

# Empowerment for people with multiple and complex needs

Evaluation of Fulfilling Lives South East 2017  
(Year 3)

Written by Juliette Hough



Combating Homelessness  
Creating Opportunities  
Promoting Change



**FULLILLING LIVES**  
South East Partnership



JH Research

Research conducted and report written by Juliette Hough  
December 2017

This research was conducted for Fulfilling Lives South East, which aims to support people with multiple and complex needs to become more empowered and influence positive change, both for themselves and to the wider system.

### **Acknowledgements**

With thanks to all those who took part in this research.

### **About Juliette Hough**

Juliette is an independent social researcher who specialises in conducting research with people experiencing homelessness, complex needs and other types of inequality. She is conducting the independent evaluation of Fulfilling Lives South East.

### **About Fulfilling Lives**

The South East Project, working in East Sussex, is one of 12 projects across England where Big Lottery Fund investment is supporting people with complex needs.

As well as supporting people, the funding will evidence more effective and efficient ways for **designing, commissioning** and **delivering support services** for this group in the future.

The purpose of this initiative is to bring about lasting change in how services work with people with multiple and complex needs; this funding is a vehicle to help bring about that change.

The legacy of the eight year programme will be that systems and services in Brighton & Hove, Eastbourne and Hastings will better meet the needs of this group.

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## Executive summary

### Introduction

#### Aims of this evaluation

This report presents the findings of the independent evaluation undertaken in Year 3 of the Fulfilling Lives South East project (up to September 2017). The focus of the evaluation is:

- To what extent has Fulfilling Lives South East helped to empower people with lived experience of multiple and complex needs (in particular those who are volunteering with or employed by the project)?
- What can we learn from this to shape the future of the project?

#### About Fulfilling Lives South East

Fulfilling Lives South East operates across Brighton & Hove, Eastbourne and Hastings. It commenced in July 2014 and has been funded over eight years by the Big Lottery. The project is delivered by BHT in partnership with Equinox in Brighton & Hove, and Brighton Oasis Project in Eastbourne and Hastings.

Fulfilling Lives aims to improve the lives of people with multiple and complex needs - those with current or recent experience of two or more of the following issues: mental health issues, homelessness, drug or alcohol issues, offending.

A key project outcome is that service users are empowered to directly influence service design and delivery, both within the project and externally. People with lived experience of multiple and complex needs are involved in Fulfilling Lives South East in the following ways:

- Three **Action Groups**, made up of volunteers with lived experience of multiple and complex needs, inform and support the project.
- Nine **Project Consultants** (who have lived experience of multiple and complex needs) are employed to facilitate the Action Groups.
- **Volunteers** (often Action Group members), conduct a range of additional activities.

#### Evaluation methods

This evaluation builds on research previously conducted for Fulfilling Lives South East, which identified eight 'elements of empowerment' for people with multiple and complex needs, based on discussions with 20 people with current or recent lived experience of multiple and complex needs. These are:

- Confidence and self-worth
- Optimism and aspiration
- Resilience and responsibility
- Purpose
- Tools to make positive change
- Supportive relationships
- Being heard and valued
- Money and resources

Research activities undertaken for this evaluation took place from December 2016 to August 2017 and included:

- In-depth interviews with eight current and former Project Consultants and volunteers.
- Observation of a workshop presentation delivered by a Project Consultant about their experience of empowerment through the project.
- An in-depth interview with a commissioner who has worked with Fulfilling Lives volunteers.
- In-depth interviews with the project's Service User Engagement Coordinator and Senior Manager and BHT's Director of Advice and Support Services..

## Key findings

Overall, people with lived experience of multiple and complex needs interviewed for this evaluation who have been involved in Fulfilling Lives as volunteers, Project Consultants and in other staff roles have found the experience empowering.

*'Before Fulfilling Lives got in touch with me, I was living a very isolated existence where I was ashamed of what had happened to me and my contribution to society [...] When I came into Fulfilling Lives as a volunteer the acceptance within the project really helped me, the belief in me, the being able to see my skills when I couldn't see them anymore and help me to develop those. I was going and doing things and it was enjoyable and people were listening to me and people were valuing my contribution. So I found that I had purpose and that I started to believe in myself again, through their belief in me.'* – Fulfilling Lives volunteer

*'I came alive working [for Fulfilling Lives] ... Getting into that post catapulted me into getting to where I wanted to get ... I started to shine. It was just that feeling of, just bounding into work in the morning and feeling valued and getting some stuff done and making progress and coming home at the end of the day.'* – former Project Consultant who is now employed in the sector

## Volunteers' experiences

Volunteers interviewed for this evaluation have found their involvement in Fulfilling Lives South East very empowering. They described improvements in most of the elements of empowerment identified as important in previous research, including:

- Increased confidence and self-worth, including being able to see their lived experience as an asset which might help others.
- Developing new, clear aspirations around moving into work and continuing to make a meaningful contribution to society.
- Developing greater resilience during their time with Fulfilling Lives, including new coping mechanisms, and turning to others for support.
- Developing a new sense of purpose through their role in Fulfilling Lives.
- Gaining tools to make positive changes both in their own lives, and to services and potentially systems, including rediscovering lost skills, learning new information and skills, and developing a greater understanding of the system.

- Building supportive relationships, particularly with other Action Group members.
- Feeling heard and valued in Action Group meetings, within Fulfilling Lives as a whole, and by services and commissioners they had worked with.
- Starting to think about the possibility of moving into employment and earning money (although people could also experience fear about moving off the security of benefits into employment).

### **Staff members' experiences**

Most staff members with lived experience of multiple and complex needs, including Project Consultants, said their overall experience of working on Fulfilling Lives was empowering. Some had mixed experiences. Staff members described:

- Increased confidence and self-worth, although perceived criticism in the role, which was experienced by some, could negatively affect this.
- Developing greater resilience during their time with Fulfilling Lives, including new coping mechanisms, turning to others for support, and dealing well with difficulties after moving on from Fulfilling Lives.
- Developing a new sense of purpose both through their role in Fulfilling Lives and after moving on from the project.
- Gaining tools to make positive changes both in their own lives, and to services and potentially systems, including rediscovering lost skills, learning new information and skills, and developing a greater understanding of the system.
- Building supportive relationships with peers on the project, and, for some, developing lasting friendships.
- Mixed experiences in relation to feeling heard and valued within the project. Some people reported very positive experiences; they described receiving positive feedback, support and encouragement, and raising ideas and seeing them come to fruition. Others did not feel fully heard or valued. Issues some people raised were: (i) not feeling praised for their work; (ii) not having their own needs or difficulties noticed by busy managers; and (iii) raising issues or ideas about how Fulfilling Lives could be improved but neither feeling heard, feeling these ideas were valued, or seeing changes in relation to these. One Project Consultant said their experience of working for the project had been disempowering and had contributed to a deterioration in their mental health; project managers are aware of this and are currently supporting this person.
- Enjoying having control over their own money, although where the job felt precarious (because of fears about illness, performance issues or the fixed-term contract coming to an end) the possibility of losing paid work could be a source of stress and worry.

### **The employment pathway**

There are examples of volunteers successfully moving into Project Consultant roles, and of Project Consultants successfully moving into other employment after moving on from the project. One volunteer and one Project Consultant have moved into other staff roles within Fulfilling Lives. A recently implemented monitoring system will enable the project to quantify these outcomes.

## Conclusions and recommendations

- Fulfilling Lives South East is helping people with lived experience of multiple and complex needs to become more empowered, as a result of volunteering and working on the project. It is helping people to feel increased confidence and self-worth, build supportive relationships, develop aspirations and a sense of purpose, and develop tools for making positive changes in their lives and to services. It is also enabling staff members to earn an income.
- People with lived experience of multiple and complex needs play a crucial role in the project. They have conducted a broad range of activities aimed at changing attitudes, understanding, processes and service design, and ultimately influencing a more empowering system.
- The role of 'expert by experience' sometimes requires vulnerability (for example when reflecting on and talking openly about experiences) and can bring up difficult emotions. Overall, people said that Fulfilling Lives recognised their potential vulnerability and provided good support around this. Two people described some detrimental effects of their involvement on their well-being; they described perceived criticism in the role lowering their sense of purpose and self-worth.
- Volunteers were overwhelmingly positive about their experiences on the project. They described receiving very good support and encouragement from Project Consultants and other Fulfilling Lives staff, and felt heard and valued both within the project and by services and commissioners they had worked with. Project Consultants should ensure they prioritise mentoring sessions, which are hugely valued by Action Group members.
- The project often welcomes ideas being raised by staff and volunteers, and there are several examples of such ideas being implemented. However, several staff members with lived experience said that they did not always feel heard or valued. It would be helpful for managers and team members to explore the reasons for this and how people could feel more heard and valued.
- Fulfilling Lives South East has put useful processes in place to support staff members with lived experience, and continues to learn and adapt in order to do so.
- People gave some examples of power dynamics at work within the project. It could be helpful for all project staff to learn about theories of power dynamics, and to engage in reflective practice around this.
- There are early examples of the employment pathway working well. It would be helpful for future research to capture longer-term outcomes for Project Consultants after they move on from the project.
- Further research will help to capture and share learning about employing people with lived experience of multiple and complex needs.

