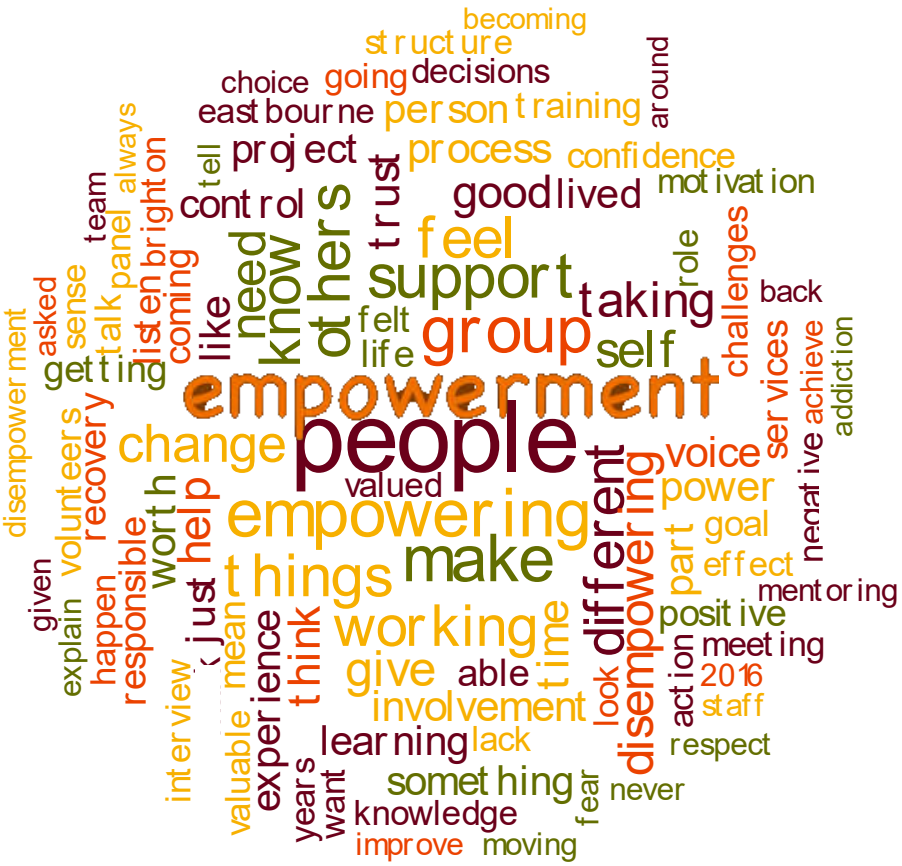
Empowerment for people with multiple and complex needs

What it means and how it can be measured

Written by Juliette Hough



Combating Homelessness
Creating Opportunities
Promoting Change

FULFILLING LIVES
South East Partnership

JH Research

Research conducted and report written by Juliette Hough

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With thanks to the Action Group volunteers, Project Consultants and other Fulfilling Lives staff who took part in this research, and special thanks to Kim Kelly for writing the Introduction.

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.

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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 all Brighton & Hove, Eastbourne and Hastings will better meet the needs of this group.

Introduction

By Kim Kelly

People with multiple and complex needs[1] can often feel 'disempowered'.

We can experience:

- Stigma from members of the public, professionals and ourselves.
- Lack of control over important decisions in our lives (like where we live).
- Low self-confidence, self-worth and hopelessness.

It is widely agreed that people with multiple and complex needs should be more 'empowered'. This is important, first of all, because everyone should have a fair chance to make decisions about the important things in their lives.

It is also important because, if people are able to have a say about the services available for us, these are more likely to help us. And that can benefit everyone, as, if we get the support we need, we can make a big contribution to society, which in itself is empowering. A feeling of empowerment will spread to other areas of a person's life, helping to develop a 'can do attitude', rather than feeling so overwhelmed that nothing is possible. This in turn can lead to less destructive behavior, stability and employment. Most people who have come through this experience are strongly motivated to 'give back' and help other people, and have many hidden talents and skills.

What does empowerment mean?

