involved in influencing policy can bring many benefits for experts by experience. When discussing why they volunteer to take part in policy influencing work, experts by experience at Opportunity Nottingham said it helped them to:

- give something back to the services that supported them;
- raise issues that affect others who don't have a voice; and
- help them to keep busy and stay focused.

They also felt it was important that people with their level of expertise were able to influence and shape policies to ensure that they had a positive impact on people's lives.

There are many ways that frontline organisations can involve experts by experience in their policy influencing work. As everyone has different skills and life experiences it is essential that organisations utilise a range of different approaches, to ensure that each person can engage in the way that is most beneficial for them.

Meeting policy makers face-to-face

You can support experts by experience to meet policy makers face to face, for instance by:

- arranging a meeting on a one-to-one basis, such as at an MP's constituency office;
- inviting a decision maker to your service to meet a group of people and hear their views;
- asking an expert by experience to attend a meeting on behalf of your organisation (accompanied by a member of staff, if necessary).

It may be that your organisation is a member of a strategic group such as a community safety partnership or local Healthwatch, and someone with lived experience could attend that meeting, enabling them to contribute to discussions.

Attending and speaking at events

If a member of staff is going to an event or a conference where policy decision makers are likely to be in attendance, one option is to attend accompanied by someone with lived experience of multiple needs. This will allow experts by experience to share their views with other delegates but also enable them to become more aware of developments in the policy landscape.

Equally, if you or a partner organisation are arranging an event, you could invite someone with lived experience to be a keynote speaker or take part in a discussion panel.



Speakers at the Voice from the Frontline launch, November 2015 (photo: Mike Kear)

Case study: Voices From the Frontline Parliamentary day

Through Voices from the Frontline, the Making Every Adult Matter coalition works to bring the voices of people experiencing multiple needs and those who support them to the heart of policy debate.

During 2014-15, we produced three reports summarising evidence from surveys, consultations and focus groups, exploring how to improve support for people experiencing multiple needs. The final report, *Solutions from the Frontline*, makes recommendations on how policymakers can do this nationally, locally and at the frontline.

The MEAM coalition believes that those experiencing multiple needs should be involved in the debate about how they are supported, so it was important to involve participants not just in producing the report, but also in presenting it to policymakers.



We arranged for five people involved in producing the recommendations to meet with MPs and Peers as part of a day in parliament. The aim was to raise awareness of multiple needs with MPs and Peers; promote the recommendations of the report; and give participants the opportunity to talk about their own ideas to improve support.

As well as meeting five MPs in small groups accompanied by staff from across the MEAM coalition, participants were supported beforehand to decide what they wanted to talk about, how they would do this and what 'ask' they would leave with the MP.

While we learned things from the day which we will take into account the next time we meet with politicians (such as the importance of providing a clear structure for the meetings), all participants not only enjoyed the experience but found it productive and left feeling more confident in contacting their own MP independently.

Putting views in writing or on film

Not everyone with lived experience will be comfortable sharing their views with policy makers in person, or speaking to a large group. Other ways they can make their voices heard include writing or co-writing articles or blogs posted on websites, or sending a letter to a policy maker about a particular issue.

Case studies can be an effective way of sharing people's stories. You might publish a case study online, or include it in a publication.

As not everyone will want to write their views down, video or photo stories featuring experts by experience can also be effective.

Facilitate consultations

National and local policy makers often consult publicly about policy changes that they are thinking of making, seeking the views of key stakeholders including experts by experience.

If you become aware of a consultation and have the capacity to do so, you could bring together a group of experts by experience in a group or speak to people individually to gather their views and recommendations. This could then inform your submission to the consultation and help ensure that it is based on people's experiences, improving it and giving it greater credibility.

Bring together a group of experts by experience in a group or speak to them individually to gather their views and recommendations

Larger or national organisations, including those in the MEAM coalition, often have greater capacity to respond to these consultations, so if you do not have the resources to submit your own response you could contribute to theirs.

They will often ask for views on national policy consultations through their newsletters or through a call out to their members. As part of this, they will want to hear a wide range of views, particularly those based on personal experience.

However, you do not have to wait for a consultation to seek the views of experts by experience. Use the first part of this guide, *Influencing local policy*, to identify opportunities to draw on the views and suggestions of experts by experience and present these to decision makers.

Set up an expert by experience panel or forum

Establishing an expert by experience panel or forum that has membership of people with direct experience of multiple needs provides a way of discussing both the delivery of services and wider policy issues.

Further reading:

[Service user involvement: a volunteering and mentoring guide](#), published by Clinks.

Establishing a regular panel is very resource intensive, and not all organisations will be able to do this, although there are many advocacy organisations that you could approach to support you. Alternatively, you could work in partnership with other organisations that host an expert citizen panel in your local area, directing policy makers to them where appropriate.

