Improving access to mental health support for people experiencing multiple disadvantage

Evaluation of Fulfilling Lives:
Supporting people with multiple needs

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CFE Research and The University of Sheffield,
with the Systems Change Action Network

COMMUNITY FUND

Contents

Summary

Fulfilling Lives is a National Lottery Community Fund supported programme helping people with experience of multiple disadvantage to access more joined-up services tailored to their needs. This is a summary of a more detailed report on access to mental health services, which brings together independent evaluation findings with insights and recommendations from the Systems Change Action Network (SCAN). SCAN comprises the programme leads from each of the Fulfilling Lives partnerships.

Key messages

Mental health and multiple disadvantage

Mental ill-health is both a cause and a consequence of multiple disadvantage. Almost all (93 per cent, n = 3,152) of Fulfilling Lives beneficiaries experience mental health problems. Evidence from the national and local evaluations indicates that **getting help with mental health, and in particular counselling and psychological therapies, is linked to people making better progress.** But very few people receive this kind of help. All 12 Fulfilling Lives partnerships report difficulties in accessing appropriate mental health support and have collectively identified this as a strategic priority for systemic change.

90 per cent of beneficiaries with a mental health problem also have a substance misuse need.

Navigating the system

The system of mental health services, agencies, professionals and referral routes can be complex to find your way through. For people affected by multiple disadvantage this is magnified due to the sheer number and variety of different services they need to connect with. **Fulfilling Lives navigators play an important role in advocating for beneficiaries.** In order to do this effectively, navigators need to be equipped with up to date knowledge of legal rights and entitlements and referral pathways and procedures. They also need the time, skills and confidence to be patient and persistent. Access can be reliant on personal relationships with professionals and the attitudes of individual staff members. Fulfilling Lives partnerships have helped to formalise this by providing opportunities for professionals from a variety of sectors and disciplines to come together to enhance understanding of multiple disadvantage, different roles and how they can work more collaboratively.

Getting appropriate support

The hard work of partnerships has resulted in some successes in getting beneficiaries treatment and support services. However, a navigator can only take you so far. People experiencing multiple disadvantage are often denied access to primary care and the assessments required for a diagnosis and

treatment. 90 per cent of beneficiaries with mental health problems also have a substance misuse need. Despite national best practice guidance to the contrary, people are frequently required to address substance misuse before they can access mental health treatment. People experiencing multiple needs are often considered by mainstream services as too complex, too chaotic, too high risk to support and unlikely to benefit from treatment available. However, several of the Fulfilling Lives partnerships have commissioned bespoke mental health support services that demonstrate that this group can be engaged and effectively supported.

What makes a difference

Evidence from Fulfilling Lives suggests that the key is **providing treatment in a way that is flexible and person-centred**, taking time to build trust between therapist and beneficiary, delivering services where beneficiaries are comfortable and acknowledging and allowing for the other factors (such as homelessness, poor physical health, addiction, poverty etc.) that affect people's ability to engage with treatment. **Approaches that are psychologically- and trauma-informed,**[1] and which take into account people's past experience, provide useful frameworks for working with this group. Help with mental health also needs to be provided alongside support to address other issues, such as accessing correct benefit entitlements and securing appropriate accommodation.

Psychologically- and trauma-informed approaches are important.

A different way of working

By paying for bespoke, specialist services, Fulfilling Lives shows what can be achieved, but this approach is essentially by-passing the statutory mental health system. What is needed is to incorporate the learning from the programme at all levels so that statutory mental health services effectively provide for this group of people. Involving people with lived experience from the start in strategy development and service redesign should ensure that services are built with their needs in mind. **Educating the wide range of professionals whose work affects people experiencing multiple disadvantage** is important in developing understanding of why people behave the way they do and how best to support them. Co-producing training and awareness raising activities with people with lived experience

Support that is more flexible, specialised and targeted is often needed to meet the needs of people affected by multiple disadvantage

of multiple disadvantage ensures their authentic voice is heard. Personal testimony can be powerful in creating understanding and empathy. Fulfilling Lives partnerships provide a wealth of experience in how to involve people with lived experience in a meaningful way.

For people with experience of multiple disadvantage, getting appropriate help with mental health is challenging, but Fulfilling Lives partnerships have demonstrated that it is possible. The full report shows how they have done this, the impact of their work, what they have learned and the challenges that remain, which require further action at national and local level.

Recommendations

Based on the findings of this report the Systems Change Action Network (SCAN – a group representing the programme leads from each of the Fulfilling Lives partnerships) offers the following recommendations to national and local decision makers in order to improve mental health provision for people experiencing multiple disadvantage. These recommendations are the collective view of the SCAN members and not of CFE Research, The University of Sheffield or the National Lottery Community Fund.

Difficulty in accessing mental health support

The report identifies barriers around primary healthcare registration, the complexity of the mental health system, unsuitable assessments, the exclusion of people with co-occurring needs and a lack of understanding from staff leading to stigma and discrimination.

SCAN makes the following priority recommendations:

1. **The Department of Health and Social Care and its associated agencies, in particular Health Education England, should lead a national programme of work to embed the principles of psychologically- and trauma-informed care in mental health assessment processes.**

There should be a national programme of work to inform the mental health workforce about psychologically- and trauma-informed care and embed a trauma-informed approach into assessment processes. This would enable better assessment and help individuals to engage with the mental health support they need. The workforce require sufficient support, supervision, training and space for reflection in order to be able to deliver psychologically- and trauma-informed care.

2. **The Department of Health and Social Care, NHS England, Public Health England and the Care Quality Commission should ensure that national guidance on co-occurring mental ill-health and substance misuse is followed locally.**

Staff at all levels of the mental health system should be supported and challenged to ensure assessment and the provision of services for people with co-occurring issues, in line with the national guidance from NICE and Public Health England. Good practice in Fulfilling Lives and other areas has demonstrated that mental health support can be provided to individuals facing co-occurring issues and that it can be effective. The Care Quality Commission should investigate when guidance is not being followed.

3. **Local commissioners, statutory bodies and voluntary sector support providers should work collaboratively, taking a whole systems approach to addressing multiple disadvantage.**

Local authority and health commissioners, statutory agencies and voluntary sector support providers should work together to improve access to mental health support for people affected by multiple disadvantage. It is essential that representatives of mental health services are involved in partnership approaches to addressing multiple disadvantage. Sustainability and Transformation Partnerships and Integrated Care Systems will have an important role to play. A systems-thinking approach is needed to consider how decisions and changes in one part of the system may affect outcomes in another. Referral and care pathways, which often involve multiple organisations, need to be easier to navigate with varied points of access. This could be achieved through the use of common assessment and monitoring tools, which can reduce the number of times that people explain why they are seeking to access services and provide a fuller picture for service providers.

Unsuitable mental health support

The report identifies barriers around services struggling to deal with complex issues and behaviours, traditional 'appointment' models of healthcare excluding people and services that are not provided in a gender-informed way.

SCAN makes the following priority recommendations:

4. **Commissioners and support providers should ensure that mental health support is suitable for people affected by multiple disadvantage. National commissioning guidelines on mental health services should support the development of flexible and specialised services.**

Support that is more flexible, specialised and targeted is often needed to meet the needs of people affected by multiple disadvantage. This includes appropriate pathways that are gender and culturally informed. The need for pre-treatment/stabilisation support and the role of peer support programmes should be considered. The use of personal budgets could be explored for people experiencing multiple disadvantage to co-produce their journeys through the mental health system. Clinical intervention may not always be required and community-based services may be more appropriate.

Government should develop national commissioning guidelines that make the case for these interventions and support local commissioners to put services in place. These guidelines should encourage trauma-informed approaches and psychologically-informed environments in all services.

A mental health system that is not designed or resourced to meet the needs of people experiencing multiple disadvantage

The report identifies barriers around local mental health strategies not reflecting the needs of people experiencing multiple disadvantage, people not being consulted about the design and delivery of services, the commissioning cycle inhibiting innovation, a lack of specialist services and a gap between service thresholds.

SCAN makes the following priority recommendations:

5. **Joint Strategic Needs Assessments should include analysis of individuals experiencing multiple disadvantage.**

Joint Strategic Needs Assessments should take a wider view of social determinants of health in order to improve Joint Health and Wellbeing Strategies. National guidance should be refreshed to support Health and Wellbeing Boards to develop health and wellbeing metrics for people experiencing multiple disadvantage. This would help encourage the commissioning of health services that are suitable to the needs and circumstance of these individuals.

6. **Commissioners and support providers should ensure that people with experience of multiple disadvantage are involved in designing all aspects of mental health strategy, policy and services, as well as monitoring success. Government guidance should promote this approach.**

Local Integrated Care System (ICS) plans and mental health strategies should be co-produced with people experiencing multiple disadvantage. Plans should reflect the specific needs of these individuals and ensure the provision of a range of support that meets their needs. The strategies should address the identified issues around eligibility thresholds and the provision of specialist services.

Local commissioning should ensure that people experiencing multiple disadvantage are involved in the design, delivery and evaluation of services, involving them at all stages of the commissioning cycle. Government guidance to commissioners should promote this approach.