Although there is agreement that empowerment is important, there are not many definitions of what 'empowerment' means or feels like. So staff and volunteers with lived experience of multiple and complex needs at Fulfilling Lives South East have been working with a researcher to define what empowerment means.

20 people with current or recent lived experience of multiple and complex needs discussed what empowerment means to them, and what they said is in this report.

This research is important. I hope it will help more people to understand what empowerment means for people with multiple and complex needs, and help us create a more empowering system together.

Kim Kelly

Former Project Consultant, Fulfilling Lives

[1] People experiencing several of the following issues: homelessness, mental health problems, drug or alcohol problems and/or a history of offending.

Being disempowered and becoming empowered

Disempowerment and multiple and complex needs

Almost everyone involved in the research thought that people with multiple and complex needs are often 'disempowered'. People said:

- Stigma is a very common issue that can lead to social exclusion and can stop you getting the support you need.
- Often the support on offer doesn't take into account your needs, so doesn't work. It is difficult to engage with, it can be punitive, and it can set you up to fail.
- Drug and alcohol use can be a way of trying to take control when you have none.
- These things can lead to low self-worth and feeling that you can't control the important things in your life.

Becoming empowered

The 20 people who took part in the research were all involved in Fulfilling Lives South East, either as volunteers or members of staff. They described a process of becoming empowered, based on this experience. They said that:

- Empowerment starts small and develops in a positive spiral, slowly increasing over time.
- You might not know you're disempowered – realising that you are disempowered is an important first step.
- You might have set-backs. If you are asked your opinion and then not listened to, for example, this can make you feel less empowered than when you started.

People said that empowerment isn't always easy. It involves:

- Being willing to take positive risks – eg. turning up to your first meeting, speaking in a group, or taking on things that scare you.
- Being willing to be challenged and learn from your mistakes. This helps you build resilience.
- Facing your fears. Many people said they had feelings that they weren't good enough, or couldn't do what they were being asked to do – but they did it anyway.

People had found that being part of a supportive group is really important to help you while you're on this journey. People said it's possible to be empowered on your own, but it's much easier in a group.

As you become more empowered you start to notice bigger changes in yourself. People said they were more confident, more likely to give things a go, more willing to stand up and say what they think:

> *'Empowerment means self worth – you matter.'*
>
> *'I can express my opinion, and it's listened to and valued.'*
>
> *'I'm a different person now – I'm calmer, more diplomatic, more confident - I take empowerment with me (into all parts of my life).'*

Different types of control

Theory about empowerment says that there are two types of control:[1]

1. **Sense of control** – how far you believe you can influence change.
2. **Actual control** – the external conditions that make it possible for you to influence change.

To have control you need to have both of these: the belief that encourages you to try to make or influence positive changes, and the external conditions that help you to succeed in this. These types of control influence each other – if one increases the other is likely to increase; but if one decreases then the other is likely to decrease too.[2]

This suggests that, if you are someone with multiple and complex needs who wants to have control, you need:

1. To believe that it is possible for you to influence positive change.
2. External conditions – for example in the systems around you – that enable you to influence positive change. This might include what support services provide, having your skills and abilities recognized and having a chance to use them, and being listened to by people in decision-making positions.

What empowerment means for people with multiple and complex needs

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 the diagram below. Some of them relate to ‘sense of control’ and some to ‘actual control’.