## Introduction

This report presents the findings of the independent evaluation undertaken in Year 3 of the Fulfilling Lives South East project. The focus of the evaluation is:

- To what extent has Fulfilling Lives South East helped to empower people with lived experience of multiple and complex needs (in particular those who are volunteering for or employed by the project).
- What can we learn from this to shape the future of the project.

This evaluation draws on research conducted earlier in the project that identified what empowerment means for people with multiple and complex needs. This research is presented in a separate report [\*Empowerment for people with multiple and complex needs: what it means and how it can be measured\*](#).<sup>1</sup>

## About Fulfilling Lives South East

The Fulfilling Lives South East project operates across Brighton & Hove, Eastbourne and Hastings. It commenced in July 2014 and has been funded over eight years by the Big Lottery.

The project aims to achieve the following:

- People with multiple and complex needs, previously not engaging well with services, self-report that they are better able to manage their lives, as a result of services being more accessible, targeted and better coordinated.
- Service users are empowered to directly influence service design and delivery both within the project and externally.
- Services and roles will better meet the needs of service users, through undergoing a process of review and evaluation, leading to lasting change in design and delivery.
- Long term improvements in systems, commissioning and policy will be achieved through shared learning and strengthened outcomes evaluation.

The project is delivered by BHT in partnership with Equinox in Brighton & Hove, and Brighton Oasis Project in Eastbourne and Hastings. In each of the three areas, there is a team consisting of: an Area Lead, a Service Improvement Officer (responsible for leading on the systems change element of the project), two Specialist Workers (one focusing on supporting people with dual diagnosis and one on supporting women with multiple and complex needs), and three Project Consultants (people with lived experience of multiple and complex needs who oversee the work of the Action Groups). A Service User Engagement Coordinator manages the Project Consultants. Three Action Groups (one in each of the project's geographic areas), made up of volunteers with lived experience of multiple and complex needs, inform and support the project. The project is also supported by a Core Group, and three Steering Groups across each of the three locations.

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<sup>1</sup> Hough, J. (2017) *Empowerment for people with multiple and complex needs: what it means and how it can be measured*. Fulfilling Lives South East Partnership, BHT, JH Research. Can be accessed at: [https://www.bht.org.uk/wp-content/uploads/2016/08/What-empowerment-means-Oct-2017\\_.pdf](https://www.bht.org.uk/wp-content/uploads/2016/08/What-empowerment-means-Oct-2017_.pdf)

## Defining multiple and complex needs

Fulfilling Lives South East aims to improve the lives of people with multiple and complex needs - those with current or recent experience of two or more of the following issues: mental health issues, homelessness, drug or alcohol issues, and offending.

## Defining empowerment for people with multiple and complex needs

In research previously conducted for Fulfilling Lives South East project, we asked 20 people with current or recent lived experience of multiple and complex needs, across Brighton & Hove, Eastbourne and Hastings, what empowerment meant to them.

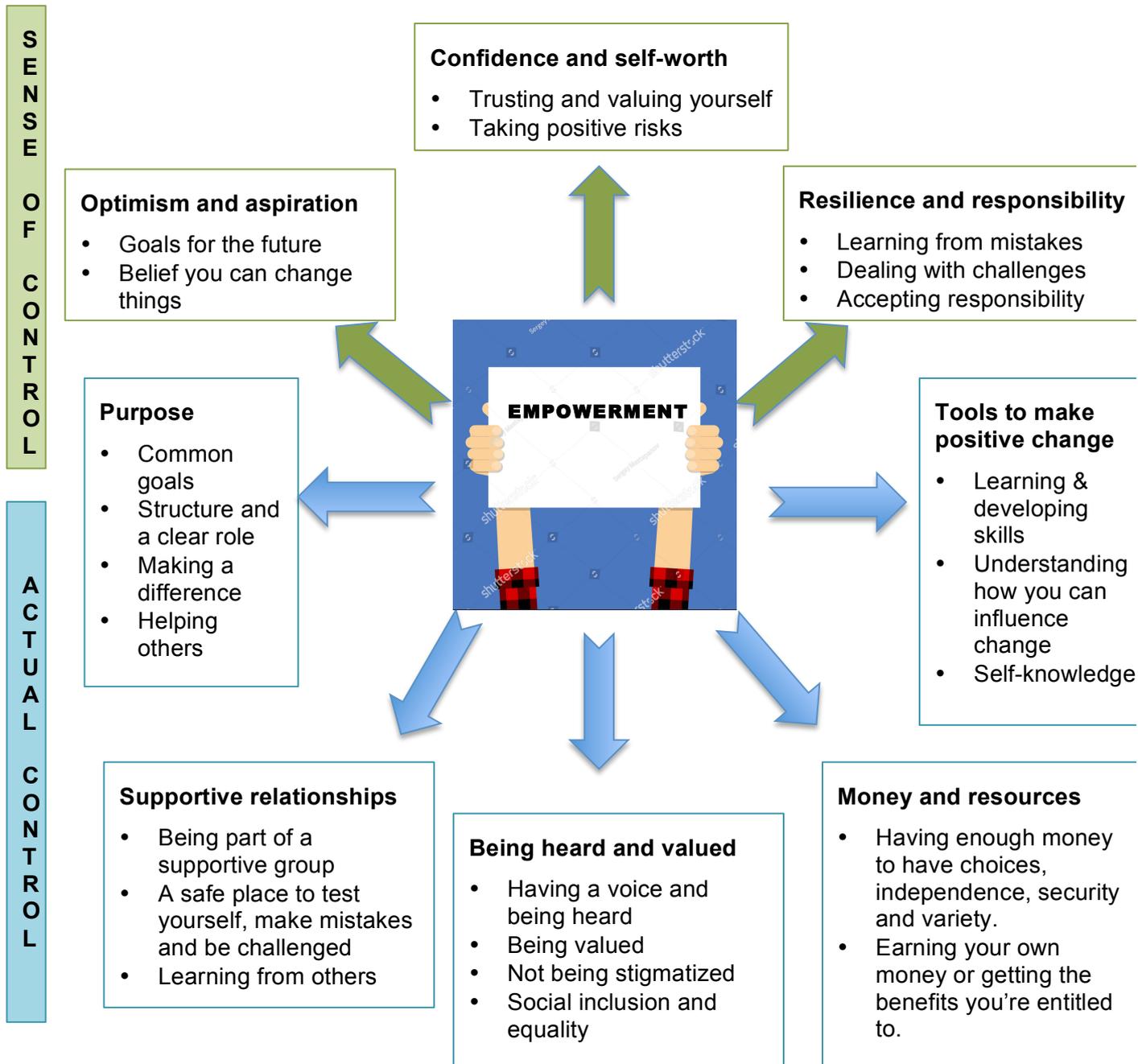
The things they talked about fell into eight main themes. These are the eight 'elements of empowerment' in figure (a) below. Some of them relate to a 'sense of control' (how far you believe you can influence change) and some to 'actual control' (the external conditions that make it possible for you to influence change).

## Opportunities for involvement in Fulfilling Lives South East

People with lived experience of multiple and complex needs are involved in Fulfilling Lives South East in the following ways:

- Three **Action Groups**, made up of volunteers with lived experience of multiple and complex needs, inform and support the project. The groups meet weekly although many volunteers have more frequent involvement. They conduct a range of activities including: identifying gaps and barriers in services and systems, conducting consultation activities to inform systems change activity, working with commissioners and services to inform service delivery, and evaluating the extent to which agreed changes to services and systems have taken place. Approximately 6-8 people sit on each Action Group at any one time.
- Nine **Project Consultants** (who have lived experience of multiple and complex needs) are employed by the project to facilitate the Action Groups.
- **Volunteers** (often Action Group members), conduct a range of activities including:
  - Representation on the Core Group and Steering Groups.
  - Interviewing applicants for staff roles and delivery partners. Applicants are interviewed by a staff panel and a service user panel of project volunteers. Each panel has equal weight in decision making.
  - Peer mentoring.
  - Conducting peer research.
  - Representation on the Research and Evaluation Working Group.