Fulfilling Lives has shown how people affected by multiple disadvantage can be supported

Endnotes

1. Psychologically informed environments are "services that are designed and delivered in a way that takes into account the emotional and psychological needs of the individuals using them." (Homeless Link (2017) *An introduction to Psychologically Informed Environments and Trauma Informed Care* https://www.homeless.org.uk/sites/default/files/site-attachments/TIC%20PIE%20briefing%20March%202017_0.pdf). Trauma-informed approaches can be defined as "a system development model that is grounded in and directed by a complete understanding of how trauma exposure affects service user's neurological, biological, psychological and social development" (Paterson, 2014 cited in Sweeney, A. Clement, C. Filson, B. and Kennedy, A (2016) Trauma-informed mental healthcare in the UK: what is it and how can we further its development? *Mental Health Review Journal* vol. 21, 3, pp. 174–192 http://dx.doi.org/10.1108/MHRJ-01-2015-0006)

Full Report

About Fulfilling Lives

The National Lottery Community Fund has invested £112 million over 8 years in local partnerships in 12 areas across England, helping people with experience of multiple disadvantage access more joined-up services tailored to their needs. The programme aims to change lives, change systems and involve beneficiaries.

The Fulfilling Lives partnerships[1] provide intensive support to help people experiencing multiple disadvantage navigate their way through local services. They are also committed to changing the wider system that affects people on a daily basis. To develop an understanding of what works and what does not, areas are trialling new ideas and initiatives and working with local stakeholders, including those with lived experience of multiple disadvantage, to create long-term and sustainable change.

About this report

This paper is the first in a series of themed reports from the Fulfilling Lives programme. It brings together independent evaluation findings with insights from a series of in-depth conversations with the Systems Change Action Network (SCAN) – a group representing the programme leads from each of the Fulfilling Lives partnerships.[2] See Appendix 2 for further information on the evaluation methods. The report considers the barriers to getting help with mental health faced by people experiencing multiple disadvantage, examines the response of the Fulfilling Lives partnerships and presents evidence and learning from five in-depth case studies. The Fulfilling Lives partnerships present their recommendations for how change can be achieved at the end of the report.

Almost all of Fulfilling Lives beneficiaries experience mental health problems

Mental health and multiple disadvantage

There is a strong association between complex trauma and multiple disadvantage.

The Fulfilling Lives programme defines multiple disadvantage as experience of two or more of homelessness, offending, substance misuse and mental ill-health. Mental ill-health is both a cause and a consequence of multiple disadvantage. Almost all (93 per cent, n = 3,152) of Fulfilling Lives beneficiaries experience mental health problems. These can range from common mental health problems, such as depression and anxiety, to severe mental illness, such as psychosis. 90 per cent of Fulfilling Lives beneficiaries experience both mental ill-health and substance misuse and a high proportion are also affected by other types of disadvantage, including other long-term health conditions and disabilities, poor literacy and domestic abuse.[3] In particular, there is a very strong association between experience of complex trauma and multiple disadvantage.[4] While mental health problems are prevalent across the population as a whole, this report is concerned with the particular needs of, and challenges faced by, those who are also experiencing other severe forms of social exclusion and disadvantage. Combined, these issues result in extreme inequality,[5] avoidable use of crisis services and serious social, economic and human costs.[6]

Evidence from the national and local evaluations indicates that getting help with mental health, and in particular counselling and psychological therapies, are linked to people making better progress. Beneficiaries who get support in the form of counselling and/or psychological therapies over their first 15 months with the programme are more likely to also experience improvements in their wellbeing and self-reliance and a reduction in need and risk over the same period.[7]

However, very few beneficiaries receive this type of help. As reported in our recent briefing series, only 17 per cent of beneficiaries received counselling or therapy within their first three months on the programme.[8]

Policy and service context

Mental health services remain under acute pressure, both financially and in terms of demand, but there is also renewed political interest in these services and the contribution they make to improving people's lives. There is also an increasing focus on better meeting the needs of people experiencing multiple disadvantage.

The Five Year Forward View for Mental Health,[9] published in 2016, sets out priority actions for transforming mental health care delivered through the NHS by 2020/21. The report acknowledges that needs are addressed in isolation, if at all, that referral pathways have become more complex and people with mental health and substance misuse problems do not receive planned, holistic care. The report also emphasises the importance of co-producing commissioning and service design with experts-by-experience. The more recent 2019 NHS Long Term Plan[10] provides a vision for an NHS that is more joined-up and coordinated, but also offers more individualised provision.

Most people receive mental health support through primary care.[11] The Improving Access to Psychological Therapies (IAPT) programme,[12] launched in 2008, provides access to evidence-based talking therapies to address common mental health conditions. The NHS Long Term Plan sets out plans to expand the programme to another 380,000 adults by 2023/24. However, as we explore further in this report, Fulfilling Lives partnerships have not found IAPT as currently delivered to be accessible to people experiencing multiple disadvantage.

Co-occurring mental ill-health and substance misuse is a particular issue for people experiencing multiple disadvantage. The majority of people in community substance misuse treatment also have mental health problems. Guidance from Public Health England on commissioning services for people with co-occurring conditions[13] is based on the principles that mental health and substance misuse services have a joint responsibility to meet the needs of individuals, and providers should have an open door policy and make every contact count. Latest IAPT guidance states that drug and alcohol misuse are not automatic exclusion criteria for the service, and highlights the need for drug, alcohol and mental health services to work together to ensure access to more specialist services if required.[14] NICE guidance on people with coexisting severe mental illness and substance misuse[15] recommends that people should not be excluded from secondary care mental health services and that

a person-centred approach should be adopted to reduce stigma and address inequity in access. A care coordinator working in mental health services should be provided and they should work with other services to address the person's social care, housing, physical and other support needs. NICE does not recommend the creation of specialist dual diagnosis teams. The PHE guidance[16] instead suggests that the prevalence of co-existing conditions is such that it is vital that **all** services are equipped to respond to these needs.

What are the barriers to getting mental health support for people experiencing multiple disadvantage?

Our research identified a series of barriers to getting mental health support for people with experience of multiple disadvantage. These barriers are numerous, extensive and interlinked. They can be grouped into three main challenges:

- Difficulty in accessing mental health support
- Unsuitable mental health support
- A mental health system that is not designed or resourced to meet the needs of people experiencing multiple disadvantage

Challenge: Difficulty accessing mental health support

Primary health care registration is being refused in some locations. Access to secondary mental health care is generally through GP referral. The Standard Operating Principles for Patient Registration from NHS England make it clear that homeless people should not have to provide ID/proof of address in order to access primary care through a GP. Research carried out in Stoke on Trent[17] found approximately 75 per cent of GP practices are not following this guidance, meaning that homeless people face limited choices in how and where to seek help with mental ill-health.

The mental health system is complex and difficult to navigate – for people experiencing multiple disadvantage and those who support them. Where support is available it is not always well known. Fulfilling Lives staff spend significant time learning the various referral pathways and services available in their local area. Staff report frustration in struggling to identify the 'right' mental health professional to speak to about a case and referrals are often refused as inappropriate.

Mental health assessments can be unsuitable for people experiencing multiple disadvantage. Many people will struggle to attend appointments in clinical settings or to wait for long periods. A lack of suitable assessment can lead to a lack of diagnosis, which in turn can lead to exclusion from the mental health support that people need.

90 per cent of beneficiaries experience both mental ill-health and substance misuse.

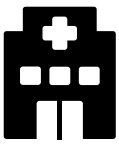
Co-occurring mental ill-health and substance misuse excludes people from getting an assessment. Substance misuse and mental ill-health are the most commonly experienced needs for beneficiaries on the Fulfilling Lives programme and there is a high degree of overlap between the two, with 90 per cent of beneficiaries experiencing both.[18] Fulfilling Lives partnerships report that the vast majority of clinical responses require an individual to address their substance misuse before mental health treatment can be provided or even a needs assessment carried out. This is despite guidance to the contrary from NICE and PHE (see pages 19–20). This leaves many beneficiaries in a 'catch 22' situation where they are unable to get support for their mental health needs because they are using substances to self-medicate symptoms of poor mental health.

A lack of understanding of multiple disadvantage can result in stigma and discrimination. A lack of understanding of how trauma can affect behaviour can result in services being unsympathetic and judgemental. Fulfilling Lives partnerships gave examples of people experiencing multiple disadvantage being refused assessments as symptoms of trauma, such as drug-use, behavioural problems or staying in violent or abusive relationships, are assumed to be 'lifestyle choices'. The difficulties beneficiaries face in accessing a system not designed to accommodate their needs results in services perceiving them as 'untreatable' and 'difficult'.

Challenge: Unsuitable mental health support

Services struggle to deal with complex issues and behaviours. Perceptions of risk can lead to services that are already stretched being unwilling to work with people with the most chaotic lifestyles. Mental health treatment is regularly withdrawn from individuals who present with challenging behaviour, or simply fail to attend. There is no incentive for services to attempt to keep people within treatment settings and non-attendance at appointments is difficult to chase up with people facing multiple disadvantage.

Traditional models of delivery exclude people experiencing multiple disadvantage. The traditional 'appointment' model of healthcare does not work for people facing multiple disadvantage. People are required to remember appointments, attend at times that do not take into account their needs and often have to wait for long periods between assessment and treatment. Communication methods, including mailing out appointments and telephone calls, are unsuitable for many. Appointments take place in institutional and clinical settings that are unwelcoming and feel daunting to beneficiaries; there appears to be a lack of community-based or outreach services that might be more appropriate. Beneficiaries may be ill-prepared for what to expect – anticipating that revisiting trauma will make things much worse or that accessing treatment will provide a 'magic' rapid cure.[19] Negative past experiences and repeated failure to provide appropriate care create a lack of trust in the healthcare system. Long waits for assessment or treatment can lead to disengagement. Failure to attend an appointment can often lead to re-referral being needed, placing the individual back at the beginning of the journey.



