

# APPG: Complex Needs & Dual Diagnosis

**Client:** The Big Lottery Fund  
**Project:** Fulfilling Lives: Supporting people with multiple need  
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The APPG is working with the Office for Civil Society looking for evidence around how social action (e.g. peer support, community-led initiatives, involving people with lived experience in service design) can drive better services for people with complex needs e.g. by improving outcomes, preventing crisis, reducing stigma or developing more responsive joined up services. This paper provides evidence from the Big Lottery Fund's Fulfilling Lives: Supporting people with multiple needs programme.

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## Introduction

The Big Lottery Fund's 'Fulfilling Lives: Supporting people with multiple needs' programme is an £112 million investment to improve the stability, confidence and capability of people with multiple and complex needs to lead better lives as a result of timely, supportive and coordinated services so that they spend less time in prison, reduce their drug abuse, are in stable accommodation and have better mental health. A core objective of the programme is to have services that are more tailored and better connected, and empower users to full take part in effective service design and delivery.

The programme operates in 12 areas around England: Blackpool, Liverpool, Manchester, West Yorkshire, Newcastle & Gateshead, Birmingham, Nottingham, Bristol, Stoke-on-Trent, Camden & Islington, Lambeth, Southwark & Lewisham and the South East (Brighton & Hove, Eastbourne and Hastings). The programme works with individuals who have experience of two or more of the following: homelessness, substance misuse, mental ill health and offending

behaviour. Projects work primarily with adults aged 18 year or over. The programme runs until 2021. This paper provides evidence from across the programme areas.

**Key findings are written in bold within the text and surmised in ‘key points’ purple boxed inserts. Case studies are provided in blue boxed inserts to further illustrate points.**

## **Types of Social Action implemented across the programme**

The APPG defines ‘social action’ as: *people with lived experience, and the wider community, getting involved in the design and delivery of services, either within existing services or setting up new projects.* The Office for Civil Society defines social action as: *Social action is about people coming together to help improve their lives and solve the problems that are important in their communities. It can broadly be defined as practical action in the service of others, which is 1) carried out by individuals or groups of people working together, 2) not mandated and not for profit, 3) done for the good of others – individualism communities and/or society, and 4) bringing about social change and or value.*

Accessing volunteers and employing individuals, both with lived experience, is a central component of the Fulfilling Lives: Multiple Needs programme. Projects have actively involved individuals from the initial compilation of funding bids to the Big Lottery, through to recruitment of staff, attendance at reference, steering and strategic groups and communities of practice. It is critical that the voice of those who have, and are using, services are heard and utilised to shape and deliver services more efficiently and effectively. There are different roles and pathways for individuals with lived experience to be able to conduct this work within the programme:

1. Peer mentoring
2. Local Expert Groups
3. National Expert Citizen Group

The availability and role descriptions vary across the programme with some roles being paid in some projects and others having a similar role as voluntary. The table below outlines the roles available in a sample of projects across the programme.



<b>Project</b>	<b>Lived experience role[s] available at project – please specify if volunteer or paid role</b>	<b>Number of people undertaking each role</b>
<b>Birmingham</b>	Peer Mentors – paid role	6
	Liaison and Diversion Peer Mentors – paid role	2
	Experts by Experience – volunteer	12
	Involvement Champion - volunteer	4
	Project support assistant – paid role	1
<b>Manchester</b>	Peer mentor volunteer role	12
	GROW Trainees paid role	8
	Women’s Voices	14
	Core Group	Currently 5 – new recruitment happening after many individuals gained employment
<b>Nottingham</b>	Beneficiary Ambassadors – paid role	4
	Expert Citizens – volunteer role	10
	Peer Mentors – volunteer role	9
	Peer Researchers – volunteer role	2



<p><b>Newcastle &amp; Gateshead</b></p>	<p>Three level 2 Navigator Posts ring-fenced specifically for people with lived experience. Involves managing a small caseload whilst also developing education/skills.</p> <p>One Engagement and co-production co-ordinator whose responsibilities involve co-ordinating our experts by experience group.</p> <p>We are currently reviewing our volunteer posts within our experts group to decide on their job description.</p> <p>It is worth noting a number of non-ring-fenced Broker and Navigator posts have been filled by people with lived experience.</p>	
<p><b>South East</b></p>	<p>Project consultant (full time paid employment)</p> <p>Project consultant assistant (part time paid employment)</p>	<p>3</p> <p>6</p>
<p><b>West Yorkshire</b></p>	<p>Co-Production and Engagement Workers – paid</p> <p>Co-Production Champions (5 roles) - paid</p> <p>Trainee Navigators- paid</p> <p>Peer Mentors (completed a CERTA accredited training) – voluntary</p> <p>Peer Learning Assistants – voluntary</p> <p>WY-FI Network Members- voluntary</p>	<p>2</p> <p>brand new roles currently out for recruitment</p> <p>5</p> <p>54 over the course of the project, 20 currently active</p> <p>2</p> <p>15</p>



A staff survey in December 2016 showed that over 50% of paid project staff have lived experience

## Peer mentoring

### HOW PEER MENTORING IS APPLIED ACROSS THE PROGRAMME

Peer mentoring is used across the programme, in some projects the role is paid and in others it is a voluntary position seen as an opportunity to develop employment skills whilst still receiving support for their own recovery. **Peer mentoring is primarily used for outreach and engagement activities because they provide ‘living proof’ that change is possible and can share valuable personal experiences with potential (and current) service users.** They undertake a number of different activities as part of this role:

- *Support accessing mutual aid and peer support*
- *Input around the benefits of a drug/alcohol free, and harm reduction, lifestyle*
- *Input on the coping and self-management techniques they use to sustain recovery*
- *Input on how they managed to stop associating with drug using friends or partners*
- *Accompanying service users to a range of rehabilitation/reintegration activities such as meditation/fitness/museum trips.*
- *Accompanying to welfare related appointments such as CAB (Citizen’s Advice Bureau) or appeals*
- *Supporting people to adjust to new tenancies and maintain existing ones*

### Outreach

Across the projects outreach is both pre-planned & structure and ad-hoc following leads and intelligence that Peer Mentors have acquired via their sources. The use of peer mentors in outreach has been seen as highly beneficial for achieving more expedient and successful outreach work.