**Figure (a): What empowerment means for people with multiple and complex needs**



## How Fulfilling Lives South East aims to help empower people

Fulfilling Lives South East aims both to help empower people with multiple and complex needs and to influence a more empowering system.

It aims to:

- Influence people's 'sense of control' – for example by training, mentoring, supporting and employing them, and listening to and acting on their views.
- Influence 'actual control' by providing ways for people with lived experience to directly influence Fulfilling Lives, and by influencing the systems that people are part of.

The 'theory of empowerment' outlined in this section, and described in figure (c) below, describes how Fulfilling Lives South East aims to help create this change. This is based on discussions with 20 Fulfilling Lives staff members and volunteers with lived experience of multiple and complex needs, as well as interviews with senior Fulfilling Lives staff members.

### Fulfilling Lives South East partners

Fulfilling Lives staff and volunteers are working closely with a wide range of formal and informal partners to create a more empowering system. This includes frontline staff and managers in statutory and voluntary services, commissioners and policy makers. They play a vital role in:

- Championing, innovating, testing and spreading empowering approaches and processes.
- Changing policy and practice within their own organisations.
- Changing cultures, attitudes and understanding among those they work with.

### Fulfilling Lives South East activities

The project is working to:

1. **Create a pathway to employment:** supporting volunteers to move into paid work on the project, and for employees to move into further external employment (see figure (b)). The project has a range of fixed-term volunteer opportunities and part time and full time roles specifically for people with lived experience. These are seen as developmental roles in which people are supported to gain the skills, experience and confidence to enable them to move into other work once the role comes to an end.
2. **Exemplify good practice in service user involvement and employment:** by employing a minimum of nine members of staff with lived experience at any one time, and facilitating three volunteer groups, the project is helping to demonstrate the value of involvement, and is building evidence of what works, and capturing and sharing its learning.
3. **Engage and influence** others in the system to adopt more empowering approaches and processes.

**Figure (b): A pathway to employment through Fulfilling Lives South East**

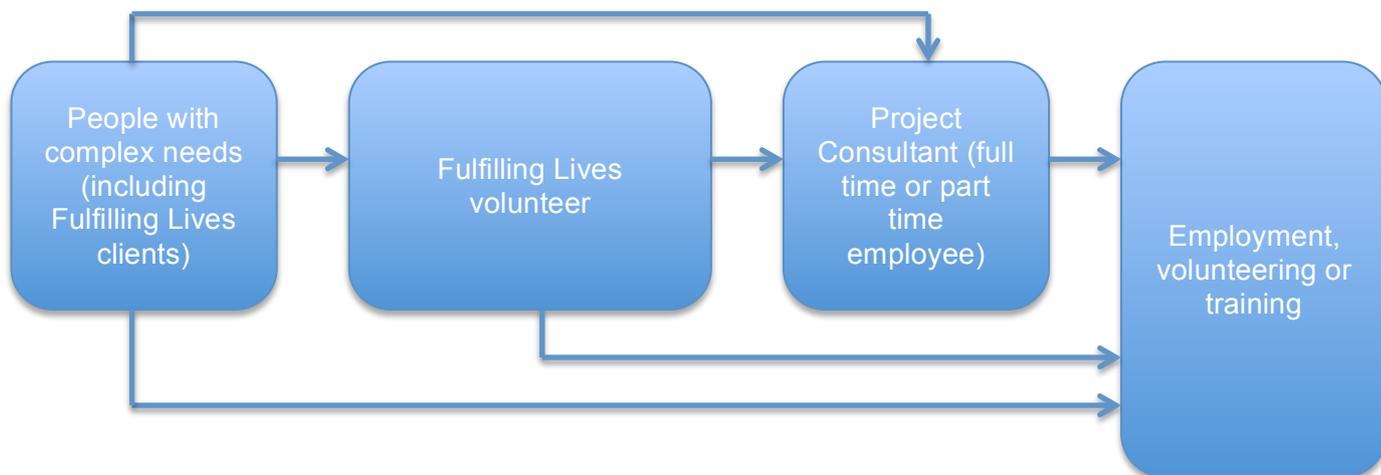
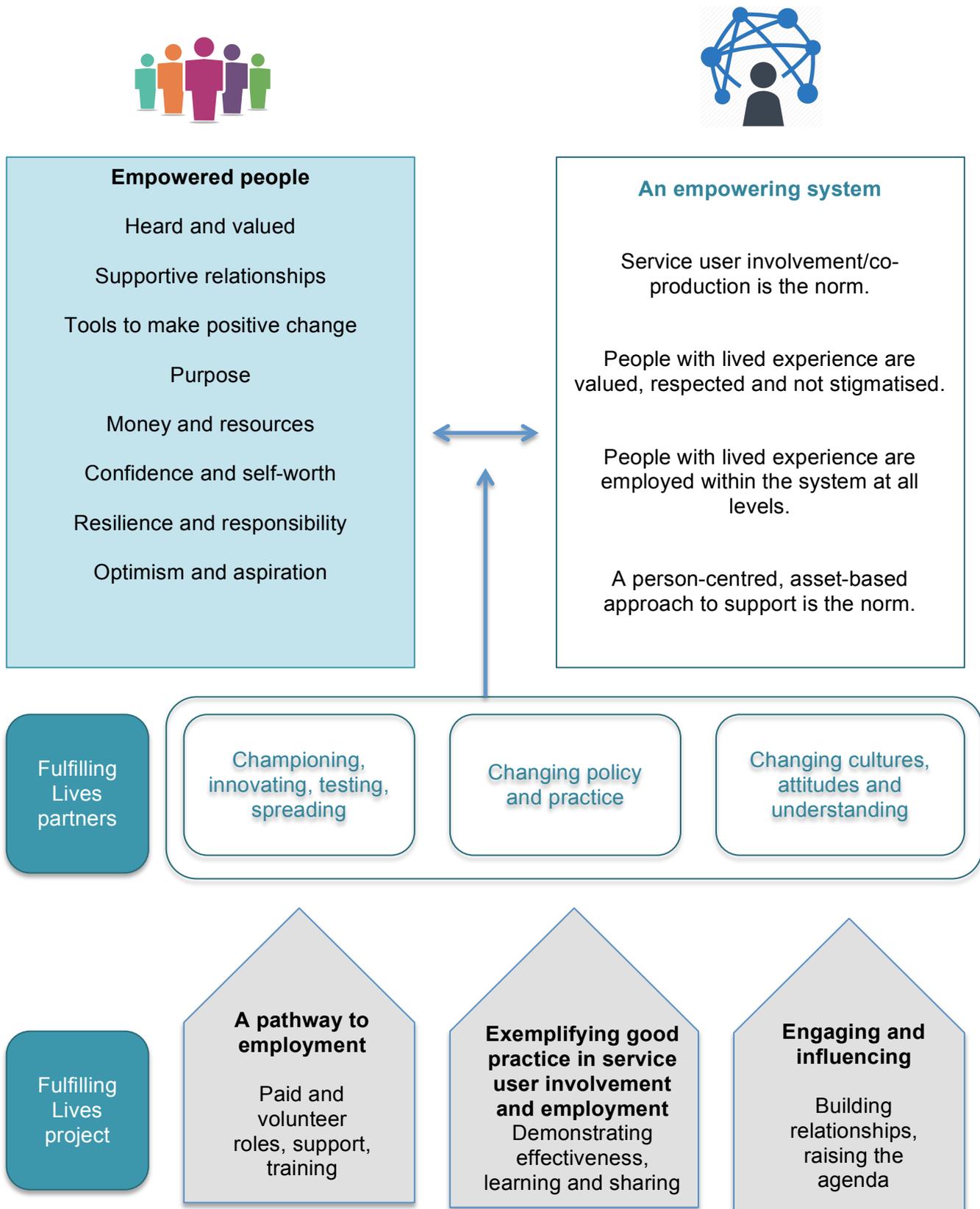


Figure (c): A theory of empowerment for Fulfilling Lives South East



## **Empowerment through specialist support**

Specialist Workers directly support a small caseload of clients with multiple and complex needs. Their aim is to empower people to be better able to manage their lives through assertive outreach, personalised support and advocacy, negotiating systems flexes with services, and modeling good practice. Personal budgets are also available. This research focuses on the empowerment of volunteers and staff members rather than clients.