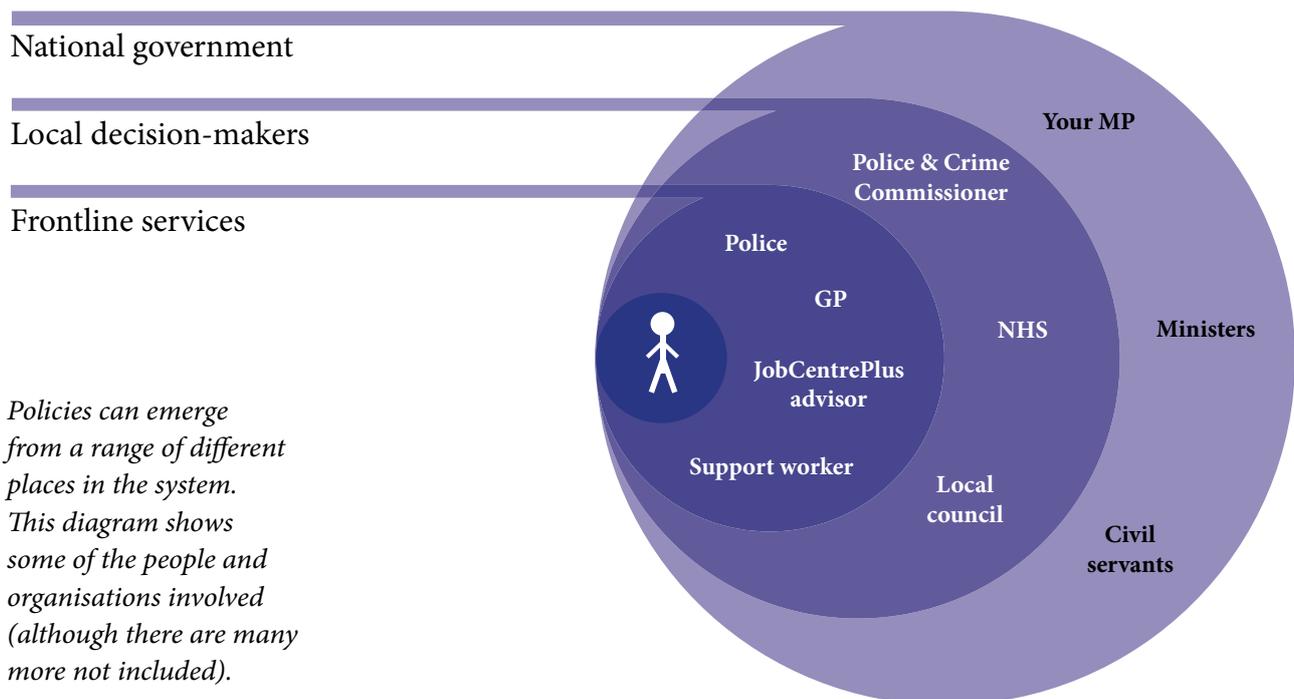
Thinking about systems change

Further reading:

[Systems change: a guide to what it is and how to do it](#), published by New Philanthropy Capital and LankellyChase Foundation.

Discussions about policy can broaden into a wider debate about 'system change', the idea that individuals can work together to "bring about lasting change by altering underlying structures and supporting mechanisms which make the system operate in a particular way [such as] policies, routines, relationships, resources, power structures and values." If you are exploring this, it can often be helpful to start with practical and immediate issues, before working outwards to influence the bigger policy changes that affect them.

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Case study: Opportunity Nottingham Expert Citizen Group explores system change

Opportunity Nottingham's Expert Citizens (a group of people with lived experience of multiple needs working with the service) identified that they would like to develop and deliver an interactive workshop on system change with beneficiaries, service providers, partners and other external stakeholders. The aim of this workshop was to allow a collective focus on:

- what system change means;
- how to address system change from a range of perspectives.

As part of the workshop expert citizens developed a role play exercise called 'the people's perspective'. This allowed them to show how systems feel from a range of perspectives, including those of a beneficiary, receptionist and support worker. It was based on the expert citizens' experiences and designed to surface issues they felt strongly about. Attendees were asked to discuss the scenario presented to them and identify challenges faced by each person in the scenario and whether it matched with their experiences.

From this, the group developed recommendations on what works well, what needs improving, what the barriers are to treating each other well and how to make the system work better for everyone. The workshop gave attendees an understanding of different perspectives and the space to think about the role they can play.

The information gathered from the workshop has been used in Opportunity Nottingham's system change strategy and also led to the development of a new joint working approach, particularly with under-represented individuals and services. Following on from the success of this event, Expert Citizens have agreed to undertake the workshop with other groups.



Section two

Good practice

When working with experts by experience to influence policy, there are some important things that organisations should be conscious of and work to support. The following discusses some basic principles you can follow to ensure effective and ethical involvement of experts by experience in policy influencing work.

Take a person-centred approach

Further reading:
[*Beyond the Usual Suspects*](#), published by Shaping Our Lives provides detailed and helpful advice on how to make sure your involvement work is inclusive and accessible.