In Birmingham they are monitoring referrals into their project by lead workers and peer mentors. To date, lead workers (12 in post) have brought in 23 individuals into the service. Comparatively, peer mentors (6 in post) have brought in 26 individuals.

*Please note there are other referral routes into the programme too.*

Projects have reported that through outreach work Peer Mentors have become well known in their geographical locations – particularly within the street sleeping community. They have built relationships of trust and projects have observed a number of self-referrals to the programme based on these relationships. For individuals not yet wishing to enter the



programme, a large number have been found willing to provide information and intelligence based on street living and individuals within that community – particularly in Birmingham.

### Engaging with services

Peer mentors who conduct outreach alone will help facilitate the introduction between the service user and the lead worker assigned to them. In some projects peer mentors are paired with lead workers and this introduction will already have occurred. **Projects have found that for service users less willing to engage with services, peer mentors have been able to successfully lead on initial assessment and introduction to the programme.** During the initial assessments Peer Mentors have been also been successful at identifying pressing underlying needs and urgent requirements for medical intervention. In Birmingham, it is at this stage that ‘general’ support needs are parked and Peer Mentors will intervene, persuade (if necessary) and accompany, clients in attending A&E or appropriate services.

Peer Mentors provide guidance to Lead Workers in relation to client circumstance and underlying need, in many cases this will result in multiple ‘informal’ meets with clients before mandatory processes such as consent, Outcome Stars and support plans are considered.

In cases whereby it is clear that a client is reserved in their trust with a Lead Worker, the Peer Mentor will complete Outcome Stars and support plans. **We have also found that clients are more open and honest in relation to their circumstances when speaking with Peer Mentors.** Clients have told us that they do not feel judged when speaking with Peer Mentors that they believe that Peer Mentors understand them.

Where necessary and appropriate Peer Mentors have carried out support sessions alone, without Lead Workers. In these occasions there has been more of a focus on emotional support, rather than practical. There have been occasions whereby clients have used this time as an opportunity to safely disclose new information such as: early childhood trauma, abuse and criminal activity.

### Providing emotional support

FL Newcastle and Gateshead facilitate the local “Freedom Program” for people experiencing domestic violence. This was delivered by an expert by experience member until she left to gain full time employment. Service Navigators support delivery until we can train an alternative person to deliver the session from the Experts network.



### (3.1 C) EVIDENCE ON THE IMPACT OF PEER SUPPORT FOR BOTH THE BENEFICIARY AND THE PEER.

#### For the Peer Mentor

Peer mentoring is an excellent, and much needed, opportunity to progress an individual with multiple needs into a position where they have increased confidence and employability. Valuable work skills are learned in the role including time management, professionalism and organisation.

For many that have been in the paid Peer Mentor posts, it has been a first taster of formal employment and an opportunity to make a supported transition from recovery based volunteering to full time work. Staff at projects have been told by several individuals that they did not believe that they would ever have the opportunity to join an established organisation due to stigmas associated with things such as; criminal history, lack of checkable work history and previous and current health issues.

In addition to the above, Peer Mentors joining the service have been supported in maintaining their recovery whilst in full time employment, and this has included time in work to attend appointments and activities.

There are many benefits that projects have seen in relation to personal development and progression. Peer Mentors that have joined the service have had access to additional training such as formal Health & Social Care qualifications, and external shadowing and placement opportunities. This along with the work based exposure and experience that they have acquired has led to successful 'exits' from the Peer Mentor role. Examples of further employment progression and development include:

- *Domestic Abuse Support Worker*
- *Family Support Worker*
- *Recovery Coach*
- *Lead Worker*
- *Youth Intervention Worker*
- *Founder of a CIC*
- *Data Administrator*

All the above have been paid, salary based roles.

*"I moved forwards from ICM's support once I reached a point where I felt confident to manage my life independently. However, my journey with ICM didn't end there. I felt very passionate towards the people who had supported me and I also realised that I had a lot to offer to people who are in vulnerable situations, people who are at the start of a similar*



*journey, whatever their own complex needs may be. So, I applied to be a peer mentor with ICM partner – CLI. I now work alongside and support other people with similar life experiences to me. During this time, I have developed an awareness that there are lots of varied reasons why people face the issues that they do. ICM has given me the belief in my own abilities to make a positive difference to people's lives".*

Peer mentor, Inspiring Change Manchester

#### For the service user/client

The ultimate benefit/impact of using a Peer Mentor is that it increases the likelihood that an individual with multiple needs will engage with the relevant services.

Birmingham's local evaluation found that staff attributed the longer length of stay for those assigned a Peer Mentor to various factors including; the shared lived experience; the trust gained by the Peer Mentors; the Lead Worker and Peer Mentor partnership with the mix of professional and lived practical experience; and the programme itself. All staff unanimously rate the input from the Peer Mentors and the positive aspects this brings, and this is not limited to the lived experience. Many staff believe that some clients would not have engaged at all with the programme after referral had it not been for the input of the Peer mentor:

*"After the referral comes in the initial assessment is critical – lots of the referrals don't get past the initial assessment if there is no PM there."*

For Birmingham, this quote demonstrates the value of the peer mentor's lived experience, their intrinsic awareness of the client and the ease in which they support engagement adds to their way of simply 'being with' the client. Staff assert that professionalism can be learned (i.e. the role of a support worker) whereas the lived experience (PM role) can't be taught; it is this intuitive appreciation and understanding of the clients and their innate experience of utilising services for themselves that staff attribute to successful engagement.

