

Making Every Adult Matter coalition response to the APPG for Complex Needs and Dual Diagnosis call for evidence on social action

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About MEAM

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 that have an interest in the criminal justice, substance misuse, homelessness and mental health sectors. MEAM also supports local areas to use the MEAM Approach, which helps them to design and deliver better coordinated services for people with multiple needs. It's currently being used by partnerships of statutory and voluntary agencies in 15 local areas across England.

People with multiple needs face a combination of problems including homelessness, substance misuse, contact with the criminal justice system and mental ill health. They are likely to live in poverty and experience stigma, discrimination, isolation and loneliness. It is estimated that 58,000 people face problems of homelessness, substance misuse and offending in any one year. Within this group, a majority will have experienced mental health problems.

About this submission

We welcome the opportunity to respond to the All Party Parliamentary Group (APPG)'s call for evidence on how social action can drive better services for people with complex needs. Our submission is informed by our experiences and approach to involving people with lived experience of multiple needs in social action, and those of the respective sectors we represent. In response to the committee's guidance to submitting evidence, our submission:

- demonstrates the key principles needed to successfully engage people with experience of multiple and complex needs in social action;
- highlights some of the barriers to successfully engaging people with experience of multiple needs in social action and ways these can be overcome;
- includes case study examples;
- and provides a list and summary of key publications and resources.

In order to prepare our response we collected case studies from a range of voluntary organisations, including some who have adopted the MEAM Approach and others who are local partners in the [Big Lottery Fund's Fulfilling Lives Programme](#). As well as including case study examples throughout the submission, we have also included in-depth case studies to demonstrate the different ways people with lived experience¹ are involved in social action. We also refer the APPG to the case study examples submitted by the National Expert Citizens Group working with the Big Lottery Fund's Fulfilling Lives programme, whose evidence we fully endorse.

We have structured our response around the questions in the call for evidence and have focused on those that are of most relevance to the MEAM coalition and its respective partners.

Introduction

There are many different ways through which people with lived experience of multiple needs can be involved in social action, which the Office for Civil Society has defined as *"people coming together to help improve their lives and solve the problems that are important in their communities."* Social action can also take different forms and be peer led such as 'recovery communities' where diverse groups of people who share a common sense of identity and lived experiences including addiction, treatment, and/or recovery informally come together, or be through formal involvement in the work of voluntary sector organisations. We have focused our response on instances where people with multiple needs take part in social action through being involved in the work of voluntary organisations, which can include:

- being part of a lived experience forum or group to influence the design or delivery of services (by that organisation and/or others) or to influence local and national policy;
- attending meetings or events on behalf of the organisation;
- taking part in peer research, quality assurance and monitoring services;
- leading a voluntary organisation, through being a senior member of staff or trustee;
- providing peer support;
- and volunteering for an organisation.

¹ Please note that we have chosen to use the terms 'lived experience' and 'experts by experience' to describe people who have experience of multiple and complex needs.

As well as there being different forms of social action that people can be involved in, Arenstein's ladder of participation shows that there are different levels of participation.² These range from people with lived experience being involved but having no control of the services they are engaging with, right up to full control of decision making at the highest level of the organisation.³ It will depend on what role someone undertakes and at what stage they are in their recovery journey as to what their level of their involvement should be. Indeed, User Voice highlight that good practice in service user involvement entails using 'the right rung for the right job.'

In what follows we highlight a range of examples of different forms and levels of social action, as well as outlining the enablers and barriers to these taking place. Firstly however, we examine what impact involving people with lived experience of multiple needs in social action can have.

1. The impact of involving people with lived experience in social action

Involving people with lived experience of multiple and complex needs in the design and delivery of services can have many benefits-both for them, and the organisations supporting them. As highlighted in MEAM's report *Solutions from the frontline*, people experiencing multiple needs feel that their issues and experiences are not well-understood which both contributes to and is heightened by the stigma and discrimination they often face.⁴ This can lead to social exclusion, isolation and low self-esteem. Being involved in social action, and feeling that their voice is being heard can be really powerful for people and contribute to addressing this. One person with lived experience of multiple needs said:

"Having our voices heard and making an impact has been a very rewarding experience. It has become part of our own recovery journey."

This was supported by another person who told us that their confidence had increased from being involved in social action. They said:

"I have only been involved with the Experts By Experience Network for a short time but already my confidence has increased massively; the buzz I get from actually having a voice that is listened to and not just heard is better than anything I have ever experienced in my life."

Being involved in social action can also: help to break down some of the barriers between people with lived experience and professionals, leading to greater understanding and positive service outcomes; support them on their journey to recovery; and enable them to give something back to help other people with similar experiences to their own. People with lived experience told us the following:

² For more information please see Clinks and Revolving Door Agency (2016) [Service user involvement and co-production](#)

³ Clinks and Revolving Door Agency (2016) [Service user involvement and co-production](#)

⁴ MEAM (2015) [Solutions from the Frontline](#)

“I have been able to explain to professionals what it’s like living with MCN (Multiple and Complex Needs) and hopefully getting them to have some empathy with those similar to me. I’ve been able to explain what it feels like when trying to access services, being judged for my sexuality, being judged for my mental health, substance misuse and criminality.”