## **Evaluation methods**

Research activities undertaken for this evaluation took place from December 2016 to August 2017 and included:

- In-depth interviews with eight people with lived experience of multiple and complex needs, comprising current and former Project Consultants and volunteers from across the three project locations. This includes Fulfilling Lives staff members with lived experience currently employed in non-Project Consultant roles.
- Observation of a workshop presentation delivered by a Project Consultant about their experience of empowerment through the project.
- An in-depth interview with a commissioner who has worked with Fulfilling Lives volunteers and Project Consultants.
- In-depth interviews with the project's Service User Engagement Coordinator and Senior Manager and BHT's Director of Advice and Support Services.

This evaluation report also draws on the following evaluation activities, undertaken in the same period, in order to define what empowerment means for people with multiple and complex needs:

- Group discussions with the three project Action Groups (a total of 12 volunteers from across the three project locations were involved in the discussions).
- A group discussion with eight Project Consultants.

The research builds on previous research conducted in years 1 and 2 of the project and reported in previous evaluation reports, including interviews and discussions with volunteers, Project Consultants and other Fulfilling Lives staff members.

## **A note on attribution of quotations and anonymity**

Some identifying details in quotations have been removed or changed in order to protect the anonymity of interviewees.

Quotations of both current and former volunteers are attributed to 'volunteers'.

Quotations of both current and former Project Consultants, and of staff members with lived experience employed in other roles in the project, are attributed to 'staff members'. Where quotations by current and former Project Consultants are only relevant to the Project Consultant role, they are attributed to 'Project Consultants'.

'Fulfilling Lives South East' is sometimes shortened to 'Fulfilling Lives' in this report.

## Findings

### Examples of involvement

People with lived experience of multiple and complex needs are closely involved in Fulfilling Lives South East. Interviewees described a number of examples of activities they had been involved in. Examples include (this list is not exhaustive):

- Identifying the need for targeted work around stigma, forming a Stigma Working Group and putting on a well-attended and well-received local anti-stigma event.
- Working with the local commissioner to shape the redesign of Brighton & Hove City Council's supported housing referral form to be asset-based, and on the development of a new women's service.
- Sitting on the interview panel for the commissioning of a new General Practice.
- Presenting at several conferences, including the National Summit on Tackling Multiple Disadvantage, and the Community Works Supporting Volunteers Conference in Brighton, on their experiences of empowerment through Fulfilling Lives and the learning from this for others.
- Identifying gaps and barriers in the system, some of which have been developed into System and Service Reviews – for example, the development of a map of homelessness services in Eastbourne.
- Conducting direct consultation with service users, for example at the women's drop-in session at First Base Day Centre in Brighton.
- Conducting mystery shopping for Hastings Borough Council's housing team.

### Outcomes – empowered people

This section is primarily based on the experiences of volunteers and staff members with lived experience of multiple and complex needs reported in interviews. It explores the extent to which they feel their involvement in Fulfilling Lives has helped them to feel more empowered, looking at each of the 'elements of empowerment' identified in the model in figure (a): 'What empowerment means for people with multiple and complex needs'.

### Overall experiences

Action Group members (volunteers) who were interviewed described feeling very empowered by their involvement with Fulfilling Lives:

*'Before Fulfilling Lives got in touch with me, I was living a very isolated existence where I was ashamed of what had happened to me and my contribution to society [...] When I came into Fulfilling Lives as a volunteer the acceptance within the project really helped me, the belief in me, the being able to see my skills when I couldn't see them anymore and help me to develop those. I was going and doing things and it was enjoyable and people were listening to me and people were valuing my contribution. So I found that I had purpose and that I started to believe in myself again, through their belief in me.'* – Volunteer

Most Project Consultants who were interviewed reported that their involvement in Fulfilling Lives had been empowering, including some very positive experiences:

*'I came alive working [for Fulfilling Lives] ... Getting into that post catapulted me into getting to where I wanted to get ... I started to shine. It was just that*

*feeling of, just bounding into work in the morning and feeling valued and getting some stuff done and making progress and coming home at the end of the day.’ – former Project Consultant who is now employed in the sector*

Current and former staff members with lived experience of multiple and complex needs described more mixed experiences of involvement than volunteers, including some disempowering experiences. These less positive experiences are explored in more detail in the section ‘Difficult and disempowering experiences’ below.

### **Confidence and self-worth**

Almost everyone interviewed described their confidence and self-worth growing as a result of their involvement in Fulfilling Lives. For many, this began at the point they were encouraged to get involved, were offered employment on the project or asked to join the Action Group. They described their sense of identity and self-worth changing as they rediscovered lost skills and developed new ones, and began to see themselves and their experiences in a more positive light.

Project Consultants and volunteers said that this new confidence helped them to speak up in meetings or even in conferences:

*‘It developed my confidence levels. When I started [my previous job], in team meetings I was really nervous. At Fulfilling Lives I was involved in management meetings and I had the courage to speak ... for example in big team meetings. [I realised]: yes, I can verbalise my opinion.’ – Project Consultant*

Volunteers attributed their growth in confidence and self-worth in part to the faith, support and encouragement that Project Consultants and other staff members and volunteers had in them:

*‘18 months ago I’d never have stood up here and spoken to a roomful of people. [It comes from] knowing people have faith in you, challenging yourself, and overcoming obstacles. Over [my period of employment] my feelings of confidence and self-esteem have grown week by week. I feel my opinions are valuable and I’m listened to and trusted to do the job properly, it’s a really nice feeling.’ – Project Consultant*

Several volunteers described feeling that they were no longer a ‘bad person’ as a result of their involvement. They were able to see their lived experience as an asset to others, rather than solely as a cause of suffering:

*‘I feel a better person today. I’m not a junkie and even when I was I still wasn’t a bad person [...] Today I do feel part of society [...] Because I’ve been through the hostel system, I’ve been through the drug and alcohol system, so I do ... I think I am a bit of an asset. I think we all are [in the Action Group] really because we’ve all been through it, life experience does count for a lot.’ – Volunteer*

A small number of staff members said that their involvement had been detrimental to their confidence and self-worth, particularly when they felt that their performance was being criticised:

*‘I felt bombarded [in a meeting, I was being asked] what have you done with this and that. I was crying that evening [...] It’s implied that I’m not good enough, it’s never good enough, I’m not doing the job properly.’ – Staff Member*

## **Optimism and aspiration**

The volunteers interviewed all described developing new aspirations as a result of their involvement in Fulfilling Lives. These were often around moving into work and continuing to make a meaningful contribution to society:

*'I've changed a lot. I'm doing many, many things and I kind of have an idea where I would like to work. I'm going to be doing a college course and I'm doing a peer mentoring course at the moment. And I think that I wouldn't be doing it if I had not got involved with Fulfilling Lives in the first place.'* – Volunteer

*'In a year, I'd love to go for one of the Project Consultant roles. Even if I don't go for Project Consultant, I'd like to work in the services in some way, I've set myself that goal.'* – Volunteer

## **Resilience and responsibility**

Volunteers and Project Consultants described developing greater resilience during their time with Fulfilling Lives. This included developing new coping mechanisms, and turning to others for support:

*'I think it comes down to not being scared if there is a challenge, just to face the challenge rather than hide from it. If I don't know something I can come here and say, "Guys, do you know how to do it? [...]" I would never be able to do that [before...], usually I was just hiding from the problems or trying to ignore them or getting depressed and not getting off my bed. Where now I'm like, "OK, it's not good but if I can't deal with it, I know that someone can help me to deal with that".'* – Volunteer

*'It's made me who I am today, and that's a much stronger and much more resilient person that's able to now use all the stuff [my experiences] to help other people [...] I'm just finding new coping mechanisms all the time because I was facing challenges every day at work [after leaving Fulfilling Lives] and [at] home.'* – former Project Consultant

Two former Project Consultants described facing challenges in the work they moved onto after Fulfilling Lives, finding that their new jobs put a lot of pressure on them and potentially posed a threat to their recovery. However, they were able to recognise this, and to take action to look after themselves and to find new work.