Indeed, as of March 31<sup>st</sup> 2017, in Birmingham, – clients with a peer mentor averaged five weeks longer on the Fulfilling Lives programme than those without. Of the clients who have left the programme, 45% of disengaged leavers had a peer mentor compared to 55% of those who only had a lead worker. Over half (52%) the individuals who leave the programme 'no longer requiring support' had a peer mentor, compared to 48% of those who only had a lead worker.



## West Yorkshire Finding Independence (WY-FI) – Evidence of Impact of Peer Support

The Centre for Regional Economic and Social Research (CRESR) at Sheffield Hallam University is evaluating the West Yorkshire Finding Independence (WY-FI) project. As part of this, they have explored the role played by Peer Mentors in supporting beneficiaries. Key findings emerging from the study suggest that:

- *It was felt that together peer mentors and navigators can provide a more 'complete' package of support.*
- *Peer mentors are often able to better understand clients, through their lived experience including being better-able to engage clients as well as spot problematic behaviours.*
- *Peer mentors are also able to spend more time with beneficiaries engaging in emotional support and social activities with clients to support the recovery process. These activities can make a big difference for clients who are isolated or suffer from anxiety and mental health conditions.*
- *Individuals are motivated to become mentors due to an altruistic desire to 'give something back' as well as to sustain their recovery and improve their employment prospects.*
- *For mentors, the role provides: routine and structure; raises self-esteem and confidence; and provides valuable work-based skills together with a 'safe' transition back into work.*
- *Deploying those with 'lived experience' to provide peer support brings unique challenges which necessitates the implementation of effective recruitment, training and support processes.*
- *Peer mentoring within WY-FI provides individuals with more opportunities than previous volunteering roles.*
- *Some WY-FI localities have been able to better-embed peer mentoring in their service delivery model than others.*
- *The specific role played by peer mentors differs across the five localities.*
- *Despite differences in the approach, the deployment of peer mentors has worked well and helped to significantly improve service delivery.*

### Inspiring Change Manchester [ICM] case study - John

I had been living in a hostel for 4 years and I was sick of it, it was full of people with drug problems and I knew it was doing me no good. I was drinking all day, all the time, and I never went out cos being around people annoyed me. I've had prison for violence before and



being in new situations makes me anxious and depressed. Anyway, so I went to Shelter to try and find a flat and after a bit they got me one. From there I went onto ICM and into my Housing First property.

As well as finding a new place, they set me up with some stuff for it like a cooker, a bed and a toaster. They also got me a wardrobe from the Mustard Tree but that collapsed. My support worker got me a bicycle so I could get out more, though I didn't use it much because I get leg pains, so I passed it on to my son and he uses it to get to work. He came to stay with me for a bit which cheered me up.

Through ICM peer mentoring and engagement I was introduced to an alcohol worker, but I didn't really connect with him. In the end, I managed to get off the beer by myself. My ICM mental health support is excellent, I like talking to them as I get to offload and get things off my chest; they listen well. My current peer mentor is very helpful, we have been on trips out together on the bus to places like the football museum and a football stadium tour and I couldn't have done that by myself.

With his [peer mentor's] help, I also made an application for a Personal Independent Payment which has helped me buy a few new things and save a bit. I was pleased I finally got my own place but now I realise I feel a bit isolated and away from my friends in the north of the city.

I've dealt with the drinking and now I'm trying to cut out smoking altogether as well. I get out a bit more by myself now and I'm more optimistic about the future. I'm planning to go on holidays with a friend for a few days in the summer.

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ICM - This case study shows that not every intervention is perfect as there may be issues that arise along the way such as; when John refers to not connecting with his alcohol worker for example. Being part of a team around the person support network, offers alternatives to that, whereby the clients can seek the support they need from a variety of areas of the programme without having to lose out on other support if they decide that one approach doesn't suit their needs. It shows that, where peer mentoring and a support offer is flexible, it addresses the immediate issues first and focuses on more longstanding ones when there is emotional space to do so. i.e. moving to a more suitable area.

Also, by working alongside a peer mentor, confidence and self-esteem can be built to enhance your social interactions and enable you to enjoy areas of your life that you may not have done previously. The peer support takes you away from continuously talking about the



issues you are facing and can introduce you to new and more positive ways to enjoy life, in a way that may not have been possible to this point.

### **(3.1. G) EVIDENCE THAT THERE ARE SUBSTANTIALLY IMPROVED HEALTH AND WELLBEING OUTCOMES, REDUCED INAPPROPRIATE USE OF THE STATUTORY HEALTH AND CARE SYSTEM AS A RESULT OF PEER SUPPORT INCLUDING MUTUAL AID?**

Although not part of the Fulfilling Lives programme, Nesta's 'Realising the Value'<sup>1</sup> report highlights the value of peer support, particular for those with mental health issues. The report found that peer support for mental and physical health and wellbeing has been shown to lead to significant improvements for people with long-term physical and mental health conditions across a range of health and wellbeing outcomes, including: individuals' knowledge, skills and confidence to manage their health and care; physical wellbeing; adherence to medication, quality of life and social functioning. The report considers the financial sustainability of peer mentoring and self-management education in the areas of health and wellbeing. It outlined that there may be the potential for up to £950 million per year in savings. The report stated that particular conditions were expected to see the most benefit with the available evidence suggesting peer support for mental health issues providing the greatest net gain.