People facing multiple needs are experts in their own right: from their experiences they know what has worked to support them and what needs to improve. This knowledge can help to ensure that services provide the best possible response to meet their needs. Someone with lived experience of multiple needs said one of the benefits of being involved in the design and delivery of services has enabled them to “*explain what I would have liked when I first sought help 20 years and 10 years ago.*” In support of this, an organisation working to support people with multiple needs said “*they can tell us what works and what doesn’t. The people we support have lived it, where we haven’t.*”

Case study: Real Insight

After being a service user for many years, I felt the need to draw on my lived experience of multiple and complex needs to engage, enable and empower both service users and service providers. I believed there was an opportunity to work in a collaborative manner to improve services by harnessing mine, and others, experiences.

Two years ago, funded by Lankelly Chase Foundation, I set up Real Insight – a company whose mission is to improve services using the skills of peers. We are now working with a range of public sector and charitable organisations. Lankelly Chase has been pivotal to our development. They encouraged us as a user group and empowered us to get meaningfully involved.

We have created an approach which combines service user involvement with product design and economic analysis to create a sophisticated offer to organisations and peers. This means we are able to do workshops in a new way; to offer service users financial modelling tools that they can use; and to facilitate joint working with commissioners and peers using a common design framework. This is a new approach and is proving popular.

We often have the feeling we are not taken seriously, and some organisations are unable to see our potential – seeing us only as service users, not service designers. We also question the authenticity of some organisations’ commitment to meaningful peer engagement and whether it extends beyond glossy reports and customer charters.

I would emphasise the learning from those experiences. It has been a challenging journey but mostly rewarding and fulfilling. It has equipped us with the knowledge to embrace new challenges with energy and confidence. Having our voices heard and making an impact has been a very rewarding experience. It has become a part of our own recovery journey.

Case study: User Voice community councils

User Voice exists to enable and promote productive collaboration between service users, commissioners, policy makers and service providers. With over 85% of staff having an offending background, work is led and delivered almost entirely by people with lived experience. This gives a special ability to access, gain the trust of, and gather insight from people within the Criminal Justice System.

User Voice works to achieve its aims via service user consultations and research; and through councils which provide a platform for service users to have a voice, both within prisons and in the community for Community Rehabilitation Companies, Youth Offending Teams, and other services. Both prison and community council models share common approaches and principles, though the different environments require slightly different delivery methods.

User Voice is working in two-thirds of the Community Rehabilitation Companies (CRCs) to establish its service user councils. Anyone that has been on a community order within the past two years is eligible to become a council member. All council representatives (reps) receive accredited training, developed and delivered by User Voice. Once qualified, council reps engage with current service users in probation reception areas and other community services to identify issues and recruit new reps. Feedback from this process is collated by the reps and discussed at regular proposal hub meetings. Members collectively develop a proposal or proposals to present at the subsequent council meetings in the community, chaired by senior staff within the CRC, usually the chief executive. A number of principles underpin the council model:

- The councils are 100% user led.
- They are independent. User Voice does not deliver services in the traditional sense so there is no inherent bias or conflict of interest.
- The council model is democratic. The community in which the council operates selects its members. This minimises the risk of 'professional service users' being recruited by services.
- Discussions are issue-based, not personal, making sure they are representative of wider community issues.
- The model is solution-focused which validates it in many organisations' minds.

Clinks and Revolving Doors Agency's guide to service user involvement and co-production lists the core benefits of involving people with lived experience in the design and delivery of services.⁵ Although the focus of the guide is on involving people with experience of the criminal justice system, the benefits are also applicable to people experiencing multiple needs. We have listed some of the core benefits, as follows:

⁵ Ibid.

Benefits for people with lived experience	Benefits for organisations
Offers them a 'voice' if they have felt excluded	Models to service users that inclusion is possible and real
Makes them feel valued and respected	Improves communication and understanding between staff/volunteers and service users
Gives them ownership of the services provided for them	Creates a sense of service ownership, by ensuring that services reflect the needs and wishes of those who use them
Enhances their understanding of services and how they work	Breaks down organisational hierarchy and adds value to service planning, development and delivery
Improves skills and abilities	Helps staff/volunteers develop their skills and enables organisations to draw upon and make effective use of people's skills and capabilities
Builds confidence	Can lead to service improvements and improve the quality of service provision

The impact of peer support

Peer support 'occurs when people with the same shared experience provide knowledge, experience, or emotional, social or practical help to each other.'⁶ Taking part in peer support programmes through providing or receiving peer support can have many benefits for people experiencing multiple needs as it can help someone develop skills and confidence and support them in their recovery.

Whilst some organisations work to embed peer support as a specific project or programme within their service, other organisations are set up and run specifically by people with lived experience as peer-led peer support services, such as the service user involvement team at Wolverhampton Voluntary Sector Council.