What empowerment means for people with multiple and complex needs

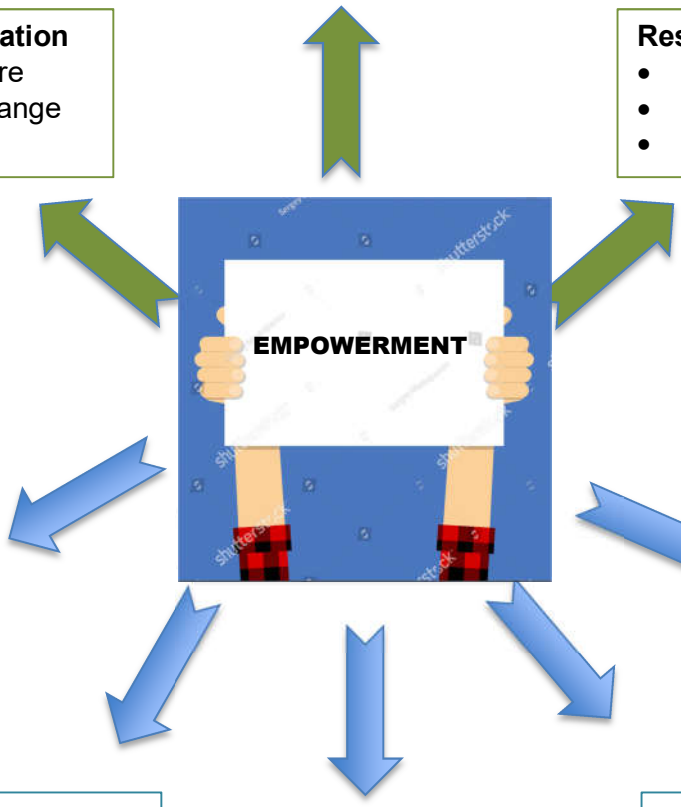
SENSE OF CONTROL

ACTUAL CONTROL

Confidence and self-worth
- Trusting and valuing yourself
- Taking positive risks

Optimism and aspiration
- Goals for the future
- Belief you can change things

Resilience and responsibility
- Learning from mistakes
- Dealing with challenges
- Accepting responsibility



Purpose
- Common goals
- Structure and a clear role
- Making a difference
- Helping others

Tools to make positive change
- Learning & developing skills
- Understanding how you can influence change
- Self-knowledge

Supportive relationships
- Being part of a supportive group
- A safe place to test yourself, make mistakes and be challenged
- Learning from others

Being heard and valued
- Having a voice and being heard
- Being valued
- Not being stigmatized
- Social inclusion and equality

Money and resources
- Having enough money to have choices, independence, security and variety.
- Earning your own money or getting the benefits you're entitled to.

An empowering system

Fulfilling Lives is based on the belief that, for people with multiple and complex needs to be empowered, the systems that disempower them need to change. Several theorists have pointed out the importance of taking a systems approach to empowerment, not just focusing on how the individual should change:

> 'by adopting a cognitive/individual approach the individual may be able to feel empowered, but actual empowerment, in terms of economic and political power, does not occur.'[3]

Those spoken to for this research said that an empowering system includes the following important elements:

- 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.
- A person-centred, asset-based approach to support is the norm.

How Fulfilling Lives South East aims to help empower people

Fulfilling Lives South East 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 describes how Fulfilling Lives South East hopes to help create this change. This is based on the discussions with 20 Fulfilling Lives staff members and volunteers with lived experience, as well as interviews with senior Fulfilling Lives staff members.

Fulfilling Lives 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 providing statutory and voluntary services, commissioners and policymakers. They play a vital role in:

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

Fulfilling Lives activities: The project is working to:

- **Create a pathway to employment**, supporting volunteers to move into paid work on the project, and employees to move into further external employment.
- **Exemplify good practice in service user involvement and employment**. By employing at least 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, building evidence about what works, and capturing and sharing its learning.
- **Engage and influence** others in the system to adopt more empowering approaches and processes.

A theory of empowerment for Fulfilling Lives South East

Empowered people

Heard and valued

Supportive relationships

Tools to make positive change

Purpose

Money and resources

Confidence and self-worth

Resilience and responsibility

Optimism and aspiration

An empowering system

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.