Within the Fulfilling Lives: Multiple Needs programme the Newcastle and Gateshead project is currently implementing a new process within their Experts Network (group of individuals with lived experience) to help identify and record health and wellbeing improvements for members. Data for this will be available in the future. In addition, the same project has successfully co-produced the design of an innovative multi-agency Mental Health Crisis service which is now attached to the Mental Health Crisis response team – this is called Together in a Crisis [TiaC].

#### **Newcastle & Gateshead - Together in a Crisis**

Along with other parties in the local area, Fulfilling Lives Newcastle Gateshead [FLNG] inputted into the Mental Health Trust's "Deciding Together" consultation, which has highlighted the need to improve local service responses to people who identify as having an urgent mental health need. As a result, an Urgent Care Model has been developed, that is supported by Newcastle/ Gateshead Mental Health programme board.

This new model includes Together in a Crisis [TiaC], which is a new type of service. Newcastle/Gateshead CCG have secured funds for a 12 month 'proof of concept'

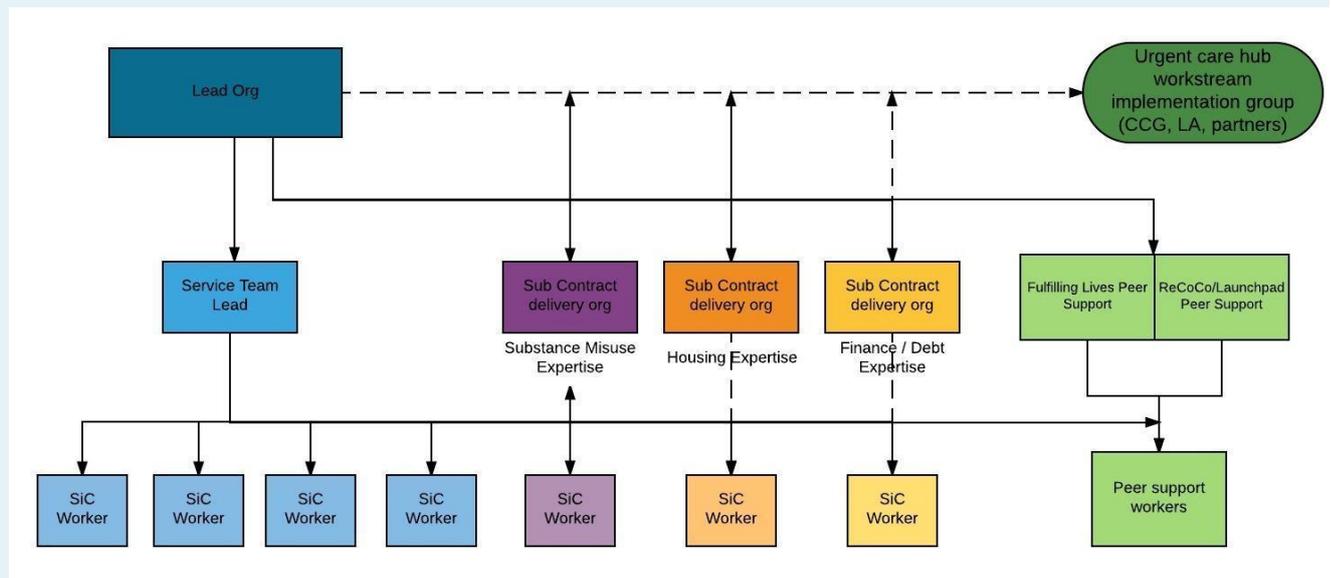
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<sup>1</sup> <https://www.nesta.org.uk/project/realising-value>



initiative to test the effectiveness of this new service in Newcastle. FLNG will contribute £15k to support the pilot and ensure the robust peer evaluation of the pilot project.

TiaC will provide a rapid response to adults aged 18 and over who live Newcastle who, following contact with NTW Crisis Team, are deemed not in need of an urgent statutory response, but who nevertheless are in emotional and psychological distress and may require an immediate response to their personally-defined need. This service will provide non-clinical support focussed on active, empathic listening, before helping the person to develop coping strategies, to problem solve, and to link into services and other local support resources.



**Figure 1 - Together In A Crisis programme structure**

This service is due to become operational from 15<sup>th</sup> May 2017 in line with the Crisis Care Concordat. It has 7 staff from specialist areas in order to deal holistically with presenting multiple and complex needs.

The ‘proof of concept’ of the Together in a Crisis Service is the first phase of the implementation of the Urgent Care model. It is a developmental project designed to improve services to the Newcastle population and to provide intelligence and evidence about the effectiveness of the Together in a Crisis service. It will measure the outcomes achieved by the service and inform recommendations for future planning of urgent care services. The partners delivering this service are: Mental Health Concern (lead agency) and partner organisations Home Group, Citizens Advice Newcastle and Changing Lives.



### 3.2 CHALLENGES/BARRIERS TO DEVELOPING OPPORTUNITIES FOR PEER SUPPORT?

There are a number of challenges and barriers to developing opportunities for peer support – these can be both for the organisation and for the peer, we address both below.

#### Organisational challenges/barriers

- *Risk of relapse and contingency planning. Peer Mentors can't be set up to fail.*
- *The pressure and challenges on the fellow workers must be considered and discussed.*
- *HR difficulties such as secondments and issues such as differences in pay and other benefits. Secondments can lead to feelings of a lack of belonging and confusion over which policies to follow. Birmingham's project no longer uses secondment as an HR tool when employing staff with lived experience because of this.*
- *Policies, Procedures, organisational culture & national guidelines can stop professionals from being able to do co-production/offer peer support to the extent they would like to*

Birmingham have noted that naturally they have experienced fall-out of Peer Mentors and not all that began employment with them, completed their probationary period. There have been many reasons behind this, but the total number of Peer Mentors that have left the service, for less than positive reasons, has been no more than they have seen within the Lead Worker Team.