The MEAM report *Solutions from the Frontline* demonstrates that many people with experiences of multiple needs said how much they value peer support, as they found it easier to trust someone who understands what they have been through.⁷ Someone told us:

"Those people that are in, or still around the madness, if they've got someone who's been there, seen it, done it, I've even used with them, they can trust them, d'you know what I mean? That element of 'right, what are they out for here?' is taken away, the person can relax and tell an honest story"

⁶ Clinks (2012) [Volunteer peer support: A volunteering and mentoring guide](#)

⁷ MEAM (2015) [Solutions from the Frontline](#)

Case study: Service User Involvement Team (SUIT) at Wolverhampton Voluntary Sector Council

Being a peer led substance misuse community service, we all have lived experience of addiction and other associated challenges including poor mental health, homelessness, indebtedness, poverty etc. We ensure that we have a structured approach to recruiting and supporting volunteers (who make up 75% of our workforce) and regularly provide opportunities to feedback their experiences of supporting vulnerable individuals that access our services for help, support and guidance.

Other than case management of individuals, we are involved in the following – service user consultation and representation, delivery of training and raising awareness, arranging events and conferences, supporting the development of user led activities, social media and online presence, drug warning system, family and carer support, consultation projects, translation services plus more.

We have developed a delivery model based on the needs, wants, requirements and aspirations of our service users – whilst at the same time understanding the constraints and barriers that services and systems around us face. Working in this way has increased our ability to understand and empower individuals. Over the past 6 year period we supported 159 individuals into employment and between April and December 2016, we:

- Supported 829 individuals and delivered 3309 one to one sessions
- Made 1235 welfare interventions, offered 673 employability interventions
- Arranged 303 training and educational interventions
- Supported people in accessing 241 volunteering placements
- Delivered 352 housing related interventions
- Referred 107 people into structured drug/alcohol treatment
- Provided 133 health based interventions
- The unit cost of each intervention during this period of time was £24.46.

February 2017 marked the 10 year anniversary for SUIT and we have continually developed our service to work to influence systemic change.

Working to influence policy

There are also many benefits to involving people with lived experience of multiple needs in policy influencing, both at a local and national level. When discussing why they volunteer to take part in policy influencing work, people who are part of an experts by experience group at Opportunity Nottingham said it helped them to⁸:

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

⁸ MEAM (2015) [Solutions from the frontline](#)

They also said that they felt it was important for them to be involved in influencing policy as it can lead to decision makers implementing positive change that can ensure people get the support that they need.

The MEAM report *Solutions from the Frontline* drew on the views and experiences of people with multiple needs and frontline staff to argue that people with experience of multiple needs should be encouraged to take part in social action thorough working to influence government policy.⁹ To support this we recommended that Ministers should identify a structured way to listen to the voices of people with multiple needs and the frontline staff who support them, to ensure that policies properly reflect their experiences and meet their needs.

2. The enablers for engaging people with lived experience in social action

As Clinks and Revolving Doors Agency's *good practice in service user involvement and co-production* guide shows, there are some essential requirements for enabling people with lived experience to be involved in social action.¹⁰ The guide uses case study examples to demonstrate these requirements in detail, but we have provided a summarised list as follows:

- the development of a clear strategy for involvement, which covers why an organisation wants to engage with people, what it is aiming to achieve and how it will do this;
- buy in from senior members of staff;
- the development and implementation of appropriate policies such as, payment/reward, recruitment and training of service users, diversity, safeguarding
- training and support for both people with lived experience and staff/volunteers
- ensuring there is continued good communication between staff/volunteers and people with lived experience.

Many organisations are seeking to go beyond these principles, and taking an approach that seeks to ensure that people with lived experience can to engage in the work of organisations on an equal footing with staff who have professional experience. This might involve:

- ensuring that decision-making on strategic issues involves or is led by people with lived experience
- creating structured employment opportunities for people with lived experience in a range of roles across the organisation
- working with commissioners or funders to ensure that new services or initiatives are co-produced with people with lived experience from the start.

⁹ MEAM (2015) [Solutions from the Frontline](#)

¹⁰ Clinks and Revolving Door Agency (2016) [Service user involvement and co-production](#)

Case study: Liaison and diversion lived experience team, Revolving Doors Agency

Revolving Doors Agency is part of the Offender Health Collaborative, supporting the national roll out of liaison and diversion services, which came about as a response to the 2009 Bradley Report into people with mental health problems or learning disabilities in the Criminal Justice System. Liaison and diversion places support into police custody and courts, meaning that people coming into contact with the criminal justice system who have mental health problems and other social care needs will be better identified and referred to the support they need. Using funding from NHS England to support its input, Revolving Doors is involving service users in the development of the national operating model for liaison and diversion and is supporting local schemes to embed service user involvement.

The Lived Experience Team (LET) comprises seven people with multiple needs and direct experience of the criminal justice system. The team forms an Advisory Board to the Liaison and Diversion Programme Board at NHS England. One of the essential requirements that ensured the success of the programme is the continued training for members of the lived experience team. One member of the lived experience team said:

“Revolving Doors are brilliant. They support us and make sure everything runs smoothly. We wouldn’t be where we are without all the training they’ve provided in things like facilitation, commissioning, governance, events, presentation skills, and presenting findings.”

Setting up, facilitating and maintaining clear structures through which people with lived experience are able to influence the design and delivery of services needs sufficient resource, in terms of both time and finance. It is important that organisations plan and budget for this, especially as the more successful the engagement becomes, the more resource it is likely to need to support it.