## **Purpose**

The sense of purpose provided by Fulfilling Lives came out very strongly in most interviews. All interviewees expressed a strong commitment to the aims of Fulfilling Lives and to helping improve things for others with complex needs. Many interviewees described developing a new sense of purpose through their role with Fulfilling Lives and after moving on from the project:

*'The more I've done with Fulfilling Lives, the more passionate I get about it. It's just giving me something to do with my life, giving me a sense of purpose I suppose. Because I was lost, when I got out of prison... The best thing I've ever done really is get involved with this because it's just helped me, helped me get a little bit more focus.'* – Volunteer

*'The work that I've done with some people is invaluable, priceless, to be able to give back some of my experience and to help people turn their lives around, possibly save lives and make that difference, and that's what it's all*

*about. So, that's priceless.' – Former Project Consultant now working in the sector*

*'It made me feel I was a useful person again, because I lost that.' – Project Consultant*

For many people, their sense of purpose was closely related to a sense of self-worth. Working on a project that aimed to make positive changes for others helped people to develop new understandings of difficult life experiences; these could now be sources of positive change, and people could develop a new sense of identity which included having value and self-worth:

*'In the Action Group, whatever I say is seen as a positive thing, a thing that can change something. So I'm not looking at myself thinking, 'Oh my God, what a horrible person I am for doing this and that and hurting this and that'. I'm thinking, 'OK, I've done it, how can I use it to do something better?' And by seeing myself like that, my experiences, seeing them in a positive way gave me confidence to believe that actually I'm not that bad a person. I had a bad time, but I've changed and I can do something that maybe others can't, I can do something to change some things that need to be changed.'* – Volunteer

Some people said that project targets (for example creating a target number of SSRs – System and Service Reviews) could detract from them having a sense of common purpose. They said that sometimes it felt that their work was more about targets and as a result they and others could lose sight of the ultimate purpose of improving the system for people with multiple and complex needs.

### **Tools to make positive change**

Volunteers and Project Consultants described developing tools to make positive changes both in their own lives, and to services and potentially systems. This included rediscovering lost skills, learning new information and skills, and developing a greater understanding of the system:

*'I have a skill-set that was lost along the way, and working for Fulfilling Lives put me in an environment where I could give me time to grow and feel supported and kind of reignite some of those old skills, put them back into place, as well as giving me new stuff to work with.'* – Project Consultant

*'I've learnt about interviewing [by sitting on an interview panel]. Now I'm not that scared to go to a [job] interview because I've done it myself so I now understand the other side of the panel. I do have a better understanding of how services work, how the commissioners work.'* – Volunteer

Several people described how the skills they had developed for their roles on Fulfilling Lives had 'rippled out' into their personal lives, helping them to make positive changes in their lives outside work:

*'Now I feel much more able to stand up for myself and I've started doing things I'd stopped doing. I was too scared to go out of the front door, I was scared of the phone, I couldn't answer it. Now I've got more used to answering it. [...] It's rippled out to my personal life as well, I've got a lot more self-awareness than I started with, it's about knowing what I can do.'* – Project Consultant

*I'm getting involved in stuff like at my daughter's school which I would never do before. I offered to talk to the Ofsted people [...] just to support the school*

*because they helped me a lot. I'm going to the children's parade tomorrow at school as well, just little things like this.'* – Volunteer

### **Supportive relationships**

Most interviewees described supportive relationships, particularly with their peers on the Action Group (for volunteers) or in their team (for staff members). These relationships were particularly important for volunteers, and could motivate people to keep attending the Action Groups even if they felt nervous. Several people said that they had been isolated before their involvement in Fulfilling Lives. Some Project Consultants and volunteers described making close friendships with peers that have endured after leaving the project:

*'The [Action Group] did make me feel part of the group straightaway [...] That's what kept me coming back really because I could see they were good people and the support, everyone was supporting each other, and I had no one [else], to tell the truth, supporting me. I was just keeping myself to myself.'* – Volunteer

*'It's like having a little family, I've made long lasting friends from it.'* – Volunteer

*'I'm being sociable again, being part of a team and valued by colleagues [...] Fulfilling Lives is a really safe place to develop and learn, you're not judged or stigmatized [...] When I've had hiccups, my colleagues have been there. I've had blips with my mental health [during my employment] but the support I've had meant I moved on from that quicker than I had in the past.'* – Project Consultant

One volunteer said that her involvement had helped her make new friendships outside the project:

*'I've made more friends because I'm more confident in maybe letting my guard down and letting some people in my life, because I always had problems with that. I used to just drop my daughter off and just run [away from] the school. Now I know the teachers, I know the volunteers there, I know the mums of my daughter's class and we're going out and we went on holiday with one of the mums. I think it's because my confidence and self-esteem is just so grown since I first came to Fulfilling Lives.'* – Volunteer

Finding lasting sources of support after leaving the project was difficult for some people. One former Project Consultant said that they do not have family or friends to support them, and have not been able to find an appropriate support network. This person said it was difficult to prioritise attending 12 step peer support meetings when working full time.

### **Being heard and valued**

Volunteers described feeling heard and valued in Action Group meetings, within Fulfilling Lives as a whole, and by services and commissioners they had worked with, and said this had a powerful effect on them:

*'Talking to these top commissioners [...] and they're sat listening to us. It's massive for me, that [...] They were asking for our input, like 'How do you think this would work?' or 'What do you think would work better?' [...] I have found my voice and it is being heard.'* – Volunteer

*'I managed to say something and the point was taken in, listened to, and actually afterwards [my idea] went on the [new housing] form [...] I was shaking [when I spoke...] it was scary. I felt good after that.'* – Volunteer

Volunteers attend the project's strategic Core Group meetings and have a regular Agenda item for feed back to this group. A volunteer who attended Core Group meetings said that they felt supported and listened to in the group.

A commissioner interviewed for this evaluation had worked with the Brighton Action Group on several areas of work, including on redesigning the supported accommodation referral form to be more asset-based and on helping to develop the service specification for a new women's service. They said the group was widely respected, and that the involvement of the Action Group had made a significant difference to their work:

*'There's a credibility around having consulted with them [the Action Group]. They're seen as a resource and a model of good practice. [...] Their involvement] made a huge difference around the pieces of work I've been involved with.'* – Commissioner

Several volunteers and Project Consultants described opportunities through Fulfilling Lives to speak to others within the system, including those in positions of power and authority. This included through joint work, attending meetings and speaking at conferences and events. The commissioner interviewed described one Project Consultant presenting a housing referral form that the Action Group had helped to redesign:

*'[Project Consultant] was brilliant, he took it upon himself, he attended a hostel managers meeting and presented the form, he says they received it well. They're happy with the change in the form, it went down well.'* – Commissioner

Staff members reported more mixed experiences in relation to feeling heard and valued by those more senior to them within the project. Some people reported very positive experiences:

*'The people at the top set this tone and I find that very stimulating and invigorating, you can talk to them and you can express a view and they genuinely take it on board.'* – Staff Member

However, other staff members said that they did not feel fully heard or valued. Issues some people raised were: (i) not feeling praised for their work; (ii) not having their own needs or difficulties noticed by busy managers; and (iii) raising issues or ideas about how Fulfilling Lives could be improved but neither feeling heard, feeling these ideas were valued, or seeing changes in relation to these:

*'I never seem to get any praise or recognition [for my work]'* – Staff Member

*'Because of [some difficult team dynamics] it was uncomfortable, and it made me... I shut down because I couldn't get my voice heard'* – Staff Member

More than one Project Consultant interviewed over the course of the evaluation described times when their passion for the project led to them feeling frustrated and emotional, when they did not feel heard or did not understand why their ideas were not taken forward. These people described similar experiences, saying that when they presented ideas or raised issues in an emotional way this could prevent them from being heard, and they felt they were being seen as 'troublemakers' when they were passionate about the project:

*'I'm then cast as some kind of troublemaker which is impacting on me so much. It's just some simple changes so just do them'* – Staff Member

These experiences are explored in more detail in the section 'Difficult and disempowering experiences' below.

### **Money and resources**

Project Consultants described the importance of not just having money but of earning their own income that the role enabled:

*'Having control over my own money, coming off benefits, seeing my first wage packet, felt really good. I felt more independent; I felt I needed someone to help me before. Fulfilling Lives gave me a chance when others wouldn't.'* – Project Consultant

For volunteers, the possibility of earning money and having a better quality of life as a result, was an important motivator in starting to think about moving into employment. For example, one person hoped to get a job so that he could take his girlfriend out.