#### Peer challenges/barriers

The following are the core challenges experience by peers:

- *When the buildings where services are offered are intimidating (e.g. too corporate- everyone dressed in formal office-wear- key fob access to all doors which people in "peer roles" don't have access to)*
- *When the language that is used by professionals they are working alongside is hard to understand*
- *When there isn't the right level of support and guidance for people with lived experience (i.e. they don't feel sure about what their role is or it feels like a tick-box exercise and they don't get the chance to make a real difference)*
- *People feeling scared that their opinion isn't relevant or helpful because they have not gone to university or professional experience*
- *When professionals get paid for their time and input and people and people with lived experience are just expected to fit in with their agenda/structure with no personal benefits*
- *Peer roles involve people with lived experience disclosing personal details about their life experiences, but professionals do not have to do this. This can potentially create a power imbalance where people in peer roles feel the only thing they have to offer is their past*



Due to the challenges experienced by peers it is felt that any organisation offering such a service requires a dedicated coordinator (minimum 1 full time) that can provide consistency in support to ensure that peers are getting what they need from the role and feel able to contribute in a meaningful way to develop both personally and professionally. Further information on overcoming challenges/barriers for employed roles can be found here: [Employment of staff with lived experience](#).

## Employment of staff with lived experience

The employment of staff with lived experience varies across projects within the programme. The examples below outline some of the models implemented.

### SOUTH EAST PARTNERSHIP

The South East Partnership project employs individuals with lived experience into the roles of 'Project Consultant' (full time) and 'Project Consultant Assistant' (part time). The role of the Project Consultant is:

- *To lead and facilitate the 'Voice of the Streets Action Group' to gain information about services and systems for people with Multiple and Complex Needs (MCN).*
- *To work with the Action Group to explore, research and to propose solutions.*
- *To visit local services and to consult with their service users about the barriers they face accessing and engaging with services.*
- *To collate information to help the project review and improve services, systems, processes and protocols for people with Multiple Complex Needs.*

This role offers people with lived experience of multiple needs an opportunity to access employment and to move further in their professional career. The individuals act as positive role models for service users, volunteers and the staff team. The role is key in challenging the stigma associated with multiple and complex needs and breaks down barriers between professionals and people with lived experience (experts by experience).

### **South East Partnership Case Study – individual with lived experience went from volunteer to employment within 12 months.**

I began my first volunteering experience with the Fulfilling Lives Project on 2<sup>nd</sup> December, 2016. By 13<sup>th</sup> December 2017 I was employed as Service Improvement Officer for Fulfilling Lives in Hastings! In a way, the answer to "How has Fulfilling Lives helped you to develop?" could end there with those two sentences, such is the impact that the Project has had on my life.



I came to Fulfilling Lives with multiple and complex needs. I found it difficult to leave the house and when I did go outside I edited my “things to do list” on route to make sure that I did only the essential, in as fast a time as possible. I would not interact with anyone for weeks at a time. My confidence was low, my self-esteem was non-existent and my anxiety levels were through the roof.

A Project Consultant from the Project came to visit me, in my home, to talk to me about the prospect of volunteering; using my past, lived experience to help improve the lives of others with multiple and complex needs, who were not in a position to talk for themselves. I would be supported, I would be mentored, I would be amongst people with similar needs, who were also trying to put their lives back together again, but more importantly I would be able to “put something back”.

In the beginning my colleagues reflect that I was quiet and just listened (something my colleagues today might remark upon!). A two hour meeting, amongst utterly charming and welcoming people and I had to go home afterwards and sleep for two hours! I found it impossible to attend sometimes because of my agoraphobia and anxiety, but my mentor rang me and supported me and gradually I was not only attending regularly, but I was contributing and, most the amazing thing was that people were listening!

Mentoring sessions (with an absolutely amazing mentor who missed nothing) helped me through the early days. It was here that I was able to talk about what the future might look like for me and how I would like to develop. When I said that I was interested in using my previous experience of working at a strategic level I was invited onto the Core Group by the Senior Manager of the Fulfilling Lives Project. People were valuing my input and promoting my development. I was beginning to examine the self-imposed stigma which had been holding me back, “No one will want to listen to you after your background”. Here people wanted to listen to me **because of** my background. The Project made me re-examine how I looked at myself and if I could not listen to myself, I **would** listen to others.

Soon I was volunteering for anything my mentor thought me capable of and luckily for me he thought I was capable of a lot. I got involved with working groups, staff recruitment, volunteer recruitment, verification audits, writing the final report in a System & Service Review, questionnaire analysis, presenting findings in meetings; telling my story at the Stigma Learning Event, attending an external conference as part of the National Project and much, much more. Before I really had a chance to look down my self-esteem and confidence were high and I could manage my anxiety.

I became a complete convert to the Fulfilling Lives Project, so much so that I wanted to work for the Project myself and to try to make a difference every day of the week. When the position for Service Improvement Officer came up within one of the most deprived areas of



the country i.e. Hastings, I knew that I had found a role which would challenge all those skills I had learnt when I was in employment and the resilience and determination I had learnt during my years in the wilderness. After three interviews for the role of Service Improvement Officer it was those skills acquired in the wilderness which proved most useful!

I am now thoroughly enjoying my new role within Fulfilling Lives. The Project continues to support and nurture and I am looking forward to contributing to the work of the Project in Hastings. If anyone were to ask me whether Fulfilling Lives really was a Project which learns and values the experience of those with lived experience, I would answer, most emphatically, “YES!”