Negative past experiences can create a lack of trust in the healthcare system.

Mental health services are not set up in a gender-sensitive way for people experiencing multiple disadvantage. Women and men experience multiple disadvantage in a very different way. Women experiencing multiple disadvantage tend to have higher levels of self-harm and an increased risk from others, including a high prevalence of domestic abuse and violence.[20] The National Commission on Domestic and Sexual Violence and Multiple Disadvantage[21] found that the services women experiencing multiple disadvantage come into contact with often do not have the required skills or capacity to support them and that many mental health practitioners are not routinely enquiring about women's experiences of domestic and sexual abuse, despite the significant overlap between the two. There are still

instances of mixed-sex mental health wards, which presents a risk factor for sexual safety, especially for women.[22]

Challenge: A mental health system that is not designed or resourced to meet the needs of people experiencing multiple disadvantage

Lack of appropriate services puts greater demand on other parts of the system.

Local mental health strategies are not built around the needs of people experiencing multiple disadvantage. The nature and complexity of clinical and non-clinical issues that affect people experiencing multiple disadvantage effectively result in a lack of service for many of them. The strategic vision around mental health often misses the needs of people experiencing multiple disadvantage. This in turn leads to commissioned services and outcomes that are not focused on their needs.

People with lived experience are not consulted in the design of services. In many Fulfilling Lives areas, mental health services are commissioned without real input from people with lived experience of multiple disadvantage, and the services that are then commissioned often do not fully take account their needs. Clinical expertise is vital to ensure high quality medical care but this needs to be coupled with the insight from people who are likely to use a service, or be most in need of it.

The commissioning process can inhibit innovation in mental health practice. The commissioning cycle elicits behaviours that are often risk-averse and do not seek to share responsibility for beneficiaries across the system. Commissioning cycles are often too short to evaluate the real impact of a service. Fulfilling Lives partnerships report mental health services unable to engage with people experiencing multiple disadvantage because "we are not commissioned to do that", even if it is clear that greater flexibility in the provision of treatment may likely achieve better outcomes for a beneficiary.

Lack of specialist services. Partnerships spoke of dwindling numbers of, and in some areas, a complete lack of, specialist commissioned services that can effectively respond to the needs of people facing multiple disadvantage. This puts greater demand on services which already struggle to meet the needs of people experiencing multiple disadvantage.

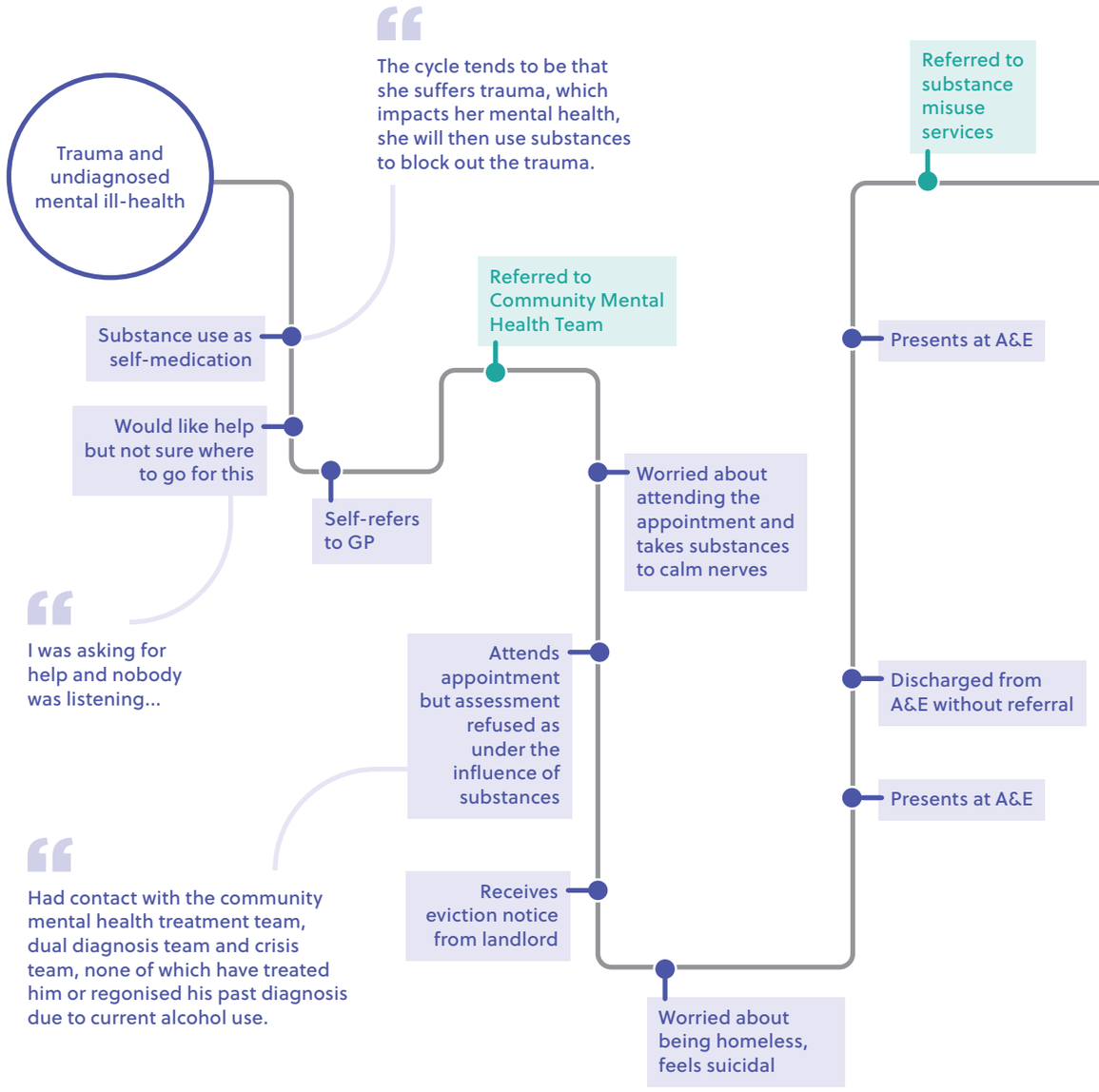
Gap between service thresholds. Many Fulfilling Lives beneficiaries are reported to be caught between gaps in the current structure of local mental health services. They are generally considered too complex for primary services (such as IAPT – Improving Access to Psychological Therapy) but are also often below the eligibility threshold for more specialist secondary care. Constrained resources and increasing demand has led to increasingly high thresholds for this type of care. Sometimes situations need to escalate to a crisis before people can access support, or they will seek help through less appropriate channels, such as visiting A&E.

Journey map 1: Barriers to getting help

The journey map illustrates how some of the common barriers combine to thwart people's efforts to get help with mental health problems, creating unnecessary demand on other services. The journey maps have been created based on real life examples from across all of the Fulfilling Lives partnerships. Significant time can elapse between steps in the journey and we know many people's experiences are circular rather than linear, as they find themselves trapped in a cycle of crisis and unhelpful service response. See appendix 2 for further detail on how the journey maps were created.

Key

- Barrier or negative experience
- Support or positive experience



> Talking to other professionals and saying, 'look, we may not have the solutions, and it's not like one service against each other, let's come together and work collaboratively.' So, there's a cultural shift, particularly people working with us as a project, and there's a trust now from other services.

How have Fulfilling Lives partnerships responded to these challenges?

The accompanying case studies explore in detail just some of the ways Fulfilling Lives partnerships have addressed the barriers described above. A number of common themes and approaches are evident across the partnerships. These are summarised below under the same three headings used to categorise the barriers.

Response to difficulty accessing mental health support – help beneficiaries navigate the system and advocate on their behalf

Fulfilling Lives partnerships have pushed at the boundaries of the system to overcome barriers and get beneficiaries into services. This has often been through the use of **navigators.** Navigators play an important role in advocating on behalf of beneficiaries, and standing up for their rights when required. This can be through challenging decisions made by statutory services, persevering with a service and advocating if they feel that a refusal or denial by a service is contrary to policy or legislation. Navigators have built positive working relationships with some service providers and helped enhance understanding of the needs of people affected by multiple disadvantage. Partnerships have made the case for more joint working as a better way to support people.

In order to advocate effectively, navigators need **up-to-date knowledge of legal rights and entitlements** and referral pathways and procedures. They need to be able to understand the range of services available and how to make an appropriate referral. Tools and training developed by Fulfilling Lives partnerships, such as VOICES' Care Act Toolkit (see case study 1) help to equip them with the necessary expertise and confidence. Navigators also need the time to be patient and persistent – smaller caseloads are part of this.

Navigators play a vital role in supporting beneficiaries.

Navigators also have a vital role in **supporting beneficiaries by preparing and accompanying them to appointments and assessments**, for example going through the types of questions that might be asked, so beneficiaries are less anxious and more likely to attend. **Peer mentors can also be a valuable source of additional support**, able to build relationships through common experiences.[23]

Our research has found that negotiating access is too often reliant on personal relationships between professionals and the attitudes of individual staff members at different organisations. Fulfilling Lives partnerships have helped to enhance and formalise these relationships by providing opportunities for professionals from a variety of sectors and disciplines to come together to **enhance understanding of different professions and services and how they can work more collaboratively.** Partnership initiatives including communities of practice, multi-agency training sessions and co-location of mental health professionals within Fulfilling Lives teams, are all reported to have led to improved relationships and greater understanding of different services, what they do and how best to access them. The Respond training taking place in the North East that Experts by Experience from Fulfilling Lives Newcastle and Gateshead have been instrumental in designing and delivering is just one example (see case study 2).