However, money could be a source of stress and worry; in particular some people were concerned about the implications if something went wrong and they were no longer able to work, became ill, or lost their job. One volunteer described their fear of moving off the security of benefits:

*'In a year, I'd love to go for one of the Project Consultant roles. I wanted to do it this year, but couldn't make it work with my benefits, I was far too anxious about it all [...] I found out that once you start working they look at your claim again [...] It was fear. I was worried about losing PIP [Personal Independence Payment]. I'd have taken a drop of £300 a month if I'd kept PIP [or] £800 a month [if I'd lost it]. I desperately wanted to go for the job and felt I was ready and could be a good Project Consultant. [But] the worry about losing my PIP was keeping me up at night.'* – Volunteer

### **Difficult and disempowering experiences**

The volunteers interviewed were overwhelmingly positive about their experiences in Fulfilling Lives. Several staff members described more mixed experiences, including some aspects of their experience that they found disempowering. Less positive experiences described by some staff members and volunteers are described here. Many of these are issues that Fulfilling Lives managers are actively aware of, learning from, and exploring solutions to. Most quotations are not attributed in this section, in order to protect anonymity.

### **Vulnerability, recovery and empowerment**

Overall, people said that Fulfilling Lives recognised their potential vulnerability and provided good support for this. However, they stressed the importance of project staff remaining mindful of the vulnerability that was sometimes required for their role (for example when reflecting on and talking openly about their experiences), the difficult emotions this might bring up, and the effect this might have on them.

One volunteer said:

*'Sometimes when I speak at an event, because I'm spilling my guts in front of everyone, it makes you feel very vulnerable. People can look at you in a certain way [...] It does affect you, I do sometimes go home and have a cry. You think you've done so much and come such a long way, but you come up*

*against it [stigma] all the time. It feels like you're battling it all the time.'* – Volunteer

This person said that positive feedback, or hearing that people were going to change the way they worked because of what they had said, made the vulnerable feeling worthwhile. They said they had had good support from peers and Fulfilling Lives staff through this process. They said their advice for the project would be:

*'Remember to be mindful people have multiple and complex needs – I know it sounds obvious, but familiarity breeds contempt.'* – Volunteer

Some people said that their involvement had been helpful to them in maintaining their recovery. Several described being supported by the project through periods of mental ill health. One person said that their involvement had had a negative impact on their mental health.

Some people said that working whilst in recovery (sometimes in quite early recovery) brought some challenges:

*'The challenges [in work] are not being able to sustain the same quality of your recovery because you haven't got the time to go to meetings, you haven't got the energy or time to be doing 12-step work ... and that becomes less of a priority and that becomes really dangerous territory ... because nine times out of ten, the people who don't put that stuff first end up relapsing, so it's trying to get the balance right of coming back to full time work. ... [Dealing with that is] really difficult. I can only speak for myself and my own tenacity and my own inner strength and my own determination to succeed.'* – Staff member

### **Power issues and dynamics**

People gave some examples of power dynamics at work within the project. One example was the perceived power that Project Consultants hold in Action Groups:

*'One of the Project Consultants, I like them very much and think they're fantastic at their job, they I think sometimes they take over in the Action Group and it ends up being about them talking about their stuff and what they think should happen.'*

Project managers are aware of this issue, which has been raised with them, and are currently exploring ways to address this. One interviewee suggested that these power dynamics could be disrupted if part-time Project Consultants and Action Group members had more involvement in facilitating meetings and minute-taking.

Another emerging issue was the limited decision-making power of the Action Group in relation to System and Service Reviews (SSRs); people described decision-making power in the SSR process as resting solely with the Service Improvement Officer (SIO):

*'The Project Consultant will take [issues we've identified] to the Service Improvement Officer. [They] will look over this and may contact the service, will decide if it's an attainable one and will feedback to us what they want us to do [...] Usually either [the SIO] approaches the service and the Project Consultant runs with it and [the SIO] will come in and feed back to us every now and again – or [the SIO] will say sorry guys it's too big, or there's nothing we can do, or the service isn't up for talking.'* – Volunteer

One person described this as problematic:

*'[Ideas for SSRs] always had to go through the [now former] SIO. Every panel, members were going on about [system issue. The SIO's response was] we don't want to deal with it, that's too big [...] Massive gaps and barriers in a service were flagged up [by the Action Group] and no one [else in Fulfilling Lives] wanted to get involved [in this as an area of systems change]. Because they didn't see it as achievable. They wanted to tick boxes [...] It's supposed to be coming from the bottom up, from service users, but that gets diluted at every level.'*

Project managers stress that decision-making about SSRs should take place collaboratively between the SIO and Action Groups, but this research suggests that this is not always taking place in practice. If the decision-making power on which SSRs are taken forward sits with the SIO the SSR process has a potential to limit the empowerment of those with lived experience.

### **Experiences of performance management**

Several people described feeling the project provided a safe space to make mistakes, and being supported to learn from these mistakes. Fulfilling Lives has developed a range of processes in order to support people and manage their performance, including introducing a Performance Monitoring Form and taking a clear, consistent formal approach to conduct issues.

However, a small number of people described feeling more criticised than supported by managers. They felt there was a stronger focus on the tasks they had not done than praise for the tasks they had achieved, or conversations about their own well-being.

One Project Consultant who was really struggling said:

*'I've been getting more and more frustrated and angry and it's having a big impact on my life and welfare ... I'm feeling disempowered, undermined, not listened to and devalued.'* – Project Consultant

Although the project had put in place measures to support them, they believed they were at risk of losing their job, and this had been very detrimental to their well-being. Further action is currently being taken, with the support of the employing organisation's Human Resources team, to explore what has gone wrong for this person, and how (if at all) they could have been better supported by Fulfilling Lives.

The interviews undertaken show how praise and recognition for achievements can have a powerful positive impact on people, whereas perceived criticism and lack of praise can have a negative impact on people. Perceived criticism can affect people's sense of self-worth, and of working towards a greater purpose through the project.

Some interviewees said that one Project Consultant struggling with their performance can have a big impact on the rest of the team; it can affect the experiences of other Project Consultants, and of the Action Groups.

Managers report that the transition from volunteer to Project Consultant can be difficult. They have observed that people can find it hard to adapt to different expectations placed upon them as employees than as volunteers; this includes the changing nature of praise and recognition, as activities that volunteers would have been thanked and praised for become standard expectations of the role. It is hoped that the recent creation of a new role specifically to support the Project Consultants will provide additional support for people to be able to meet expectations as they make the transition into employment. Fulfilling Lives will be conducting research on what it means from an employer's perspective to employ people with multiple and complex needs, to capture the project's learning around this.

## **Feeling that ideas are not valued or translated into action**

Several people described experiences of raising ideas and feeling that these did not lead to any change. They said that this felt disempowering; they did not feel heard or valued. This was firstly in relation to areas for systems change identified by Action Groups:

*‘Everything seemed to be always being put back. [The Action Group’s] feedback didn’t come to fruition [...] There was too much red tape. No one seemed to be able to see or seize a good idea.’*

Secondly, this was in relation to ideas for improving ways of doing things in Fulfilling Lives. People felt their ideas were not always valued, or said they were told their ideas would not be possible to implement. One person described frustration around being told that change was ‘not possible’; when the suggested changes were later made they felt confused about why they had initially been told it was not possible and why the change had taken so long:

*‘There’s been a lot of: “these things [aspects of the project] are set in stone, we can’t change them”, and then [after a long time] they have changed.’*

When asked why they thought they were not being heard, possible reasons given by interviewees were:

- Some project processes and structures are not flexible enough to allow certain changes to be made quickly if at all.
- People may be unclear about what changes can and cannot be made; when the project is presented as a flexible ‘learning project’ it can be confusing when changes cannot be quickly made.
- People who present ideas or issues in less ‘professional’/more emotional terms may be less heard than others.

No one suggested there was any stigma or discrimination within the project related to their lived experience of multiple and complex needs.

## **The part-time Project Consultant role**

Several people (including someone in the role) said there were some difficulties with the part-time Project Consultant role. It was felt that a lot of time in the role was taken up with training, attending meetings or catching up, leaving little time for other aspects of the role.