## **NEWCASTLE AND GATESHEAD**

This project currently has three level 2 Navigator Posts ring-fenced specifically for people with lived experience. The role involves managing a small caseload whilst also developing their own education/skills. The project also employs one engagement and co-production co-ordinator whose responsibilities involve co-ordinating their experts by experience group. It is also worth noting a number of non-ring-fenced Broker and Navigator post have been filled by people with lived experience and one level two navigator used their experience to successfully apply to get on the degree in Mental Health Nursing, and has now moved on to do this course full time. The project is currently reviewing their volunteer posts within their experts network to decide on their job description.

**The experts by experience are involved in the recruitment of all of the program posts.** They set the questions and conduct the interview and are part of the final decision making.

**In addition FL Newcastle and Gateshead initiated and facilitated a working group involving Changing Lives and the Employing Organisations including Northumbria Community Rehabilitation Company to develop a good practice toolkit for organisations to better employ people with lived experience.** Topic covered include recruitment, HR issues, DBS, relapse policies and support in the workplace. Their coproduction lead and a system broker facilitate this group. The private sector are being invited to join this as a result of links with Changing Lives’ Employment Director.

## **CHALLENGES EXPERIENCED EMPLOYING INDIVIDUALS WITH LIVED EXPERIENCE**

One of the core challenges in employing individuals with lived experience is getting them accustomed to working in a professional environment. Projects have experienced a number of HR issues; these can be grouped in two categories:



- *Health and wellbeing issues: extra support and flexibility with work patterns has been necessary to support people to maintain their health and wellbeing.*
- *Issues around conduct in the workplace*

Projects have learnt that they need to set up the right conditions for people to succeed. In the South East Partnership they have realised that extra support is necessary to conduct throughout the employment of an individual with lived experience. A thorough 1-1 induction and a tailored HR induction has been created and is now delivered by the HR department. These changes aim to help set up a clear expectation around conduct, appropriate communication styles etc. The partnership has also recruited a new member of staff (Engagement and Development worker) whose role focusses on providing tailored support to the staff at key stages of their employment, such as during their induction, probationary period and then coaching them to move onto further employment (as the Project Consultant posts offered are for 18 months only).

In Birmingham, to address the organisational challenges and barriers to providing peer support, they have implemented a number of policy and procedural changes; these are outlined in the example below.

### **Overcoming [some of the] challenges and barriers with peer support – Birmingham’s approach**

Shelter as the employer of Peer Mentors (in Birmingham) has made numerous supportive changes to internal policies and procedures, examples include:

- *relaxed guidance in relation to appropriate reference providers*
- *implementation of alternative recruitment and selection processes*
- *additional understanding and policy amendments regarding criminal convictions (spent & unspent); and*
- *a tailored approach to formal probationary period.*

In addition to this, they have also placed a larger focus on supporting individuals prior to them commencing employment. This includes:

- *pre-starter needs assessments*
- *practical assistance with benefits and housing related matters*
- *specialist debt advice*
- *salary advances; and*
- *travel loans.*



Once employment has commenced the organisation exercises discretion in relation to a gradual build up to individual contracted hours and time in work to participate in recovery based activities.

A support package is also provided to the employee through both formal and informal channels. It is primarily provided by a dedicated Engagement & Development Worker and includes: transition into employment & pre-starter practical assistance and support, 1:1 supervision, group supervisions, personal development plans, advice & guidance and on-going support with training/formal qualifications.

In addition to the above, the Engagement & Development Worker provides on-going ad-hoc support to Peer Mentors to aid their understanding of formal procedures such as; probation, mid-year reviews, annual appraisals, grievance and disciplinary.

Peer Mentors past and present have highlighted the benefits of this support and the project has been told that having someone else to talk to, in addition to their line manager, has really made them feel supported, listened to, confident and less daunted with the formalities of the work place.

All the above has proven to be somewhat time and resource intensive. Whilst they are fortunate enough to have a dedicated team to support with this, including their partner agency Birmingham Mind (Every Step of the Way), it is recognised that the vast majority of agencies, both statutory and third sector, do not yet have the expertise and resources in place to accommodate this level of support.

### **(3.4) What are the critical enablers to support the further growth of peer support?**

Strong Leadership is a key enabler to the growth of peer support. Practically this means senior management being fully bought in to involving people with lived experience in a meaningful way. Someone needs to “showcase the possible” in relation to peer support. This means challenging unhelpful perceptions around peer support and championing best practice and being flexible enough to make the project work when barriers emerge.

In addition, having the role being paid rather than voluntary places value on the position and encourages retention.

Flexible or adapted commissioning processes are needed to encourage organisations with a strong emphasis on peer support to bid. Please refer to the section below for examples of involving individuals with lived experience in commissioning.



### **(3.4B) HOW HAS THE DEVELOPMENT OF TECHNOLOGY AND DIGITAL COMMUNICATION IMPACTED ON PEER SUPPORT INCLUDING MUTUAL AID LINKED TO IMPROVING THE LIVES OF PEOPLE LIVING WITH COMPLEX NEEDS / DUAL DIAGNOSIS?**

Newcastle & Gateshead is at the early stages of piloting an app coproduced with Newcastle University's Digital Civics "Open Lab" which would allow "Digitally Enhanced Reflection". This would allow beneficiaries to audio record their narrative / journey and then reflect and comment on their story and give permission for others, such as staff to reflect and comment also, in an open dialogue reflection about their journey and what difficulties they are discovering. This is at a very early stage of development as a pilot.

### **SERVICE-USER INVOLVEMENT IN COMMISSIONING PROCESSES**

The example below illustrates how one partnership project is involving service users in the commissioning process.

#### **South East Partnership approach on service-user involvement in local commissioning**

Involving service-users in our activities is one of three central aims of our project, as agreed with The Big Lottery. As well as trying to develop and deliver best practice internally, we have also started exploring how we can provide resource to and develop service-user engagement in local commissioning practices.