Fulfilling Lives partners

Championing, innovating, testing, spreading

Changing policy and practice

Changing cultures, attitudes and understanding

Fulfilling Lives project

A pathway to employment

Paid and volunteer roles, support, training

Exemplifying good practice in service user involvement and employment

Demonstrating effectiveness, learning and sharing

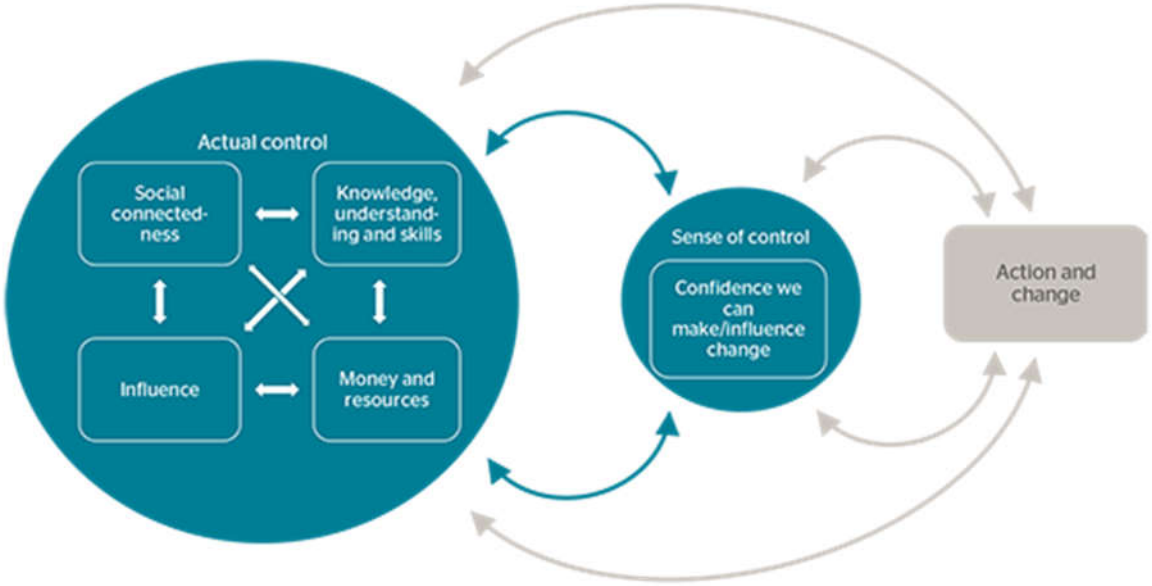
Engaging and influencing

Building relationships, raising the agenda

A model of collective control for people with multiple and complex needs

This research has drawn on the dynamic model of collective control developed by the New Economics Foundation for People's Health Trust.[4]

Figure (a): A dynamic model of collective control

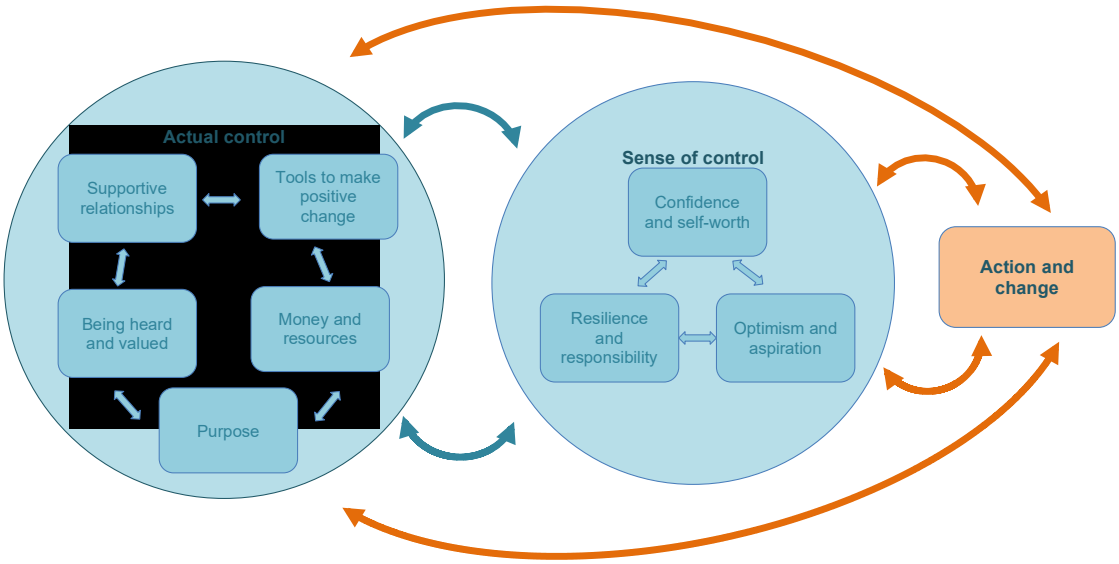


Source: New Economics Foundation and People's Health Trust

This demonstrates the ways in which actual control and a sense of control influence each other. It suggests that, in order to have real and lasting control, action and change must take place. For Fulfilling Lives, this means that people with lived experience must be able to see that their ideas are being listened to and their actions are making a difference.