## **Mechanisms of change**

This section explores the extent to which the three ‘mechanisms of change’ (the means by which it is expected that positive change will happen) set out in the project’s theory of empowerment are working. The three mechanisms of change are:

- Providing a pathway to employment
- Exemplifying good practice in service user involvement and employment
- Engaging and influencing organisational culture, understanding and practice

## **Providing a pathway to employment**

Early evidence provides examples of the employment pathway provided by Fulfilling Lives working effectively. Further evidence needs to be collected about the immediate and longer-term employment outcomes of Project Consultants after they

have moved on from the role (the project is currently putting systems for collecting this evidence in place).

### ***Fulfilling Lives clients***

One Fulfilling Lives client moved into an Action Group but became unwell and left the group. There was an attempt to contact this person as part of this evaluation, to find out whether her involvement in the group had affected her health, but she could not be contacted. She is being supported by a Fulfilling Lives Specialist Worker.

### ***Fulfilling Lives volunteers***

Seven volunteers have moved into employment with Fulfilling Lives (six as Project Consultants). Several of the volunteers interviewed described developing new aspirations, confidence and skills in relation to work as a result of their involvement in Fulfilling Lives, and described Project Consultants supporting them to develop these aspirations. Sitting on interview panels was felt to be particularly beneficial for those with little experience of being interviewed.

### ***Project Consultants***

Twelve Project Consultants have moved into employment on leaving their employment with Fulfilling Lives, out of a total of 19 whose employment outcomes are known.

Two of the former Project Consultants interviewed had moved into support worker roles outside Fulfilling Lives. Both described feeling pressure to find a job as the time to leave Fulfilling Lives came closer, and both took jobs that they believed in retrospect were not right for them and had had a detrimental effect on their well-being. However, both had recognised this and had successfully moved into other more suitable support worker roles.

Most Project Consultants said that Fulfilling Lives had helped them to develop the knowledge, skills and confidence to move into other work:

*'[The Project Consultant post] empower[ed] me to look for full time work, which I did and was successful.'* – former Project Consultant

*'Going for jobs, I now have things to put on my application form, I have something to talk about.'* – Project Consultant

Some Project Consultants have left Fulfilling Lives at the end of their contract without a job to go to,<sup>2</sup> and it would be helpful to conduct further research to learn from them about their experiences after leaving the role, and what they think would have helped them to move into work. Interviewees said that some Project Consultants had found it stressful coming to the end of their contract without having secured work.

Interviewees agreed that the extension of the Project Consultant role from 1 year to 18 months was helpful, to give more time in the role before needing to look for longer-term work.

### ***Other roles in Fulfilling Lives***

Two people with lived experience of multiple and complex needs have moved into staff roles on the project for which lived experience is not a requirement (one from a Project Consultant role, and the other from a volunteer role).

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<sup>2</sup> The project has recently implemented a process for recording whether or not Project Consultants have a job to go to when they leave Fulfilling Lives.

## **Exemplifying good practice in service user involvement and employment**

Three issues emerged in relation to the development of good practice in service user involvement: (i) experiences of support for people with lived experience who are involved in the project; (ii) opportunities for people with lived experience to raise ideas and influence the project; and (iii) the extent to which Fulfilling Lives is learning and developing its practice in response to service user involvement and moving towards its aspiration of co production.

### **Volunteers' experiences of support**

Most volunteers reported very positive experiences of support from the Project Consultants, and good relationships with others on the project. The support and encouragement of Project Consultants was instrumental in motivating people to get involved and stay involved in the Action Groups, and in developing aspirations, trying new things, and taking action towards goals.

Volunteers stressed the importance of mentoring, and several said that this more formal support was sometimes not prioritised by Project Consultants; they said that sometimes mentoring sessions would be cancelled and not rescheduled:

*'[I] always [feel] a little lift after mentoring, it makes you feel appreciated, listened to and included [...] It's been very important to help me feel valued and think about myself because you can get really caught up in everything and almost forget about your own personal needs, and people [can] get burn out or feel under appreciated and leave. It helps you to feel anchored to the project and I don't think enough importance is put on it.'* – Volunteer

One person said more practical help would be useful:

*'I think in your mentoring they should be pushing you. I've said I fancy going into [work] and they're 'oh yeah, yeah' but that's all I get out of my mentor. Give me a bit of help, tell me what I should be doing... But there again, I can't blame them for that, I should be encouraging myself.'* – Volunteer

Peer support was very important, and people described bonding by doing things together, and feeling strong as a group:

*'Doing things like conferences, where we all stand up, shaking, it makes us feel like a team because we did it together. We were scared together and we did it together.'* – Volunteer

Some volunteers described feeling vulnerable when sharing personal experiences in public. One person said they had been well supported in this by peers, Project Consultants and other colleagues, including a Specialist Worker:

*'The Project Consultant mentor was aware I was doing that work and was extra... "call me, do you need to chat". I had extra mentoring during that time. The guys [on the Action Group] said well done, it was really nice.'* – Volunteer

Several volunteers described being encouraged and nurtured, for example being given the space and opportunity to take on leadership roles:

*'You show a bit of interest, you show a bit of a skill and they take you forward with it. I think that's why it's so good because they're constantly looking for ideas and they don't care about the source.'* – Volunteer

One volunteer suggested the idea of a certificate celebrating the achievement of 100 hours volunteering, and a ceremony for presenting these, in order to recognise the huge amount of work done by volunteers.

### ***Project Consultants' experience of support***

Most Project Consultants' experience of direct support from their line manager, and working relationships with their peers and within their teams, was positive.

*'[Manager] was supportive, we had regular supervisions, she was always there if I needed to speak to her.'* – former Project Consultant

One person specified that the Wellness Action Plan and Performance Monitoring Form were helpful.

### ***Raising ideas and influencing within Fulfilling Lives***

As reported in the section 'Outcomes – empowered people', some people felt able to raise ideas and influence within the project, whilst others said they did not always feel heard and valued. There are several examples of those with lived experience influencing important elements of Fulfilling Lives' delivery and design. These include:

- The contract length for Project Consultants was extended from 12 to 18 months, primarily as a result of feedback from Project Consultants and Action Group members.
- The Action Groups now have delegated budgets and decide locally how to prioritise what they spend, for example spending less on lunches at the meeting so that they can afford group outings which they have found valuable for bonding.
- Project Consultants and volunteers identified stigma as a critical issue for people with multiple and complex needs. They set up a Stigma Working Group and designed and delivered a successful anti-stigma event.

These examples of people with lived experience successfully influencing the project reflect positively on both the volunteers and Project Consultants who raised and implemented these ideas, and on project managers who listened to these and either made changes themselves or ensured people were given the autonomy to take these ideas forward.

### ***Flexibility and learning within Fulfilling Lives***

There are several examples of the project changing processes in response to learning. These include:

- Creating a new post to support the Service User Engagement Co-ordinator, in response to learning that Project Consultants would benefit from additional support when starting employment.
- Developing a Wellness Recovery Action Plan, which is completed by Project Consultants when they start the role. This sets out an agreed and transparent plan for maintaining their well-being and recovery.
- Establishing a protocol with the delivery partner organisations, formalising joint day to day support for Project Consultants.
- During the first year of the project a more flexible approach to conduct issues was taken with Project Consultants. This was not always found to be helpful. In the second year of the project formal procedures have been more helpful in setting clear and consistent expectations of staff.
- Creating two distinct roles in the Project Consultant team: full time Project Consultants and part time Project Consultant Assistants. Those recruited as Project Consultants have the skills to support and guide the Project

Consultant Assistants and to co-ordinate the team, and have responsibility for the functioning of the Action Groups.

- Introducing a Performance Monitoring Form which enables Project Consultants to have a clearer understanding of the expectations of the role and their performance and the development needed to successfully complete their probationary period.

One staff member with lived experience described this learning in relation to a problem that had been experienced:

*'They've [managers] put things in place now to make sure that [problem] doesn't happen again [...] They learnt as they went along, they did things as they were going along to try and manage it.'* – Staff Member

### **Engaging and influencing organisational culture, understanding, practice**

It is expected that changes in the culture, understanding and practice of external organisations, as a result of Fulfilling Lives, will take place slowly over the full eight years of the project. Large-scale impacts are not expected at this stage in the project.

The Project Consultants and volunteers interviewed for this research gave examples of a number of changes they have helped to influence that they believed would make the system more empowering for people with multiple and complex needs, although it is beyond the scope of this evaluation to assess the broader impact of these. These included holding an anti-stigma event, sharing their views and experiences at conferences and events, designing an asset-based supported housing referral form, and sitting on the interview panel for the commissioning of a General Practice.