In order to explore this area of work further we created a cross-organisational working group, including those with lived experience of multiple and complex needs. The group arranged and delivered two sessions with commissioners in the local area, with the aim of creating a small network of motivated individuals from which to build momentum around service user involvement. Attendees included representation from housing, drug and alcohol and health services from across the South East. The sessions included a speaker from a leading national service-user engagement representative, who shared experiences, advice and best practice.

The sessions aimed to explore:

1. What a 'gold standard' of service user involvement might look like locally
2. The value of service-user involvement and interacting theories of involvement
3. Considering of the legitimate barriers to achieving better quality engagement
4. Discussing what we as an organisation can do to resource future development work in this area.

We aim to continue developing best practice in this area, and resourcing the work as directed by local commissioners.



Of course, there are a number of challenges in involving service users/individuals with lived experience into a commissioning process, the largest of which are around access and security. In addition, in the fields of health and justice commissioning existing service users cannot be used as a current recipient of a service due to conflicts of interest. Surrounding these core challenges exist a nervousness from both professionals and experts by experience:

- *How much value would the involvement really add to the process?*
- *Would the involvement be tokenistic or perceived to be?*
- *Are experts by experience suitably skilled and able to comment on such a complex process?*

These concerns and challenges are compounded by ‘change being scary’ and that naturally, commissioners are ‘risk adverse’.

However, there are also many benefits to involving individuals with lived experience into a commissioning process, for the commissioning organisation:

- *It can lead to improved patient/service-user engagement*
- *Services are targeted to want and need*
- *They have the opportunity to ‘learn and develop’*
- *Better use of resources*

For the experts, they benefit from feeling more empowered, gaining confidence and knowing that they have made a difference.

In West Yorkshire individuals with lived experience were involved in the local commissioning process of healthcare in their criminal justice provision. The case study below outlines the project and considers some of the ways to overcome the challenges (listed above) and what are key considerations for success in involving individuals with lived experience.

### **West Yorkshire Finding Independence (WY-FI) – experts by experience involvement with local commissioning**

NHS England has direct commissioning responsibility for healthcare for people detained in prisons and prescribed places of detention, which for this case study example includes:

- *A high security prison*
- *Two adult male prisons*



- *Two female prisons*
- *A Young offenders' institution*
- *A secure children's home*
- *£20 million budget*
- *18 month long commissioning cycle*
- *High profile*
- *High risk*

Previously, these services were commissioned by Primary Care Trusts for prisons in their locality. Consequently a range of different commissioning and contracting models were inherited, resulting in variability of provision, service quality and insufficient value for money. This was never a sustainable position and this procurement represented a critical milestone of the overall strategy to correct this.

The WY-FI experts by experience were part of the bid evaluation project team and the presentation evaluation panel. A male expert worked on the male high security prison and adult male prisons and a female expert worked on the adult female prisons. They suggested specific questions to ask providers. The experts required the following to be involved: coaching and support, IT system training, a venue/location for meetings, briefings and training and their expenses had to be covered.

To enable their inclusion into the commissioning process the WY-FI project provided:

- *Advice on accessing patient voice*
- *Access to experts*
- *Experience and expertise in working with experts*
- *Support to experts*
- *A venue/location for meetings, briefings and training*
- *Appropriate expertise*
- *A safe organisation to work with*
- *Security*
- *Risk mitigation*
- *Expert expenses paid and invoiced*

### **Keys to success in involving lived experience**

- *A clear service level agreement around roles and responsibilities of all organisations involved*
- *Being brave*



- *Ask yourself ‘What cannot be done by experts?’ rather than ‘What can experts do?’*
- *Minimal jargon*
- *Engage experts from a more diverse ethnic background*
- *Ensure commissioners are in the same room as experts more often to evidence the value added to the project from the start*
- *Robust project management*
- *Steadfast in resolve to improve / change*

### **Benefits**

For the experts, the process was considered to be interesting and enjoyable and they had clear evidence that showed their involvement was considered and valued – it was not a tokenistic gesture.

For the commissioner, patient engagement was a central part of the procurement process and the NHS were delivering against the NHS England Patient and Public Participation Policy (2015). The process allowed the NHS to meet its objectives in its Five Year Forward View and the process had a clear impact on project outputs. Now that the process has been undertaken there is a system in place to make it easier and quicker to deliver co-produced commissioning next time.

### **What to expect when involving lived experience**

- *Professional perspectives on the value of the patient voice to be challenged, and changed!*
- *The process to be time-consuming*
- *Contributes to system change*

## **Other ways social action (lived experience) is embedded into the programme.**

### **LOCAL EXPERT GROUPS**

All the funded projects within the Fulfilling Lives: Multiple Needs programme have local expert groups. These are groups, generally of volunteers, who have lived experience of multiple and complex needs. The groups are consulted and involved on a number of service design and delivery aspects of the projects. The level and type of involvement varies by project and also by individual within the local group. Below is further detail on two of the local groups in the programme and the work they have been conducting.



## Birmingham

There are 16 volunteers in the Experts by Experience [EBE] group. Current roles include such opportunities as being members of the Bridging Fund<sup>2</sup> panel, using their experiences to help the panel accept or decline applications. So far, there have been 86 applicants with 68 accepted (to the tune of approximately £17000). Other examples of work of the group include:

- *Attending the National Police Integrated Offender Management training to give an offender perspective on the training. This had the aim of encouraging police officers to consider rehabilitation via local services as opposed to conviction.*
- *Working locally with five police units, going out with the officers to help them refer suitable people in the region into the Fulfilling Lives Programme.*
- *Sitting on the recruitment panels of the Birmingham Changing Futures, having a say on who is employed in the programme.*
- *Setting up a Female Expert group trying to drive recruitment of females onto the programme.*
- *Sitting on the Core Group, updating the meeting of key Expert activity whilst also giving a service user perspective on agenda items.*

Birmingham now has an 18-month time limit on being an EBE to help prevent dependency on the group and ensure that EBE's experiences are relevant to current services.