Further to this, it is important that commissioners work to proactively involve people with lived experience of multiple needs in the full commissioning cycle and provide commissioning and procurement teams with the opportunity to meet directly with people with lived experience. This is important as it can help ensure that staff who are writing service specifications and contracts are grounded in the reality of the day to-day lives of the recipients of the service.¹¹

To enable this to take place, commissioners and procurement teams should have clear strategies for how they visit services and directly speak (and listen) to service users and their families within currently commissioned services, and involve them in future service design. To ensure this can happen, they need to ensure there is sufficient time to embed this into the full commissioning cycle.

¹¹ Clinks (2015) [More than a provider: the role of the voluntary sector in the commissioning of offender services](#)

Case study: Prisons healthcare procurement, WY-FI and NHS England Health and Justice

West Yorkshire – Finding Independence (WY-FI) is a partnership of organisations funded by the Big Lottery, led by DISC (Developing Initiatives Supporting Communities) and overseen by a board made up of experts by experience, representatives from the voluntary sector, delivery partners and statutory organisations. WY-FI aims to improve the lives and wellbeing of people with entrenched multiple needs who do not, or cannot, access services.

WY-FI are working with NHS England on the Prisons Healthcare Procurement project. NHS England has direct commissioning responsibility for healthcare for people in prisons and prescribed places of detention. With contracts due to end in March 2016, NHS England's Health and Justice commissioning team saw an opportunity to improve patient engagement, locate patient voice centrally within the procurement process and deliver against the NHS England Patient and Public Participation Policy (2015). To do this they forged a partnership with WY-FI, who had the expertise in involving experts by experience to advise the team about effectively accessing the patient voice in prisons and in the community after release from prison.

WY-FI identified the experts by experience, and in partnership with the Health and Justice commissioning team and North of England Commissioning Support (NECS), supported and prepared them to contribute to the bid evaluation process. Each expert evaluated and scored specific questions prior to attending consensus meetings as equal partners with other field experts such as prison governors, GPs, pharmacists, mental health and substance misuse professionals.

From a commissioning perspective, most of the elements considered to be essential focused on mitigating risk within the procurement process and being clear about the value of including patients in the process in a way which was more than just tokenistic.

3. The barriers to engaging people with lived experience in social action and how these can be overcome

There are many barriers that can prevent people with lived experience being able to engage in social action. Some of these barriers stem from the stigma and discrimination they experience, as they can be perceived as a 'problem' or just as a 'service user', rather than someone who is an expert due to their experiences. Indeed someone told us *"we often have the feeling we are not taken seriously, and some organisations are unable to see our potential – seeing us only as service users, not service designers."*

These issues were highlighted in two of the case studies we collected as people told us a barrier to social action is *"political unwillingness to listen to and act upon new and emerging evidence"* and *"ignorance in the community to the people we support's condition and a general lack of empathy"*.

Positively, in both cases proactive action was taken to break down these barriers- in one case the organisation had improved the skills of their staff and volunteers and undertaken policy influencing and networking. In the other, the organisation had worked to facilitate understanding

and partnership working between people with lived experience of multiple needs and members of their local community. They said, “we try to involve the people we support with activity in the community, albeit with support. This has broken down the barriers and improved understanding.”

One person with lived experience of multiple needs said that their lack of confidence when they first started being involved in social action was a barrier to them as they didn’t feel that they were worthy of being involved. They said:

“When I first attended the RESPOND training, I felt like a fish out of water. There were lots of people attending the training who I deemed to be of a higher class than myself, and I didn’t feel that I belonged as I was just a lad in early recovery who wasn’t worthy of being there.”

They went on to tell us that they nearly left the RESPOND training, but didn’t due to the intervention of the Engagement and Co-Production Worker from Fulfilling Lives Newcastle and Gateshead who provided them with support and told them that they “had a right to be there.”

Clinks and Revolving Doors Agency’s guide entitled *service user involvement and co-production*¹² lists some of the barriers to involving people with lived experience in the design and delivery of services and provides advice as to how these can be overcome.¹³

Barrier	How to overcome the barrier
Lack of management buy in	<ul style="list-style-type: none"> • Identify key champions who can promote the benefits of engaging people with lived experience. • Develop a statement or policy for your organisation. • Develop training materials for managers and trustees.
Staff apprehension- staff can sometimes be wary of involving people with lived experience because they haven’t been consulted themselves, or fear participants will be negative.	<ul style="list-style-type: none"> • Be clear from the outset about the limits of engaging people with lived experience – what is and is not up for discussion or change • Have ongoing communication with staff about project aims and outcomes.
Staff feel unprepared or unsupported: service user involvement projects require a time commitment and specialist skills that staff may not have, or know how to access.	<ul style="list-style-type: none"> • Ensure that your staff members have access to training if needed to facilitate involvement of people with lived experience • Develop appropriate policies and guidance to support implementing and sustaining engagement

¹² Clinks and Revolving Door Agency (2016) [Service user involvement and co-production](#)

¹³ As highlighted before, although the focus of the guide is involving people with experience of the criminal justice system the benefits are also applicable to people experiencing multiple needs. We have summarised this information below.