Although the commissioner interviewed for the evaluation said that if the Action Group had not existed they would have found other means to involve service users, they said the Action Group's involvement made a big difference to their work, for example in influencing the design of a new women's service. The commissioner described learning from the Action Group about what can be valuable in services to people with lived experience of multiple and complex needs:

*'They articulated lots of the softer elements of the service, they wanted it to be homely and carpeted, things that as a provider or a commissioner I might not specify in a specification [...] It was nice to try and embed that in a specification in a way that made people clear about the service ethos.'* – Commissioner

Changes like this that have been influenced by the Action Group may influence the culture, understanding and practice of service providers more broadly over time.

The commissioner also hoped to expand involvement:

*'Going forward it would be good to have some way service users can be involved with the contract management of services [...] I've talked to the Action Group at length about this, saying I wanted them involved [...] It would also be really wonderful to have a service user on the panel to assess bids for the women's service and involved with writing the service specification.'* – Commissioner

Although involvement in contract management from the point that the contract was awarded would be possible, the commissioner said that involvement in the tendering process might not be possible, because the Action Groups are funded and supported through a local service and may have a conflict of interest. They hoped a solution could be found to this issue.

Future evaluations will explore this element of the project in more detail.

## Outcomes - a more empowering system

Fulfilling Lives is in the early stages of influencing a more empowering system (this is expected to take place over the longer term). Research to be conducted on systems change in year 4 of the project (Sept 2017 to Sept 2018) will explore the extent to which Fulfilling Lives has influenced a more empowering system.

Elements of a more empowering system are likely to include:

- Service user involvement/co-production is the norm.
- People with lived experience are valued, respected and not stigmatised.
- People with lived experience are employed within the system at all levels.
- Person-centred, asset-based approach to support is the norm.

## Conclusions and recommendations

**Overall, Fulfilling Lives is helping people with lived experience of multiple and complex needs to become more empowered**, as a result of volunteering and working for the project. It is helping people to feel more confidence and self-worth, build supportive relationships, develop aspirations and a sense of purpose, and develop tools for making positive changes in their lives and to services. It is also enabling staff members to earn an income.

**People with lived experience of multiple and complex needs play a crucial role in the project. They have conducted a broad range of activities aimed at changing attitudes, understanding, processes and service design, and ultimately influencing a more empowering system.** Work that Project Consultants and Action Groups have been involved in includes: putting on an anti-stigma event; presenting about their experiences of involvement and empowerment at local and national conferences; identifying gaps and barriers in the system and informing System and Service Reviews; conducting direct consultation with service users; conducting mystery shopping for Hastings Borough Council's housing team; designing an asset-based supported housing referral form for Brighton & Hove City Council; informing the service specification for a new women's service in Brighton. The commissioner interviewed for this evaluation said the Action Groups and Project Consultants are a respected and valuable resource.

**The role of 'expert by experience' sometimes requires vulnerability (for example when reflecting on and talking openly about experiences) and can bring up difficult emotions.** Overall, people said that Fulfilling Lives recognised their potential vulnerability and provided good support around this. Some people said that their involvement in the project had been helpful to them in maintaining their recovery. Several described being supported by the project through periods of mental ill health (although one person said that their involvement had had a negative impact on their mental health.)

**Volunteers were overwhelmingly positive about their experiences on the project.** They described receiving very good support and encouragement from Project Consultants and other Fulfilling Lives staff, and felt heard and valued both within the project and by services and commissioners they had worked with. Project Consultants should ensure they prioritise mentoring sessions, which are hugely valued by Action Group members and sometimes slip. Action Groups and Project Consultants may also wish to discuss whether there are more opportunities for volunteers to receive recognition (for example by presenting certificates to recognise certain achievements or volunteering hours undertaken).

**The project often welcomes ideas being raised by staff and volunteers, and there are several examples of such ideas being implemented. However, several staff members with lived experience said that they did not always feel heard or valued.** Issues some people raised were: (i) not feeling praised for their work; (ii) not having their own needs or difficulties noticed by busy managers; and (iii) raising issues or ideas about how Fulfilling Lives could be improved but neither feeling heard, feeling these ideas were valued, or seeing changes in relation to these. It would be helpful for managers and team members to explore the reasons for this. Possible reasons suggested by this research are:

- Some project processes and structures may not be flexible enough to allow certain changes to be made quickly (if at all). People may be unclear about what changes can and cannot be made.
- People who present ideas or issues in less 'professional'/more emotional terms may be less heard than others. The literature on 'troublemakers' and

'rebels' at work might be useful to consider here. It identifies 'rebels' as people who are passionate about organisational purpose and motivated to create change, but risk getting into conflict and may not know how to navigate organisational politics. They can be mistaken for 'troublemakers', but can be distinguished from them; troublemakers complain, are pessimistic about the possibility of change, and tend to focus on their own position rather than organisational purpose. Given the right conditions and support, rebels can be important initiators and facilitators of systems change.<sup>3</sup>

- Praise and recognition for achievements can have a powerful positive impact on people, whereas perceived criticism can have a very negative impact on people. Perceived criticism can effect people's sense of self-worth, and of working towards a greater purpose through the project. Ensuring that people receive sufficient explicit recognition of achievements, encouragement and support is therefore important, including during meetings and discussions about performance.

**Fulfilling Lives South East has put useful processes in place to support staff members with lived experience, and continues to learn and adapt** in order to do so. Changes include creating an additional post to support service user engagement, and lengthening the term of the Project Consultant role.

**People gave some examples of power dynamics at work within the project.** One example was the power that Project Consultants (in particular full-time Project Consultants) hold as the facilitators of Action Groups. Distributing facilitation among full-time and part-time Project Consultants and Action Group members (with support and encouragement where necessary to do so) could help re-balance this. Another emerging issue was the perceived limited decision-making power of the Action Group in relation to System and Service Reviews (SSRs), with people describing decision-making power as resting with the Service Improvement Officer (SIO). It could be helpful for all project staff to learn about theories of power dynamics, and to engage in reflective practice around this.

**There are early examples of the employment pathway working well.** There are examples of volunteers successfully moving into Project Consultant roles. One volunteer and one Project Consultant have moved into other staff roles at Fulfilling Lives. This is important because it begins to blur the boundary between 'professionals' and 'service users' and embeds lived experience more widely within the project's delivery; it is not just contained within agreed groups or roles. Future research is needed to capture longer-term outcomes for Project Consultants after they move on from the project. Two former Project Consultants interviewed both described challenges in their new roles after Fulfilling Lives, which they said had been detrimental to their well-being (although they had successfully moved on from these initial roles to new, better jobs for them).

**Further research will help to share learning about employing people with lived experience of multiple and complex needs.** Fulfilling Lives South East is intending to conduct further research to capture learning for employers around policies, procedures, performance management and support. This will help to capture and

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<sup>3</sup> A useful blog about rebels and troublemakers in relation to systems change by Helen Bevan ('Rocking the boat and staying in it: how to succeed as a radical in healthcare') can be found here: <http://blogs.bmj.com/quality/2013/07/29/a-call-to-action-helen-bevans-blog/>. A diagram (by Tanmay Vora and informed by Rebelsatwork.com) describing the characteristics of a 'rebel' and setting out 'What rebels want from their boss' can be seen here: [gaspire.com/2017/05/19/sketchnote-what-rebels-want-from-their-boss/](http://gaspire.com/2017/05/19/sketchnote-what-rebels-want-from-their-boss/).

share the project's extensive learning around this and to identify recommendations for employers. It should also help to further refine the project's approach to this.

Questions to consider include:

- What are the challenges that people with lived experience face to accessing employment?
- How do organisations need to change in order to successfully employ people with lived experience of multiple and complex needs?
- What challenges do people with multiple and complex needs face whilst in employment?
- How can Fulfilling Lives South East develop tools to help the employer be as flexible and supportive as possible?
- To what extent should expectations of and support for people with lived experience be different from those of other staff members?
- What does recovery look like for the person? What are people's experiences around ongoing mental health needs and recovery from substance misuse?
- What can the individual and the employer do to mitigate against the risk of relapse?
- How can a balance be achieved between the needs of the employer and the individual?
- What happens when people with lived experience move into generic roles in which lived experience is not a requirement?
- Are specific roles for those with lived experience always necessary as a first step into employment?