## Newcastle and Gateshead

### Involvement in peer research

FL Newcastle and Gateshead trained and provided peer researchers to establish the health needs of Gateshead's homeless population. This report will be available in July 2017. The peer researchers were also involved in shaping the recommendation within the report. Following this research the project has been at the heart of Gateshead Council's plans for the re-commissioning of Supported Housing services, taking part in consultation and co-production events.

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<sup>2</sup> The Bridging Fund is a limited fund, which is available to Lead Worker contractors and No Wrong Door organisations as part of the Birmingham Changes Futures Together project (BCFT). The fund is intended to (a) support any specific requirements of service users with multiple and complex needs that can't be facilitated through existing provision, and (b) make emergency payments where there is **no alternative source of money available**.

## Involvement in training with frontline services

RESPOND training: The Experts by Experience group have co-produced, and now co-deliver an innovative multi-agency ‘Blue-Light’ Training for dealing with a mental health crisis. The training is delivered to multi-agency cohorts including Doctors, the Police, Psychiatrists, AMHPs, ambulance staff and social workers. The training model has the essential requirement of having an Expert by Experience as one of the co-facilitators, and for three people with lived experience to be on the training and taking part in all the exercises. In addition, our Expert By Experience group have helped to produce the training film “scenarios” – the first one being of someone on a bridge threatening to jump off. We are currently planning the filming of two more scenarios. The Pilot has been successful and has secured further funding to deliver RESPOND training across the North East, Cumbria and North Yorkshire [please refer to separate PDF document with further information].

Experts by Experience have also been involved in the creation of film resources used to train multi-agency staff teams (from all four silos) and have co-delivered the Complex Needs training in Newcastle and Gateshead. The impact of the training is currently being evaluated and will be made public in due course. The films we co-produced involved members of our Experts By Experience Network and current clients of the program. Examples can be found below:

— *Georgia’s Journey* <https://youtu.be/J6MHidZCAmI>

— *James’s Journey* <https://youtu.be/Ac6oSoOS8XY>

The Experts By Experience Network in Newcastle were also involved in group discussions around the Ladder4Life PIE Framework, devised by System Broker Ray Middleton. These discussions were recorded and have also been used for training purposes:

— *Asking for Help,*

— *Conflict,*

— *Handling Emotions,*

— *Problem Solving as a Process,*

— *Direction and Motivation*

Staff who attended these training sessions told us that they really value hearing the “Voice” of real people with complex needs, and reflecting on the issues and experiences they share has helped them develop as staff (full evaluation report is due to be made public once complete).

These film resources, which value the “Voice” of Experts By Experience, are also being used in our “Training PIE Facilitators” pilot project. Facilitators report that these films have been very helpful as the focus of a staff group reflective practice session. This pilot is due to be evaluated and the final research evaluation will be made public in the future.



## Art & creativity to showcase issues and impact system change

Across the programme individuals with lived experience have shown a preference for ‘telling their story’ or being involved in service strategy and policy in a creative way. In Newcastle & Gateshead a number of projects have been undertaken to provide this opportunity:

- *Negotiations are underway with Art Therapies UK to do a specific art project with our clients around system change.*
- *A specific project with 18-24 year olds is being developed in conjunction with a Changing lives hostel for this client group around creative arts and narratives for younger people.*
- *Currently a photography project “See the Story” is underway where people with complex needs are challenging the system visually by taking photographs around positive and negative service experience. An exhibition is planned to show these to the public in July 2017 in conjunction with Northumbria University.*

## Progressing to run their own organisations

Jigsaw Recovery Project CIC is a recovery service for young people exiting the care system. This service was born out of the activity of the FL Newcastle and Gateshead Experts By Experience Group. Funding from Gateshead Council has enabled Jigsaw to employ the former co-production lead and two former members of the EBE group.

## **NATIONAL EXPERT CITIZEN’S GROUP [NECG]**

The National Expert Citizen’s Group is a group of individuals with lived experience pooled from the 12 funded projects of the Big Lottery Fund’s Fulfilling Lives: Supporting people with multiple needs programme. The group meets once a quarter and representatives from each project are required to attend. The meetings are hosted by each of the projects in turn. Members of the group are all active in their local expert groups/projects (see above) and come together to share local learning to other projects that might help to address challenges and share best practice across the programme.

The group also gets involved in policy, strategy and service consultations; for example, the group was consulted by the Home Office on the National Drug’s Strategy. They have also recently presented at the Tackling Multiple Disadvantage Summit on how to engage individuals with multiple needs from BME communities. Many members of the group also work with Revolving Doors Agency, Making Evert Adult Matter partnership and Agenda.

The group provides a number of opportunities for individuals with lived experience:

- *Members can share experiences and learning on a national scale*
- *Members find additional opportunities to improve their personal development – particularly around group work and presenting confidently*



— *The group provides a bridge between the local group and employment for those wanting a more public-facing, system change orientated role*

The group has been facilitated by CFE Research since 2015. Since that time a number of core members have since moved on to full-time employment or higher education. Some have even set up their own community interest companies.

The NECG is currently putting together material to highlight the merits (and challenges) of social action for their first ever conference in autumn 2017.

## **Final comments**

This document provides a flavour of some of the activities, challenges and solutions to embedding social action in the field of multiple disadvantage. The Fulfilling Lives: Multiple Needs programme runs until 2021 and continues to collate data, test and pilot interventions across the country. Whilst we have not provided all the evidence that is generated across the programme we would be happy to continue to liaise with the APPG and provide data as and when required over the coming years.