<p>Role adjustment issues- staff may feel uncomfortable, or even threatened, by service users voicing their opinions.</p>	<ul style="list-style-type: none"> • Communicate clearly across your organisation why you are doing your engagement project and what you hope to achieve • Draw up a job description for the service user, which provides clear guidance on what the role does and does not cover • Emphasise the link between their input and service improvement • Remind staff that engagement can be a positive intervention in itself with a clear link to desistance and recovery pathways.
<p>Concerns over inclusion of ‘difficult voices’- Some service users may not want to participate in a project if people perceived as having ‘difficult voices’ such as those with experience of multiple and complex needs are also involved.</p>	<ul style="list-style-type: none"> • Be clear from the start that your project aims to attract a broad range of voices • Develop clear policies and guidance frameworks to assess any risks posed by inclusion of service users, and clear routes of decision making in cases of concern • Let all participants know who to speak to if they want to discuss their concerns • Ensure that forum or event facilitators are briefed on the potential problems that can arise from having a wide range of offences represented on a panel or within a room, and trained in appropriate responses.

Where people’s views are gathered through a meeting, it can be a challenge to ensure that peoples asks are effective and that meetings are chaired so that all people are able to contribute. Expert Link have developed a guide around developing asks and supporting people with lived experience to chair a meeting and so overcome some of the barriers people may have to participation such as language, understanding group dynamics and actively listening.¹⁴

People with lived experience of the criminal justice system taking social action by volunteering within the criminal justice system may face particular barriers. Clinks conducted a review into volunteer involvement in prisons in 2016 and found that security clearance for volunteers, especially those who have a criminal record can be a lengthy process that can lead to delays for people starting their roles.¹⁵ During a focus group with people who had a criminal record and had tried to volunteer in prison, there was a perception that vetting created a blanket restriction on ex-prisoners volunteering, rather than considering individuals on a case by case basis, which they saw as preferable. Further to this, someone told us that they found the vetting process was scary and issues with IT skills and literacy may also be a particular concern with ex-prisoners, and lead to drop-out. They said:

¹⁴ Expert Link (2017) [Facilitator Training: How to Chair or Facilitate a Group meeting](#)

¹⁵ Clinks (2016) [Valuing volunteering in the criminal justice system](#)

“[The vetting process] was quite scary you know. There’s a lot in there. For me at that point of time with computers and that, I weren’t sort of computer literate and it was tricky. The first one I got I couldn’t complete it.”

The lessons from this extend beyond prisons and the criminal justice system. Although it is clearly important that organisations have clear security and vetting processes for people with lived experience looking to be involved in volunteering or working for that organisation it is important that these processes are transparent and flexible to ensure they do not act as an unnecessary barrier to people’s involvement.

4. Examples of preventative social action which help people stay in work

Taking part in social action such as volunteering can help people with lived experience of multiple needs to develop their confidence and the skills that they often need to gain employment. However, as we highlight in our paper *steps towards employment*,¹⁶ even for people who are able to achieve consistent levels of stability in their lives, the prospect of employment remains extremely daunting, provoking strong feelings of fear and anxiety, which can lead to setbacks. As such, people with multiple and complex needs often require additional support to ensure they are able to access and sustain stable employment. Due to the stigma and discrimination people with multiple and complex needs face, it is also important that potential employers receive information and support to break down barriers and ensure they understand the benefits of employing people with these experiences.

Case study: GROW Trainee Model (Getting Real Opportunities of Work) by Shelter, who lead Inspiring Change Manchester

GROW Traineeships are 12 month paid roles open to anyone who has previously experienced homelessness and multiple needs services. Grow Trainees are supported throughout their placements and receive regular placement, learning and development supervisions. They are also able to access to a personal budget that they are able to spend on things including training, wellbeing, education and coaching.

The GROW Trainee programme consists of a number of elements including:

- An introduction to the traineeship, including induction, goal setting and shadowing
- Placements working within the Inspiring Change Manchester Engagement Team, including placements focussing on health, activities, mental health, accommodation, women, engagement and outreach.
- Opportunities to get involved in developing services in Manchester, using their experiences to make change.
- A ‘move on’ phase focused on learning and the evaluation of the placement, with the goal of securing future employment.

¹⁶ MEAM (2016) [Steps towards employment](#)

People who have taken part in the programme said that it has helped them to develop their confidence, skills and knowledge and enabled them to work towards positive change. Quotes from Grow Trainees are as follows:

“I wanted something that used my negative life experiences for positive change. That’s why I became an ICM (Inspiring Change Manchester) GROW trainee”

“I was fearful – but received a lot of support throughout the traineeship. My confidence has grown along with my knowledge and I know that I am making a real difference to people that were like me; judged for their history not their potential”

Inspiring Change Manchester have produced a [video about the programme](#) and published blogs [discussing its origins](#) and [exploring one participant’s experiences of it](#).

Case study: Shekinah’s Re:work programme¹⁷

Shekinah’s employability team deliver a number of programmes and events that bring business and the local community together. Using our business and community partnerships, we help people affected by homelessness and complex issues gain and sustain work. With an award winning employability programme and a recruitment service which supports businesses to recruit ex-offenders and individuals who are socially excluded, Shekinah prides itself on delivering a quality service that meets the needs of our clients and our business supporters.