A number of partnerships have developed common assessment tools and other **mechanisms for sharing information** about people across services, including mental health, housing and the criminal justice system. For example, Inspiring Change Manchester's GM-Think system is now used by over 20 agencies to share information quickly and safely.[24] This can help coordinate support through better communication between agencies and reduce the need for people to tell their story multiple times.

The hard work of partnerships has resulted in some successes in getting treatment and support services for beneficiaries. But this type of approach only takes you so far. Once needs are recognised and referrals accepted, services may not always be appropriate or even available.

Response to unsuitable mental health support – model what effective support looks like

Several of the Fulfilling Lives partnerships have created in-house, bespoke mental health services. Pilot projects, such as those run by Opportunity Nottingham (case study 3) and West Yorkshire-Finding Independence (case study 4), demonstrate that, when designed appropriately, clinical services can engage and effectively support people experiencing multiple disadvantage. Beneficiaries have received vital psychological support to help them manage mental health conditions and past trauma, allowing them to stabilise their behaviours and cope better day-to-day.

Partnerships described how psychological support can also provide a stepping stone into mainstream mental health services, for example by helping people to meet sobriety requirements or being better prepared to take part in group work. Some partnerships have provided 'pre-treatment'[25] support to help beneficiaries better manage behaviour and relationships, preparing them to engage appropriately with therapy and other professionals.[26] For example, the Fulfilling Lives South East Partnership provided therapeutic support to people who would normally be considered 'not ready'. The pilot was successful in facilitating access to other specialist therapy, although notably this was generally provided privately and not through statutory services, which remained largely inaccessible and inappropriate.[27]

> **The widespread view in a lot of services is someone's just being a pain in the arse, or they're being resistant. Psychological theory can help you to think about why they won't do the most obvious thing, what the barriers might be, why someone might keep going around the same kinds of patterns or cycles.**

The key to successfully supporting people experiencing multiple disadvantage is **providing treatments in a way that is flexible and person-centred.** Our case studies indicate that taking time to build trust between therapist and beneficiary is an important pre-cursor to treatment. **Embedding therapists within trusted navigator teams** has been an effective way of achieving this. It has also facilitated knowledge exchange between staff. The beneficiaries we spoke to were clear that they wanted to get support in settings where they felt relaxed and comfortable and found co-located services convenient. Fulfilling Lives therapists have reached out and worked with beneficiaries in their homes, in cafes and parks as well as from Fulfilling Lives premises. **Appointments were designed with people facing multiple disadvantage in mind.** They were longer than the usual hour and allowances made for people turning up late or missing

appointments. Afternoon appointments generally appear to work best. The evidence we gathered suggests that this flexibility pays off over time with better engagement with beneficiaries.

Some mental health professionals may not be comfortable taking this approach. Partnerships have sometimes struggled to recruit and retain appropriate staff. As well as having experience of working with people who may also be homeless or misusing substances, **therapists need to be suitably proactive and confident to work flexibly and try new things.**

Psychologically- and trauma-informed approaches[28] that take into account a person's past history provide useful frameworks for working with this group and have been widely used across Fulfilling Lives partnerships. Enabling professionals, within and beyond Fulfilling Lives, to understand why someone may be behaving a particular way has helped to improve empathy and create more appropriate responses.

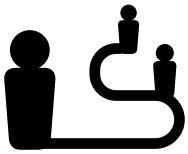
Psychologically- and trauma-informed approaches are important.

Importantly, **help with mental ill-health needs to be provided alongside support to address other issues**, such as accessing correct benefit entitlements and securing appropriate accommodation.

A few partnerships have commissioned expert needs assessments for individual beneficiaries. We came across numerous examples where this had helped people to unlock access to appropriate care. More strategically, partnerships also report that the evidence from these needs assessments is helping to demonstrate unmet need and make the case for gaps in commissioning and service responses.

The in-house services piloted by Fulfilling Lives demonstrate that people experiencing multiple disadvantage are not 'untreatable' or 'too difficult' to help. However, these approaches are essentially by-passing the mainstream statutory system rather than changing it. Some stakeholders questioned the ethics of buying assessments and support for people that others are unable to get. The substantial investment of Fulfilling Lives is unlikely to be repeated, so it is essential that the learning from the programme informs future commissioning of services so that it is no longer necessary to side-step the system in this way.

Response to a mental health system that is not designed or resourced to meet needs of people experiencing multiple disadvantage – involve people with lived experience to co-produce strategy



People with lived experience should be involved throughout the process.

Ultimately, the mental health system and relevant statutory and other services need to work differently to engage people with experience of multiple disadvantage to ensure that they can access the support that they desperately need. All Fulfilling Lives partnerships are working towards this but it is a long and continually challenging process.

Involving people with lived experience of multiple disadvantage from the start in mental health strategy development and service redesign should ensure that services are built with their needs in mind. Golden Key have supported people with lived experience to contribute to the development of the local care commissioning group's ten-year mental health strategy (see case study 5). This demonstrates that involving people with recent experience of multiple disadvantage is not just possible, but beneficial in highlighting new perspectives. The report Cause & Consequence: Mental Health in Manchester[29] was co-produced by people with experience of homelessness and poor mental health and sets out a blueprint for 'getting it right'. All the recommendations from the report are being adopted locally.

Key ingredients of successful involvement include **gaining buy-in from all stakeholders** from the start about what co-production looks like and why it is valuable. People with lived experience should be involved throughout the process of developing a strategy, not just in initial problem identification, but in developing potential solutions and reviewing the strategy as it emerges.

> **Get people with lived experience in there. People that are using the service. Fresh heads, not stale ones. Because you always have to be up-to-date with services to know what's going on.**

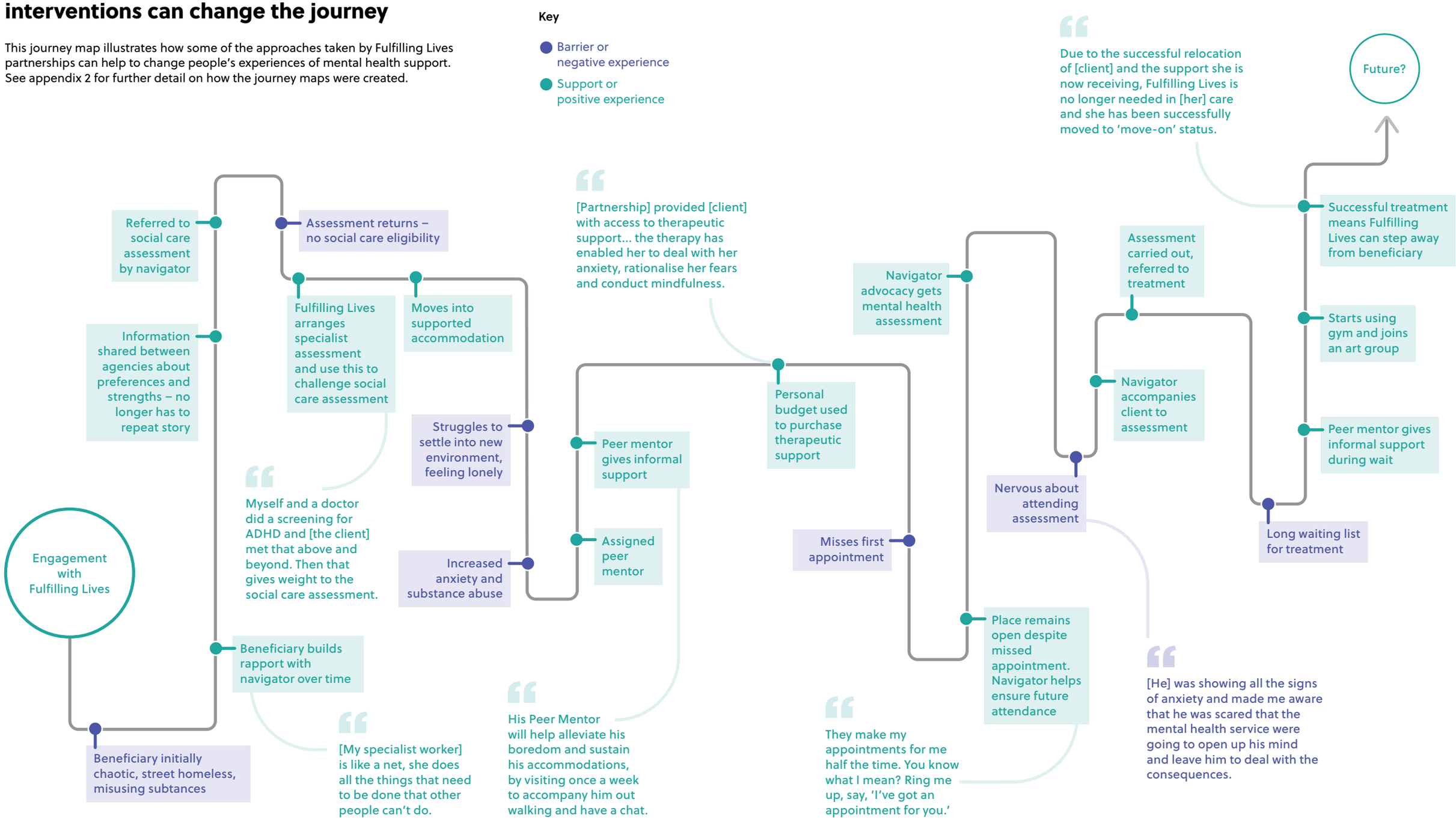
Some organisations unused to genuine co-production of strategies and services may underestimate the time and resource needed to effectively engage and support people with lived experience. There is always a risk that people will be adversely affected by discussing difficult experiences, and so it is vital that **people with lived experience are supported throughout** the process and are engaged when they are ready to do so. They may also need additional training to develop the confidence and skills needed to contribute. People need to have a reached a point in their recovery journey where they feel ready to contribute. But ideally, their **experiences of services need to be recent** enough for them to provide relevant insights. However, Golden Key have shown that, with enough support, it is possible to ensure that even the voices of those with the highest levels of need can be heard.