Experts by experience should take a central role in designing policy influencing work. They are the best people to decide when they would like to take part, what they would like to be involved in and what they are comfortable with. It is therefore important to offer a range of ways for people to get involved in policy influencing, as different approaches will work for different people.

Given that expert citizens may well share some of their personal experiences with you and decision makers, which can be challenging for them, it is important to have a discussion before beginning any influencing work to ensure that they have the type and level of involvement that is most appropriate for them. It may also be necessary to provide them with or signpost them to any support they might need after they have taken part.

People can feel pressure to be involved in policy influencing work due to their desire to help the organisation that provided them with support

Experts by experience at Opportunity Nottingham explained how, at times, people can feel pressure to be involved in policy influencing work due to their desire to help the organisation that provided them with support. For instance, a person might agree to take part in a meeting and then on the day feel unable to do so, but not want to let anyone down.

You should be alive to these issues, and work flexibly to respond to them. For instance, it can be helpful to invite more than one person with lived experience to participate in policy influencing work at one time, so if someone does drop out there are other people who are able to take part.

Involve people as early as possible – and keep them informed

When planning influencing work, you should involve people as early as possible, and keep them informed about key developments and any progress that has been made. If someone has invested their time to support policy influencing work, you have a responsibility to keep them up-to-date in a way that works for them. For example, not everyone has an email address, so you need to be flexible with how you contact people. Where you can, you should nominate a named individual who people can contact if they have any questions or concerns.

It is also important that you encourage decision makers that experts by experience have met with to come back and update you on any changes they have made in light of your suggestions. Whether or not they choose to do this is out of your hands, but it is important you communicate the steps you have taken to try and ensure this occurs.

Be honest, open and transparent

When working to influence policy, you are engaging with an external environment that is highly unpredictable, which means that things might not happen exactly as you anticipated. You might need to change your influencing approach or you may not be able to deliver on something that you have told your stakeholders that you originally planned to do. This is largely unavoidable, but you should keep the experts by experience who have been involved in the work updated with any new developments, and if things change explain why that is.

It is also important that you manage people's expectations, as there are limits to what you can achieve. Influencing policy change can take a considerable amount of time: often there might be 'small wins' on the way, or a decision maker might implement a significant change that you didn't quite expect. If experts by experience are new to policy influencing, you will need to let them know this, and ensure that they are aware of some of the constraints on decision makers, whose power to change things is also limited.

Manage decision makers' expectations

When you are meeting with a decision maker it is important that you brief them to make sure they are well prepared and understand what they can do to make things go smoothly. If they are meeting with experts by experience they need to be open to really listening to what they have to say, and be prepared to hear things that they did not expect to hear. It is helpful if you are able to provide as much information as you can on who is attending and the context of the meeting ahead of time.



Further resources

There are other helpful resources available on involving and engaging people, some of which we have included below.

Not all of these are directly about involving people with lived experience in policy influencing work, but they provide useful guidance about some of the issues and suggestions we have highlighted in the guide.

Guides to involvement

- Clinks (2010), [*Service user involvement: a volunteering and mentoring guide*](#)
- Shaping Our Lives (2013), [*Beyond the Usual Suspects*](#)
- National Survivor User Network and Together for Mental Wellbeing (2014), [*Service user involvement in the delivery of mental health services*](#)
- Institute for Government (2015), [*Smarter engagement: Harnessing public voice in policy challenges*](#)

Appendix: Checklist for organisations

The information below is based on the 'Good practice' section of this guide, and aims to provide a basic checklist for working with experts by experience.

Planning

- Have you involved experts by experience at the earliest opportunity?
- Have you established the level of involvement that would be best for both organisers and participants?
- Have you explored a range of options for experts by experience to contribute to policy influencing work?
- Before meetings and events, have you ensured that you have fully briefed people who are attending?
- Have you ensured that any decision makers you plan to meet are well briefed?

During and after the influencing activity

- Is there a nominated person experts by experience can contact about the policy influencing work?
- Have you kept people updated on any developments?
- If things haven't gone exactly as planned, and you have either had to change your plans or not been able to deliver something you previously said you would, have you explained why that is the case?
- Do you need to signpost people to any additional support?

Making Every Adult Matter

Making Every Adult Matter (MEAM) is a coalition of Clinks, Homeless Link and Mind formed to improve policy and services for people facing multiple needs. Together the charities represent over 1,300 frontline organisations and have an interest in the criminal justice, substance misuse, homelessness and mental health sectors.



LankellyChase Foundation

The LankellyChase Foundation works to bring about change that will transform the quality of life of people who face severe and multiple disadvantage. It focuses on the persistent clustering of social harms such as homelessness, substance misuse, mental and physical illness, extreme poverty, and violence and abuse. LankellyChase also wants to drive systems change in order to radically reshape the services designed to reduce these harms.

Lankelly Chase

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