Re:work is a socially responsible employment service which has been launched as a social enterprise in response to a growing need to provide a creative approach to recruitment in Plymouth and Torbay. Aimed at those businesses for whom work inclusion is an integral part of their business operations, Re:work helps a business consider complimentary recruitment methods and change someone’s life...for the better.

Re:work helps secure employment for those individuals who have been in prison, or have experienced homelessness, or have social barriers preventing them from accessing employment.

¹⁷ For more information please see [Shekinah’s website](#)

5. In-depth case studies

As well as including examples throughout this submission, the following gives additional, in-depth case study examples of the different ways people with lived experience are involved in social action. It is split into two sections; the first includes case studies from people with lived experience of multiple needs¹⁸ and the second is from the perspective of organisations who facilitate social action, either through facilitating a forum or group or running a peer support programme.

Case study from someone with lived experience of multiple needs Fulfilling Lives (South East Brighton Housing Trust)	
How did you get involved and what have you done?	<p>I sought help with my mental health 20 years ago and was diagnosed with OCD, depression and anxiety. 10 years ago I sought help for my substance use addiction when I lived in London. I have a criminal record, last offence 2009, and I sofa surfed for 18 months.</p> <p>Four years ago I became a service user rep for the iHear Partnership (a substance misuse service in West London). This involved using my recovery to help others, attending weekly service user forums, liaising with the staff team, attending national forums and providing training to outside agencies.</p> <p>I moved to Hastings a year ago and become a peer mentor at Pavilions in Brighton (another substance misuse service). I support a number of people who primarily have substance misuse issues but also have any number complex needs. I still do this and I also run SMART recovery groups there.</p> <p>Two months ago I finally got back to work after a four and a half year break. I know work as a Project Consultant Assistant for the South East Fulfilling Lives Project (BHT) working with people with multiple complex needs locally in Hastings and St Leonards.</p>
What helped you to get involved?	<ul style="list-style-type: none"> • Good support from local services and from people who have lived experience of issues surrounding people with multiple complex needs • Being given “a chance” • Not being judged • Being supported in my voluntary roles and my paid work • Wanting to give something back to communities and to want to help others.

¹⁸ We have not edited the case studies submitted to us from people with lived experience of multiple needs to ensure their own words and voice are reflected in our submission.

<p>What benefits have you experienced from being involved in the design and delivery of services?</p>	<p>Being able to explain what I would have liked when I first sought help 20 years ago and 10 years respectively. I have been able to explain to professionals what it's like living with multiple and complex needs (MCN) and hopefully getting them to have some empathy with those similar to me.</p> <p>I've been able to explain what it feels like when trying to access services, being judged for my sexuality, being judged for my mental health, substance misuse and criminality.</p>
<p>Did you face any challenges or barriers? If so, what were they?</p>	<ul style="list-style-type: none"> • Being gay and services not sure how to work with me • Being told "unless you stop drinking/using we won't refer you for further mental health services" • Listening to staff whilst I was heavily sedated in hospital saying "that's that mad, violent alky" • Losing my job, home and friends. • Poor health
<p>Have you been able to overcome these barriers?</p> <p>How?</p>	<ul style="list-style-type: none"> • Stuck at it! • Challenged discrimination • Got help for my addiction – recovery on going • Volunteered (very empowering) • Worked hard to overcome issues (not easy) • On-going support from peers and work colleagues • (Very) Understanding partner
<p>Is there anything you would like to add?</p>	<p>I feel very lucky and fortunate to be in the situation I am in now and I realise that many people aren't in this situation and need loads more support individually, locally and nationally. I feel passionate about this and hope to be able to achieve a change to what is going on in today's climate with the challenges faced by people with Multiple Complex Needs.</p>

<p>Case study from someone with lived experience of multiple needs Fulfilling Lives Newcastle Gateshead</p>	
<p>How did you get involved and what have you done?</p>	<p>I found out about the Experts By Experience Network through a Fulfilling Lives Newcastle Gateshead Service Navigator, who felt that I might benefit from the Network and have a platform to share my story but also help others share theirs.</p>

	<p>I have only been a member of the network for a few months but have been involved in the RESPOND¹⁹ training devised in partnership with Northumberland, Tyne and Weir NHS Foundation Trust attending as an Expert and being a large part of the group discussions with professionals from the Police, Mental Health and Ambulance sectors.</p>
<p>What helped you to get involved?</p>	<p>I knew the Fulfilling Lives Newcastle Gateshead Engagement and Co-Production Worker from his previous role, so that helped ease any anxieties as we already had a trusting relationship. I also wanted to give something back to my peers and that made it easier and made me more determined to get involved in a meaningful way: the knowledge that I would be helping others was a massive motivation.</p>
<p>What benefits have you experienced from being involved in the design and delivery of services?</p>	<p>As I said I have only been involved with the Experts By Experience Network for a short time but already my confidence has increased massively; the buzz I get from actually having a voice that is listened to and not just heard is better than anything I have ever experienced in my life.</p> <p>I am motivated to continue working with the Network and to impact change in the system both locally and nationally, something I never thought I would have the chance to do before.</p>
<p>Did you face any challenges or barriers? If so, what were they?</p>	<p>When I first attended the RESPOND training, I felt like a fish out of water. There were lots of people attending the training who I deemed to be of a higher class than myself, and I didn't feel that I belonged as I was just a lad in early recovery who wasn't worthy of being there.</p>
<p>Have you been able to overcome these barriers? How?</p>	<p>I almost left the RESPOND training, but the Engagement and Co-Production Worker from Fulfilling Lives Newcastle Gateshead spoke to me and told me that I had a right to be there and that the only way things can change is if myself and my peers share our experiences and make people think about things differently.</p> <p>As the day progressed I became more and more confident and really enjoyed sharing my opinions. I realised that my background is an asset and I deserve to be involved in these type of events.</p>