Raising awareness of multiple disadvantage and the need for more and better services is also an important part of changing the system. **Co-producing workforce training and awareness raising activities with people with lived experience** of multiple disadvantage ensures their authentic voice is heard. Personal testimony can be powerful in creating understanding and empathy.

Fulfilling Lives partnerships provide a wealth of experience in how to involve people with lived experience in a meaningful way. Just some of this is collected in the case studies that accompany this report.

Journey map 2: How Fulfilling Lives interventions can change the journey

This journey map illustrates how some of the approaches taken by Fulfilling Lives partnerships can help to change people's experiences of mental health support. See appendix 2 for further detail on how the journey maps were created.



Conclusions

Mental ill-health is just one of many disadvantages faced by Fulfilling Lives beneficiaries. And while getting help with mental health problems needs to happen alongside addressing other issues, it appears to be a critical component of making progress. Yet getting support with mental health is also one of the most intractable problems facing Fulfilling Lives partnerships.

Fulfilling Lives partnerships have modelled a more flexible and person-centred service.

The resources provided by the National Lottery Community Fund have enabled partnerships to continue to push at the boundaries of the system, being tenacious and building relationships and understanding as they go. Partnerships have modelled what a more flexible and person-centred therapeutic service could look like. In doing so they have demonstrated that it is possible to successfully engage and work with people affected by multiple disadvantage – it is less that people are hard to reach and more that the system is difficult to enter and navigate.

Involving the people affected in the design of strategies and services is recognised good practice. And Fulfilling Lives has shown how this can be achieved even for those with experience of significant trauma and disadvantage.

The evidence we have collected suggests improvements in awareness and a willingness to engage with the programme and issues at a local level. But progress is slow, many frustrations and barriers remain and it is not clear how much of a lasting legacy the programme will leave on the mental health system without more widespread and substantial transformation of the system. The substantial investment of Fulfilling Lives is unlikely to be repeated, so it is essential that the learning from the programme informs future commissioning of services.

It is worth noting that this report considers only the potential benefits of the support provided by Fulfilling Lives. Clearly the level of support provided can be resource intensive. The approaches outlined here may result in savings elsewhere, for example in other parts of the economy[30] and/or in the long term for the beneficiaries whose outcomes are improving. However, we do not consider the issue of cost effectiveness in this report.

Recommendations

SCAN have reviewed and discussed the findings presented here with support from staff from the Making Every Adult Matter (MEAM) coalition.[31] SCAN offers the following recommendations to national and local decision makers in order to improve mental health provision for people experiencing multiple disadvantage. These recommendations are the collective view of the SCAN members and not of CFE Research, The University of Sheffield or the National Lottery Community Fund. They are presented here under the same three heading used to categorise the barriers.

Difficulty in accessing mental health support

The paper identified barriers around primary healthcare registration, the complexity of the mental health system, unsuitable assessments, the exclusion of people with co-occurring needs and a lack of understanding from staff leading to stigma and discrimination.

SCAN makes the following priority recommendations:

1. **The Department of Health and Social Care and its associated agencies, in particular Health Education England, should lead a national programme of work to embed the principles of psychologically- and trauma-informed care in mental health assessment processes.**

There should be a national programme of work to inform the mental health workforce about psychologically- and trauma-informed care and embed a trauma-informed approach into assessment processes. This would enable better assessment and help individuals to engage with the mental health support they need. The workforce require sufficient support, supervision, training and space for reflection in order to be able to deliver psychologically- and trauma-informed care.

2. **The Department of Health and Social Care, NHS England, Public Health England and the Care Quality Commission should ensure that national guidance on co-occurring mental ill-health and substance misuse is followed locally.**

Staff at all levels of the mental health system should be supported and challenged to ensure assessment and the provision of services for people with co-occurring issues, in line with the national guidance from NICE and Public Health England. Good practice in Fulfilling Lives and other areas has demonstrated that mental health support can be provided to individuals facing co-occurring issues and that it can be effective. The Care Quality Commission should investigate when guidance is not being followed.

3. **Local commissioners, statutory bodies and voluntary sector support providers should work collaboratively, taking a whole systems approach to addressing multiple disadvantage.**

Local authority and health commissioners, statutory agencies and voluntary sector support providers should work together to improve access to mental health support for people affected by multiple disadvantage. It is essential that representatives of mental health services are involved in partnership approaches to addressing multiple disadvantage. Sustainability and Transformation Partnerships and Integrated Care Systems will have an important role to play. A systems-thinking approach is needed to consider how decisions and changes in one part of the system may affect outcomes in another. Referral and care pathways, which often involve multiple organisations, need to be easier to navigate with varied points of access. This could be achieved through the use of common assessment and monitoring tools, which can reduce the number of times that people explain why they are seeking to access services and provide a fuller picture for service providers.

Unsuitable mental health support

The paper identifies barriers around services struggling to deal with complex issues and behaviours, traditional 'appointment' models of healthcare excluding people and services that are not provided in a gender-informed way.

SCAN makes the following priority recommendations:

4. **Commissioners and support providers should ensure that mental health support is suitable for people affected by multiple disadvantage. National commissioning guidelines on mental health services should support the development of flexible and specialised services.**

Support that is more flexible, specialised and targeted is often needed to meet the needs of people affected by multiple disadvantage. This includes appropriate pathways that are gender and culturally informed. The need for pre-treatment/stabilisation support and the role of peer support programmes should be considered. The use of personal budgets could be explored for people experiencing multiple disadvantage to co-produce their journeys through the mental health system. Clinical intervention may not always be required and community-based services may be more appropriate.

Government should develop national commissioning guidelines that make the case for these interventions and support local commissioners to put services in place. These guidelines should encourage trauma-informed approaches and psychologically-informed environments in all services.

A mental health system that is not designed or resourced to meet the needs of people experiencing multiple disadvantage

The paper identified barriers around local mental health strategies not reflecting the needs of people experiencing multiple disadvantage, people not being consulted about the design and delivery of services, the commissioning cycle inhibiting innovation, a lack of specialist services and a gap between service thresholds.

SCAN makes the following priority recommendations:

5. **Joint Strategic Needs Assessments should include analysis of individuals experiencing multiple disadvantage.**

Joint Strategic Needs Assessments should take a wider view of social determinants of health in order to improve Joint Health and Wellbeing Strategies. National guidance should be refreshed to support Health and Wellbeing Boards to develop health and wellbeing metrics for people experiencing multiple disadvantage. This would help encourage the commissioning of health services that are suitable to the needs and circumstance of these individuals.

6. **Commissioners and support providers should ensure that people with experience of multiple disadvantage are involved in designing all aspects of mental health strategy, policy and services, as well as monitoring success. Government guidance should promote this approach.**

Local Integrated Care System (ICS) plans and mental health strategies should be co-produced with people experiencing multiple disadvantage. Plans should reflect the specific needs of these individuals and ensure the provision of a range of support that meets their needs. The strategies should address the identified issues around eligibility thresholds and the provision of specialist services.

Local commissioning should ensure that people experiencing multiple disadvantage are involved in the design, delivery and evaluation of services, involving them at all stages of the commissioning cycle. Government guidance to commissioners should promote this approach.

Endnotes

1. See Appendix 1 for further information about Fulfilling Lives partnerships
2. The group share their experiences of implementing change within their local systems and seek to use this learning to inform national policy debates. For further information see http://meam.org.uk/wp-content/uploads/2019/06/MEAMJ7105-Fulfilling-lives-publication-WEB.pdf
3. Lamb, H. Moreton, R. Welford, J. Leonardi, S. O'Donnell, J. and Howe, P. (2019a) *Understanding multiple needs* CFE Research www.fulfillinglivesevaluation.org/6370-2/
4. Bramley, G. and Fitzpatrick, S. (2015) *Hard Edges: Mapping severe and multiple disadvantage* Lankelly Chase Foundation https://lankellychase.org.uk/resources/publications/hard-edges/
5. Ibid p37
6. Lamb et al (2019a)
7. See Appendix 2: Methods and Tables 1 and 2 in Appendix 3: Data tables
8. Lamb, H. Moreton, R., Welford, J. Leonardi, S. O'Donnell, J. and Howe, P. (2019b) *What makes a difference* CFE Research www.mcnevaluation.co.uk/what-makes-a-difference-new-briefing-published/
9. Mental Health Taskforce (2016) *The Five Year Forward View for Mental Health: A report from the independent Mental Health Taskforce to the NHS in England* www.england.nhs.uk/wp-content/uploads/2016/02/Mental-Health-Taskforce-FYFV-final.pdf
10. NHS (2019) *The NHS Long Term Plan* www.longtermplan.nhs.uk/wp-content/uploads/2019/08/nhs-long-term-plan-version-1.2.pdf
11. Ibid, p8
12. NHS England (no date) *Adult Improving Access to Psychological Therapies programme* [online] Available at: www.england.nhs.uk/mental-health/adults/iapt/ [Accessed 21st October 2019]
13. Public Health England (2017) *Better care for people with co-occurring mental health and alcohol/drug use conditions: A guide for commissioners and service providers* https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/625809/Co-occurring_mental_health_and_alcohol_drug_use_conditions.pdf
14. National Collaborating Centre for Mental Health (2019) *The Improving Access to Psychological Therapies Manual* NHS www.england.nhs.uk/wp-content/uploads/2019/12/iapt-manual-v3.pdf
15. NICE (2016) *Coexisting severe mental illness and substance misuse: community health and social care services NICE guideline NG58* www.nice.org.uk/guidance/ng58/chapter/Recommendations
16. Public Health England (2017) p24