The elements of control identified by people with multiple and complex needs presented in this report closely align with the New Economics Foundation's model of collective control, but with a different emphasis that may reflect the unique experiences of people with multiple and complex needs. The model can be modified to create a model of collective control for people experiencing multiple and complex needs (see figure (b)).

Figure (b): A dynamic model of collective control for people with multiple and complex needs



Empowerment, power dynamics and systems change

The concept of power dynamics is central to empowerment. Systems change theory often emphasises power relationships as important parts of the system.[5] This is particularly pertinent for the Fulfilling Lives programme, whose ultimate aim is to change systems.

The idea that people can be 'empowered' by others raises issues about power dynamics. These include who is included in empowerment interventions and who is not.[6]

Many systems change theorists suggest that power mapping is an essential part of understanding the system, and point out that the vested interests of those in positions of power can be obstacles to systems change:

> *'It's important to remember that all innovation by its nature disturbs the balance of a system. Even minor changes can ruffle feathers and challenge vested interests. Often, what is described as systems change is in fact simply an improvement in the links between actors within the system […] it doesn't change relationships or shift the balance of power'.*[7]

It is important that an evaluation of an empowerment initiative takes account of power dynamics, the role these play in helping or hindering systems change, and the extent to which they have been changed.

How empowerment can be measured

This research was conducted to help inform the evaluation of the Fulfillling Lives South East project. This evaluation aims to understand:

- How far the project is helping to people with lived experience of multiple and complex needs to become more empowered.
- What type of empowerment is being experienced.
- What is helping people to become empowered.
- What is making it difficult for people to become empowered.
- What systemic changes are taking place that enable empowerment, and what further changes need to take place.
- What are the wider benefits of this empowerment, to individuals, other people and the system.

The evaluation will use the eight elements of empowerment and the four elements of an empowering system identified by this research as guides for assessing change. We will also be testing and refining these elements of empowerment as our understanding grows. Over the remaining five years of the project, we will be regularly:

- Conducting in-depth interviews with people with lived experience of multiple and complex needs who are involved in or employed by Fulfilling Lives South East.
- Conducting in-depth interviews with people with lived experience of multiple and complex needs who were formerly involved in or employed by Fulfilling Lives South East to capture their reflections after they have moved on from the project and identify longer-term outcomes for them.
- Tracking employment outcomes and other longer-term outcomes for Project Consultants previously employed by the project, via monitoring data, an exit interview and a regular survey after they have moved on.
- Conducting interviews with decision-makers in the wider system, including commissioners and service providers, to understand the extent to which their practice has been informed by the project.
- Conducting interviews with Fulfilling Lives South East managers to capture their learning.

Fulfilling Lives South East will be publishing its learning about empowerment as it progresses. Reports will be published on the Fulfilling Lives South East website.

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[1] Skinner, E. (1996). 'A Guide to Constructs of Control', *Journal of Personality and Social Psychology.* 1996, Vol. 7 I. No. 3., p.549.
[2] New Economics Foundation and People's Health Trust (2016): *Local Conversations 2016: An Introduction*.
[3] Jacob, F. (2013) 'Empowerment a Critique', in *British Journal of Community Health Nursing*, vol. 1, issue 8.
[4] New Economics Foundation and People's Health Trust (2016): *Local Conversations 2016: An Introduction*.
[5] See for example Draper, S. (n.d) *Creating the big shift: System innovation for sustainability.* Forum for the Future. http://www.forumforthefuture.org/thebigshift, and http://www.donellameadows.org/archives/leverage-points-places-to-intervene-in-a-system/
[6] Midgley, G. (2000) Systemic Intervention: Philosophy, Methodology and Practice, Klumer Acadmic. Cited in Burns, D. (2007) *Systemic Action Research: A strategy for whole system change*. Policy Press.
[7] Nesta (n.d) *Open Workshop: An introduction to systems change*, op. cit.

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