¹⁹ RESPOND is a multi-agency simulation training programme that aims to present frontline staff with a range of real-life scenarios to help them learn about what each agency offers to people going through a mental health crisis.

<p>Is there anything you would like to add?</p>	<p>Although I have only been involved with the Experts Network for a short time it has really given me the confidence to speak out and let people see that we all have a right to have the best future we possibly can. It is humbling to see that people actually have faith in and believe in me - something which I haven't always experienced.</p>
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The following three case studies demonstrate how organisations have facilitated social action in their work. The first two are examples of engaging people in a forum or group, whilst the last case study example is of a peer mentoring programme.

Case study: Waymarks

We support people in the community who have mild learning difficulties including autism. Most of them have forensic backgrounds. We involve them in the recruitment of the staff who work with them and they are involved in learning forums and help us through consultation in improving our service. The people we support are key in shaping our future and improving our service.

We run Listening, Learning and action events, where their views are noted and we formulate an action plan for improvement. A recent survey completed by the people we support (sometimes with help) will shape our plans for the next 12 months, in terms of how we can improve.

Full, honest and open involvement with the people we support, the teams, the families and commissioners is crucial for enabling us to implement this programme into our work. We have experienced some barriers as there is ignorance in the community about the people we support's condition and a general lack of empathy. To combat this, we try to involve the people we support with activity in the community, albeit with support, this has broken down barriers and improved understanding.

It is really beneficial for us to involve people with lived experience in this way as they can tell what works and what doesn't; the people we support have lived it, where we haven't. We have seen some positive outcomes and some of the people we support have gone from 24/7 support to needing less support. Some of our clients are also working during their unsupported time.

Case study: Nacro community voice council

As a frontline provider, Nacro delivers a range of services to vulnerable people in justice and health, education and housing across England, along with a respected national policy voice. Their delivery projects and policy work are informed by the experiences of their service users, including their national community voice council, which is made up of service users from across the organisation.

Meetings of the council are held quarterly and attended by trustees, staff and service users. During each meeting a workshop is held to review a particular policy area such as complaints or safeguarding for example.

Recently members of the community voice council critiqued Nacro's complaints policy, which led to a re write of their document entitled *have your say* to respond to the issues that were raised. The feedback also led Nacro to create a stage 2 complaints panel for independent review by service users.

There are three key elements that are essential for enabling Nacro to implement the council: active participation from both staff and people with lived experience, budget to ensure travel costs can be paid and robust risk assessments.

Service users who have taken part in the council feel valued as they feel they have been listened to and consulted for their views. At Nacro's recent 50th celebration events which showcased the work they do across the organisation one service user shared her journey of courage and success. She shared the story of her progression through three teams within Nacro services and is currently gaining a qualification at their education centre. As well as sharing powerful messages of hope, speaking at the conference in this way helped showcase Nacro's work, which in turn has assisted the organisation with new funding bids.

One of the main challenges Nacro have experienced is safeguarding, as members of the council have requested Nacro to facilitate ways through which they can communicate with each other outside of meetings. To respond to this, the organisation are in the process of costing web-development to facilitate this request.

Prisoners' Education Trust (Welsh Prisons Project)	
<p>Please explain how you involve people with lived experience of multiple needs in the design and delivery of your service</p>	<p>In December 2015, the Prisoners' Education Trust (PET) launched an 18 month pilot project aiming to improve the provision of distance learning in the four Welsh prisons. Working with prisoners and staff at HMP Cardiff, HMP & YOI Parc, HMP Swansea and HMP Usk/Prescoed.</p> <p>The Welsh Prison Project was established to identify ways that PET could be more effective in achieving positive outcomes and to do so in a sustainable and replicable manner, generating evidence of effectiveness.</p> <p>The project has produced practical materials in order to increase the numbers of prisoners accessing distance learning and has put in place measures to enhance the support PET gives to its learners in Wales.</p> <p>The project has produced: a learner pack containing study support materials which has been given to each PET funded learner in a Welsh prison, promotional materials for each prison and a guide for peer mentors which acts as a toolkit for those mentors supporting distance learners in Welsh prisons.</p> <p>The project's approach from the offset has been one of collaboration and co-production. Informal meetings have been held with learners, mentors and prison staff across the Welsh estate throughout the life of the project.</p> <p>Underpinning all this is an adherence to PET's aim of offering prisoners access to education, improving their self-esteem, supporting their desistance journey and enabling them to choose a more constructive way of life. Each element of the Welsh Prisons Project encourages prisoner learners to develop an identity as a 'student'. PET believes that this identity will help prisoners to spend their sentence in a positive, productive way and can be taken forward after release.</p>
<p>What has been critical to ensuring you were able to implement this?</p>	<p>A peer mentor's work can only take place in a prison; an environment most of us do not fully understand. It has been crucial for us to develop an understanding of what it means to be a distance learner in a prison as well as a peer mentor if we are to be able to support and encourage more prisoners to become successful learners in prison and to continue once released.</p> <p>It is important that the materials we produce and the support we give at PET is meaningful, relevant and echoes our</p>