17. Wilson, W. and Astley, P. (2016) *Gatekeepers: Access to primary care for those with multiple needs*. VOICES, Healthwatch and Expert Citizens, Stoke-on-Trent

18. Lamb et al (2019a)

19. Broadbridge, A. and Blatchford, S. (2018) *Views and experiences of local mental health services for people with homelessness or insecure housing* Healthwatch Newcastle www.healthwatchnewcastle.org.uk/wp-content/uploads/2019/04/mental-health-report-Fullfilling-Lives.pdf

20. Lamb et al (2019a)

21. The National Commission on Domestic and Sexual Violence and Multiple Disadvantage (2019) *Breaking Down the Barriers* https://avaproject.org.uk/wp-content/uploads/2019/03/Breaking-down-the-Barriers-full-report-.pdf

22. Care Quality Commission (2018) *Sexual safety on mental health wards* Newcastle: Care Quality Commission

23. For example, see Emerging Horizons (2017) *Lead Worker and Peer Mentor Fieldwork Evaluation* Birmingham Changing Futures Together

24. See https://inspiringchangemanchester.shelter.org.uk/gm-think

25. 'Pre-treatment' is an approach to supporting single homeless people to transition to housing and/or treatment alternatives developed originally in the US by Jay Levy, now being taken up in parts of the UK. The approach comprises five components: establishing safety, forming trusting relationships, creating a common language, facilitating and supporting change and cultural/ecological considerations (Conolly, J. (2018) Pre-treatment Therapy approach for single homeless people, In Cockersell, P. ed. (2018) *Social exclusion, compound trauma and recovery: Applying psychology, psychotherapy and PIE to homelessness and complex needs* London: Jessica Kingsley Publishers, Chapter 6. See also Levy, J. S. and Johnson, R. Eds. (2018) *Cross-cultural dialogues on Homelessness: From Pre-treatment strategies to psychologically-informed Environments* Ann Arbor, MI, USA Loving Healing Press

26. Three of the Fulfilling Lives partnerships, Islington and Camden, South East and Opportunity Nottingham are working with the University of Nottingham to evaluate the effectiveness of their pre-treatment therapeutic interventions

27. Fulfilling Lives South East Partnership (no date) *Pilot Specialist Psychological Therapist Evaluation*

28. Psychologically informed environments are "services that are designed and delivered in a way that takes into account the emotional and psychological needs of the individuals using them." (Homeless Link (2017) *An introduction to Psychologically Informed Environments and Trauma Informed Care* https://www.homeless.org.uk/sites/default/files/site-attachments/TIC%20PIE%20briefing%20March%202017_0.pdf). Trauma-informed approaches can be defined as "a system development model that is grounded in and directed by a complete understanding of how trauma exposure affects service user's neurological, biological, psychological and social development" (Paterson, 2014 cited in Sweeney, A. Clement, C. Filson, B. and Kennedy, A (2016) Trauma-informed mental healthcare in the UK:

what is it and how can we further its development? *Mental Health Review Journal* vol. 21, 3, pp. 174–192 http://dx.doi.org/10.1108/MHRJ-01-2015-0006)

29. Mental Health and Homelessness Action Group (2018) *Cause & Consequence: Mental Health and Homelessness in Manchester* Inspiring Change Manchester http://icmblog.shelter.org.uk/wp-content/uploads/2018/08/Shelter-Cause-Consequence-reports-2018.pdf

30. For example, see Lamb, H. Moreton, R. Welford, J. Leonardi S. and Howe, P. (2019c) *Why we need to invest in multiple needs* CFE Research www.fulfillinglivesevaluation.org/why-we-need-to-invest-in-multiple-needs-new-briefing-out-now/

31. For further information see http://meam.org.uk/

Appendix 1: Further information about Fulfilling Lives

The Fulfilling Lives programme funds voluntary-sector led partnerships in 12 areas across England. The partnerships were awarded funding in February 2014 and began working with beneficiaries between May and December 2014. They are:

- Birmingham Changing Futures Together
- Fulfilling Lives Blackpool
- Fulfilling Lives South East Partnership (Brighton and Hove, Eastbourne and Hastings)
- Golden Key (Bristol)
- FLIC (Fulfilling Lives Islington and Camden)
- Liverpool Waves of Hope
- Inspiring Change Manchester
- Fulfilling Lives Newcastle and Gateshead
- Opportunity Nottingham
- Fulfilling Lives Lambeth, Southwark and Lewisham
- VOICES (Stoke on Trent)
- West Yorkshire – Finding Independence (WY-FI)

The National Lottery Community Fund commissioned CFE Research and the University of Sheffield to carry out a national evaluation of the programme.

Appendix 2: Methods

Aims and research questions

This study aimed to:

- better understand how Fulfilling Lives partnerships have overcome systemic barriers which stop people with multiple needs getting help and treatment for mental health problems, and
- provide detailed understanding of effective actions that can be adapted and/or replicated elsewhere to improve access to mental health services.

The key research questions addressed were:

- Understanding the context: What mental health support, services and treatment is currently available to people with multiple needs? What gaps exist?
- Identifying barriers: What are the main barriers (including cultural) that prevent people from accessing services and getting the support they need?
- Overcoming barriers: What are the main ways in which Fulfilling Lives partnerships addressed these barriers? Which approaches appear promising?
- Creating change: What needs to be in place for promising approaches to be adopted or adapted elsewhere?
- Future challenges: What barriers remain? What issues need to be addressed to make further progress?

We focused particular attention on overcoming barriers and creating change to ensure a solutions-focused result.

The research comprised the following activities:

Desk review of documentation

We reviewed local evaluation reports and case studies provided by Fulfilling Lives partnerships on the topic of access to mental health and related services. We used this material to help identify common barriers and the different ways partnerships had responded to these.

Analysis of quantitative beneficiary data

A common data framework (CDF) was developed at the start of the Fulfilling Lives programme to ensure consistent data is collected by all 12 partnership areas. The CDF includes:

- demographic information on beneficiaries, their engagement with the programme and related support services
- six monthly assessments of need and risk (Homelessness Outcomes Star™[1] and New Directions Team assessment[2])

Partnerships collect data in line with the CDF and submit this to the national evaluation team quarterly. Beneficiaries are recruited to the programme on a rolling basis. The analysis carried out for this study is based on data collected up to June 2019.

Multiple linear regression analysis (5 models) using individual respondent level data was carried out to look at the association between accessing different types of support and change in total Homelessness Outcomes Star™ and New Directions Team (NDT) assessment scores between baseline and 12-month follow-up. Changes were measured such that a positive change is an improvement (so a reduction in NDT scores or an increase in Outcomes Star scores. For the support use variables, the first five quarters of data are used, to reflect the same period (baseline within first 3 months and 12 months follow-

1 For further information see http://www.outcomesstar.org.uk/using-the-star/see-the-stars/homelessness-star/

2 For further information see http://www.meam.org.uk/wp-content/uploads/2010/05/NDT-Assessment-process-summary-April-2008.pdf

up) that is covered by the change in outcome measures. 37 different support use variables were aggregated into the eight broad categories as follows:

- Advice and information: housing, addictions, legal/criminal justice, care and personal support, welfare rights, careers, immigration
- Counselling/therapies: psychotherapy, cognitive behavioural therapy, counselling
- Mentoring and befriending: peer mentoring, befriending, other mentoring
- Education and training: life skills, literacy and numeracy, behavioural, course leading to qualification, work experience placement
- Substance misuse support: contact with substance misuse support worker, detox, rehabilitation
- Activities: art/culture/libraries, sports and fitness, worship and faith related
- Social care: social work, day centre, residential or nursing care home, occupational therapy
- Health related: GP, community mental health support, outpatient treatment, inpatient treatment, community nursing, self-help and support groups

The results are shown in tables 1 and 2 on page 48–51.

In each table, the results from four specifications are presented, the difference being the different ways of measuring support use:

(2) **Any** support in category – a 1/0 dummy variable indicating whether the individual had used at least one type of service within the broader category during any one of the five quarters.

(3) **Continuous** support in category – a 1/0 dummy variable indicating whether the beneficiary had used at least one of the types of support in all five quarters, for example legal advice was recorded as received in each quarter within the advice and information category.

(4) **Total** support in category – the total number of different types of support used within a category and across the five quarters – so this will be larger for the categories with a larger number of types of support, such as advice and information.

(5) **Average** support in category – the average number of quarters in which support use within a category was recorded, so takes values between 0 and 5. This corrects for the total support measure in (4) for the fact that some categories have more types of support within them than others.

Note that the number of observations in both tables is lower in columns 4 and 5 than in columns 2 and 3. This is because in columns 2 and 3 the support variables are just dummy variables indicating any single (column 2) or continuous (column 3) service use within the category – it does not matter if other service use types within the category have a missing value. For columns 4 and 5, however, we need the total and average number of quarters in which services were used, and so any missing values on any of the service types will produce a missing value for the total or average service use variables within that category.