	<p>organisational vision, where the learner at the centre of all we do. In order to realise this we have listened to our learners and their supporters through consultation and feedback events.</p> <p>Through these events we now have a better understanding of the practical considerations when putting together materials;</p> <ul style="list-style-type: none"> • A5 as the most suitable size –easy to carry around the prison and easy to store in cell • The inclusion of a detailed table of contents so that relevant information can be found easily • A clear, concise presentation of information, without being too “wordy” • Process maps and diagrams allow information to be communicated visually • Pens and paper are always needed by peer mentors` • Case studies bring a process to life • Including aspirational pictures/photographs is important <p>Peer mentors are resourceful and experts in their role; they are often an invaluable source of information for designing products for use by prisoners.</p>
<p>What have been the benefits of engaging people with lived experience in this way?</p> <p>If you have identified any specific outcomes from the work please tell us about them</p>	<p>It is important that the materials we produce and the support we give at PET is meaningful, relevant and echoes our organisational vision, where the learner at the centre of all we do. In order to realise this we have listened to our learners and their supporters through consultation and feedback events.</p>
<p>Have you encountered any challenges or barriers? If so, what were they?</p>	<p>Time was probably the biggest challenge, for two reasons.</p> <ol style="list-style-type: none"> 1. The project has multiple objectives, keeping consultation and the learner voice a constant theme enabled the project to keep this important element as a firm priority. 2. Prisons are challenging environments; even with enthusiastic support from senior and operational staff, agreeing visit dates has on occasions been difficult.

<p>Have you been able to overcome these barriers? How?</p>	<ul style="list-style-type: none"> • Having a project plan with consultation as a major element • Being flexible, both practically and in project delivery • Working with an external evaluation team from De Montfort University • Having a clear governance structure for the project
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6. Useful resources

The following outlines some existing resources and toolkits

- [Ask Toolkit](#): The Ask Tool Kit, published by Expert Link, is there to help people with lived experience of multiple disadvantage to work out what it is that they want. It highlights all the benefits of receiving what it is that they want and will also help them to ask for it appropriately.
- [Beyond the Usual Suspects](#): The focus of this report, published by Shaping Our Lives, is to make it possible for everyone who wants to, to be more involved in and have more say over their lives and the services they use to live them. The report draws on findings from a three-year national research and development project supported by the Department of Health, which aimed to find out how inclusive user involvement could be achieved.
- [Good practice in service user involvement](#): This guide showcases six current examples of best practice in service user involvement from the voluntary sector working in criminal justice:
 - **Service user councils** – User Voice
 - **Prisoner engagement project** – Healthwatch Peterborough
 - **Liaison and diversion lived experience team** – Revolving Doors Agency
 - **Prisons healthcare procurement** – WY-FI and NHS England Health and Justice
 - **Changing the world together** – Women's Community Matters
 - **Older prisoners forums** – RECOOP

The case studies have been selected to represent as broad a range of different approaches, models, organisations and aspects of the criminal justice system as possible. Each case study identifies key project outcomes, elements considered to be essential requirements for setting up and sustaining the project, and some of the main challenges experienced along the way.

- [Guide to service user involvement and co-production](#): This guide is designed to give organisations the practical tools they need to develop an involvement programme and approach which places service users at the heart of their organisation. It provides a structured and accessible introduction to involving people with lived experience of criminal justice in their work, including examples of good practice, checklists, top tips and signposting to further information and support.

- [Involving service users in recruitment- a peer research report](#): This report describes the methodology, findings and recommendations for future practice and policy from research undertaken by peer-researchers from the National Expert Citizens Group (NECG) into the involvement of service users in recruitment processes for the 12 Big Lottery Fund funded Fulfilling Lives Projects.
- [Revolving Doors Agency toolkits](#): running a peer research project with offenders in the community; improving your prisoner involvement system; and service user involvement with offenders in the community.
- [Service user involvement in the delivery of mental health services](#): Published by the National Survivor User Network and Together for Mental Wellbeing this briefing is for those planning, commissioning, designing and overseeing mental health services, as well as those involved in the development of mental health policy. It aims to give guidance on how to make service user involvement integral to these, as well as signposting to further resources in this area.
- [Valuing volunteers in prison](#): Published by Clinks, this report explores how we can increase the amount and scope of prison volunteering across England and Wales.
- [Voices from the Frontline influencing guide](#): published by the Making Every Adult Matter Coalition, these two guides provide advice on how to engage with policy debates and involve experts by experience in this work.