Overall we found few statistically significant results; that is few significant relationships between the support used and the change in NDT or Outcomes Star. Advice and information and social care (and sometimes education and training are negatively correlated with NDT improvement. Counselling/therapies and activities are positively correlated with NDT improvement. Counselling/therapies are also positively correlated with Outcomes Star improvement. There is some evidence that advice and information is negatively correlated with Outcomes Star improvement and that mentoring and befriending is positively correlated with Outcomes Star improvement. It is worth remembering here that these are correlates of improvement and not causal analysis. It does not mean, for example, that use of social care support causes a deterioration in NDT, or that use of counselling/therapies causes an improvement in both outcomes. Causality is one possible explanation for the result but it may also be, for example, that the type of people who access social care support have other (unobserved) characteristics (that is things we cannot control for in the regression analysis because we do not have information on them) that also result in a deterioration in their NDT score.

Association between receiving different types of support and leaving with a positive destination (no longer requiring support or receiving support from elsewhere) were also explored using multiple regression analysis via probit models. This found no statistically significant association between receiving

counselling/therapies and leaving the programme with a positive destination so we do not report the results here for conciseness.

Focus groups with frontline staff

Two focus groups were held (in Leeds and London) with 21 frontline staff (navigators, support workers, personal development coordinators etc.) from all 12 Fulfilling Lives partnerships. An open invitation for frontline staff to attend the focus groups was sent to partnership managers. Up to two staff could attend from each partnership. We tested our descriptions of key barriers identified from the document review with the group and explored approaches they had found useful in overcoming the barriers.

Case study visits to five partnerships

We undertook field visits to 5 of the 12 Fulfilling Lives partnerships. Case studies were selected based on the document review. The aim was to represent the range of different approaches that partnerships had taken that local evaluations suggested had been effective. Project managers and evaluation leads were contacted and asked to broker introductions with key staff and partners involved in their approach, and to organise interviews with beneficiaries who had been involved. As part of the visits, face-to-face interviews were conducted with the following:

- 21 staff members working for Fulfilling Lives partnerships
- 11 current or former beneficiaries / people with recent lived experience of multiple disadvantage
- 9 staff representing other local partners and stakeholder organisations, such as mental health services, police and social care

All interviews and focus groups were recorded and transcribed with the consent of participants. Full transcripts were coded using specialist qualitative data analysis software (NVivo). Codes were built around identified barriers and responses to these.

Journey mapping

We developed two journey maps to illustrate some of the events and experiences which can help or hinder people experiencing multiple disadvantage when accessing mental health services. The first focuses on illustrating common barriers while the second shows how the interventions of Fulfilling Lives partnerships can make a difference to the journey.

The journey maps were created based on analysis of 26 case studies of individual beneficiaries. This information was supplemented with findings from the primary research carried out. Experiences relating to mental health services were coded by type and whether they were generally positive or negative. Experiences before and after engagement with Fulfilling Lives were compared.

Draft maps were discussed as part of the workshop (see below) and with members of the evaluation steering group. The maps were edited based on the feedback provided.

While the individual interactions are all based on real experiences, the maps are illustrative rather than a reflection of any one person's journey. Timelines have been compressed to show as many different experiences as possible in the available space; significant time can elapse between steps in the journey. We also know that many people's experiences are circular rather than linear, as they find themselves trapped in a cycle of crisis and unhelpful service response. Although the aim of the second map is to illustrate the impact of Fulfilling Lives interactions, this should not be taken as an indication that many of the barriers and problems illustrated in the first map are not still present for those getting help from the programme.

Workshop with partnerships and experts by experience

A workshop was held in London on 12 September 2019. 34 delegates from all 12 Fulfilling Lives partnerships attended, including evaluation leads, frontline staff members, people with lived experience and representatives of partner organisations. Representatives of the National Lottery Community Fund and

the Making Every Adult Matter (MEAM) coalition also attended. Emerging findings were shared with participants and round table discussions held to review and comment on promising responses to barriers identified.

Appendix 2 Data tables

Table 1: Correlates of improvements in NDT total score – baseline to 12 month follow-up

		Any	Continuous	Total	Average
	(1)	(2)	(3)	(4)	(5)
Age	0.021	0.025	0.009	0.030	0.030
	(0.033)	(0.035)	(0.035)	(0.034)	(0.034)
Sex	0.534	0.547	0.320	0.633	0.633
	(0.654)	(0.688)	(0.687)	(0.691)	(0.691)
Ethnicity	**-1.569***	**-1.575***	-1.415	-1.394	-1.394
	(0.911)	(0.935)	(0.940)	(0.950)	(0.950)
Homelessness	**-1.170***	-1.096	-1.061	-0.918	-0.918
	(0.691)	(0.707)	(0.710)	(0.722)	(0.722)
Offending	0.218	0.758	0.692	0.405	0.405
	(0.800)	(0.829)	(0.833)	(0.837)	(0.837)
Substance misuse	2.527	2.181	2.016	2.359	2.359
	(1.624)	(1.642)	(1.646)	(1.692)	(1.692)
Mental health	-1.096	-1.559	-1.396	-1.281	-1.281
	(1.280)	(1.297)	(1.298)	(1.316)	(1.316)

Advice and information		-0.319	**-0.310***	**-0.103***	**-0.823***
		(0.207)	(0.186)	(0.054)	(0.433)
Counselling/ therapies		**0.994*****	**0.859****	0.186	0.557
		(0.352)	(0.355)	(0.166)	(0.499)
Mentoring and befriending		-0.547	-0.954	-0.184	-0.552
		(0.554)	(0.725)	(0.218)	(0.653)
Education and training		-0.494	**-0.899***	-0.083	-0.414
		(0.446)	(0.502)	(0.156)	(0.778)
Substance misuse support		0.728	0.434	0.200	0.599
		(0.530)	(0.580)	(0.142)	(0.425)
Activities		**0.915****	0.370	**0.279***	**0.838***
		(0.421)	(0.465)	(0.162)	(0.485)
Social care		**-0.604****	**-0.594****	**-0.313***	**-1.252***
		(0.290)	(0.289)	(0.178)	(0.714)
Health related services		0.272	**0.320***	0.040	0.240
		(0.185)	(0.164)	(0.086)	(0.518)
Constant	**4.477***	3.811	**4.977****	**4.651***	**4.651***
	(2.402)	(2.547)	(2.498)	(2.561)	(2.561)
Observations	745	716	716	706	706
R-squared	0.014	0.046	0.042	0.034	0.034

Models estimated by OLS. Standard errors in parentheses.
*** p<0.01, ** p<0.05, * p<0.1

Table 2: Correlates of improvements in Outcomes Star total score – baseline to 12-month follow-up

		Any	Continuous	Total	Average
	(1)	(2)	(3)	(4)	(5)
Age	**0.178*** **	**0.169** **	**0.151** **	**0.184*** **	**0.184*** **
	(0.065)	(0.069)	(0.069)	(0.068)	(0.068)
Sex	-1.722	**-2.262***	**-2.325***	**-2.314***	**-2.314***
	(1.298)	(1.365)	(1.368)	(1.361)	(1.361)
Ethnicity	**-3.086***	**-3.655** **	**-3.207***	**-3.234***	**-3.234***
	(1.785)	(1.838)	(1.844)	(1.855)	(1.855)
Homelessness	**2.364***	**2.904** **	**2.985** **	**2.638***	**2.638***
	(1.381)	(1.413)	(1.420)	(1.434)	(1.434)
Offending	0.043	1.268	0.946	0.572	0.572
	(1.606)	(1.669)	(1.680)	(1.672)	(1.672)
Substance misuse	1.832	1.177	0.521	1.593	1.593
	(3.185)	(3.219)	(3.227)	(3.277)	(3.277)
Mental health	-2.509	-3.316	-3.274	-3.509	-3.509
	(2.515)	(2.560)	(2.560)	(2.581)	(2.581)
Advice and information		**-0.940** **	-0.730*	0.026	0.209
		(0.420)	(0.377)	(0.111)	(0.886)
Counselling/ therapies		**1.419** **	**1.686*** **	**0.824** **	**2.472** **
		(0.631)	(0.627)	(0.332)	(0.995)
Mentoring and befriending		**2.819*** **	**2.706** **	0.569	1.706
		(1.054)	(1.351)	(0.408)	(1.224)
Education and training		0.250	-1.379	-0.012	-0.062
		(0.892)	(0.999)	(0.290)	(1.449)

Substance misuse support		-0.390	-0.290	0.090	0.269
		(0.992)	(1.062)	(0.279)	(0.837)
Activities		1.096	0.346	0.030	0.089
		(0.945)	(1.110)	(0.335)	(1.005)
Social care		-0.728	-0.951	-0.332	-1.330
		(0.620)	(0.624)	(0.382)	(1.529)
Health related services		0.430	**0.569***	0.093	0.560
		(0.376)	(0.331)	(0.171)	(1.024)
Constant	3.969	3.153	5.575	2.006	2.006
	(4.811)	(5.092)	(4.992)	(5.032)	(5.032)
Observations	794	764	764	758	758
R-squared	0.024	0.057	0.051	0.047	0.047

Models estimated by OLS. Standard errors in parentheses.

*** p<0.01, ** p<0.05, * p<0.1

CASE STUDY #1

VOICES' Care Act Toolkit

VOICES is the Fulfilling Lives partnership working in Stoke-on-Trent.

What was the problem?

> We were making referrals to adult social care or safeguarding and either not knowing what had become of those referrals, or they were coming back to us as not suitable.

VOICES recognised early on the potential of the 2014 Care Act[1] to provide access to help for people facing multiple disadvantage. The Care Act opened up access to social care to anyone who needs help as a result of a physical or mental condition. However, initial referrals to Adult Social Services were often not successful.

Staff making referrals, most of whom worked in the voluntary sector and came from a background in homelessness services, tended to describe need in terms of events happening around the individual and the impact of these on people's lives. Referrals were often narrative accounts of the drama of people's lives. But this does not align with Care Act requirements or the way that social workers understand need. As a result, referrals were being dismissed as being behavioural problems or lifestyle choices.

How did the partnership address it?

> The toolkit was very much like the Rosetta Stone if you like... translating the multiple needs way of looking at need into a social care context.

The Care Act Toolkit is a way to help the different groups of professionals share information in a common language that all find meaningful and useful.

Once the need for a tool was recognised, Head of Services at VOICES, Bruno Ornelas, did much of the early research, looking at the legal framework for the Act to understand the key points that social workers look for when assessing someone. The focus is very much on identifying physical or mental impairments and the impact of these on a person's ability to achieve in different aspects of their life, such as maintaining personal hygiene and relationships.

The Project Director, Andy Meakin, and Bruno then worked together to develop a toolkit that is designed to be accessible and easy to use by staff. They recognised that having a form to fill in with the guidance separate means that people tend to end up ignoring the guidance. So, the guidance is presented alongside the assessment. Staff and stakeholders using the Toolkit agree it is clear and provides all the information needed.

> What I liked about the Toolkit was you didn't have to have a social work degree to fill it out... with the Toolkit all you need is the person and a good conversation.

While in development the Toolkit was shared with people with experience of multiple disadvantage who commented on its design and content. The Toolkit recognises the power imbalances between professionals, carers and client that can be inherent in some types of needs assessments. The Toolkit brings together the views of the client, the qualified assessor and the support worker.

> A crucial point is that the customers themselves needed to have a voice in that, but that voice might be very different from the other two voices.

What difference did it make?

Better referrals

Most importantly, the Toolkit has led to an increase in successful referrals for assessment, and people receiving their legal entitlement to care and support.

Assessments are now much quicker, more effective and there is less challenge and fewer barriers. Adult social care confirmed the improvement in referrals. They are more focussed, contain more robust information and the right people are being referred. The Toolkit has helped VOICES and other partner staff to exercise greater judgement about referrals. After the initial excitement and some trial and error, staff described how the Toolkit has helped them to make more informed decisions, including when not to refer.

> Sometimes we'd fill one in and think "Actually, no, not this time" and we did become really good at knowing.

Enhanced staff knowledge and confidence

The journey involved in developing, testing, refining and using the Toolkit has benefitted VOICES staff, helping them to develop their knowledge and understanding of the Care Act. Now, staff do not always need to use the Toolkit as they are so much more familiar with the information they need to provide in order to make an effective and appropriate referral. Staff are recognised as experts and have been approached by social services and other services in the city looking for advice.

> I don't feel scared accessing social care now, whereas before it was a real battle, wasn't it?

Staff members find it easier to have conversations with social services. They have all the information they need to hand in the Toolkit and can use this to guide their conversation. This has helped to enhance staff confidence and make them better able to advocate for their clients. The Toolkit provides a guideline for conversations so staff avoid waffling and can respond to questions accurately.

> It gives you everything you need... Specifics, yes, straight to the point.

The success of the Toolkit has boosted staff confidence and helped empower them to make a positive difference. Supporting people facing multiple disadvantage is often a frustrating and difficult job. Staff can become disillusioned or 'burnt out', which in turn has a negative impact on those they are seeking to support. By helping staff to achieve positive results, the Toolkit is said to have helped boost staff morale.

> [The Toolkit is] helping me keep my staff team motivated, they've got something to use and it gave them extra drive to keep on with that kind of advocacy.

Help to identify needs

As well as helping the team to make better referrals, the Toolkit provides a useful framework for understanding someone's needs. The Tool helps staff to break down issues and explore them in greater detail. It also helps to focus on current needs, problems and abilities, rather than history and past behaviour and can help professionals see beyond initial presenting issues of substance misuse.

> I think a lot of the time with our client group, it's always put down to the substances, always... Having some kind of assessment where you get an overall picture of what's going on, you identify there are actually other things going on.

The Toolkit is now being used widely and in a range of different ways to help identify and articulate needs, for example as part of claims for welfare benefits such as Personal Independence Payment (PIP) assessments. In one example provided by VOICES, a customer whose care package was reduced following a reassessment completed the Toolkit himself and used it to self-advocate. The package was reinstated as a result.

Improved relationships and understanding across different agencies

The Toolkit has improved relationships and communication between the adult social care team and voluntary sector staff making referrals. The training and community of practice meetings associated with the Toolkit have helped to bring different organisations and disciplines together to enhance mutual understanding, and build the kinds of trusting relationships that are necessary in order to collaborate effectively.

> "It's definitely brought those two arenas close together... it's been a bridge is the best way to describe it.

For the local authority, the Toolkit has helped them consider the needs of people facing multiple disadvantage, who may not be traditional adult social care clients. The Toolkit supports voluntary and other statutory sector staff to confidently and appropriately challenge decisions and this has been welcomed by Adult Social Care.

> "I personally think the challenge that [VOICES] have given back to social care is don't ignore people because you don't know what to do with them. I think that challenge back has been really positive.

The VOICES team also argue that the improvement in successful referrals for assessments is improving the extent to which the needs of people facing multiple disadvantage are recognised. Assessments record needs and place a statutory duty on local authorities to meet them. The referrals have also led to some 'awkward conversations' with partners, which VOICES see as useful in challenging attitudes and leading to a recognition of the need for services not currently available.

> "The demand is having to be acknowledged, leading to an acceptance of a commissioning gap.

Learning from experience

Bring staff from different disciplines and sectors together

Consider setting up communities of practice or other knowledge exchange opportunities for staff from different professional backgrounds to meet each other and find out more about how they work. The introduction of the Toolkit was supported by communities of practice with adult social care workers and academics from Kings College London. Meetings between voluntary and statutory sector staff helped develop understanding of each other's roles, remit and the constraints that all work within.

> "I think understanding what each service is up against, that there is a common goal, and understanding roles and remits... in the absence of understanding it seems so much more hopeless, whereas actually knowing where there is room for movement and where there isn't, that helps look more solution-focused anyway.

Arrange related training to help your staff use the Toolkit

This should include understanding the Care Act and having conversations about social care needs. Staff in a partner organisation were said to be initially sceptical and saw the Toolkit as another addition to their workload. However, the training and meeting counterparts in social care made all the difference. VOICES have done lots of talks and workshops to support the Toolkit. Demand was so high that they have produced a series of short videos as an introduction to using the Toolkit and the Care Act so people can watch it in their own time (see Find out more).

It's also important to have the necessary skills to talk to someone about often sensitive topics. Accompanying training may be useful to bolster skills around active listening and building rapport.

> You still have to have some skills to be able to hold conversations. Some of it is sensitive stuff, when you're talking about someone's personal hygiene ... I think it has to come with the training package that covers the Care Act, that covers active listening, that covers quality of conversation.

Be patient and persistent

VOICES emphasised that the Toolkit is not a magic bullet and requires persistence and assertive advocacy. Completing the Toolkit form alone is unlikely to be sufficient. It is important to engage adult social services in conversation and explore their decisions and reasoning. The Toolkit helps to frame the conversation, but the conversation is still needed. Meetings between VOICES and adult social care, once the Toolkit was in use, were important to help overcome potential animosity from social workers feeling like the voluntary sector were trying to tell them how to do their job.

> You do have that animosity. 'Who... are they trying to tell me?... I know what the Care Act says!'... Once we'd gone to meetings and started understanding exactly what the Toolkit was for and how it could support a referral... then you get rid of that animosity, because people understand each other better.

Taking it further

The Toolkit was time-consuming to develop, but has made such a difference.

The approach to the Toolkit has opened VOICES eyes to what is possible and the impact of supporting staff to advocate for client's legal entitlements. Future plans include a similar toolkit to support safeguarding cases. Partners showed interest in similar toolkits to support understanding of other complex legal frameworks.

The Toolkit has clearly made a major difference in the way referrals are made and their success. VOICES still see barriers, but these tend now to focus on lack of suitable services rather than difficulties getting needs assessments. Improving the way services are commissioned is an important issue still to be addressed.

> If we ignore the commissioning problem, we're ignoring a big chunk of the problem.

Find out more

Download the Toolkit and watch the supporting videos here: http://www.voicesofstoke.org.uk/care-act-toolkit/

VOICES staff also co-authored two academic articles relating to the Toolkit:

Cornes, M. Ornelas, B. Bennett, B. Meakin, A. Mason, K. Fuller, J. and Manthorpe, J. (2018) Increasing Access to Care Act 2014 Assessments and Personal Budgets Among People with Multiple Needs Linked to Homelessness and Exclusion: A Theoretically Informed Case Study. *Housing Care and Support*. Available: www.emeraldinsight.com/eprint/ZMDYVCVBYTS89BXS3A4S/full

Mason, K. Cornes, M. Dobson, R. Meakin, A. Ornelas, B. and Whiteford, M. (2017) Multiple Exclusion Homelessness and adult social care in England: Exploring the challenges through a researcher-practitioner partnership. *Research, Policy and Planning* (2017/18) 33(1), 3–14. Available Open Access: http://ssrg.org.uk/members/files/2018/02/1.-MASON-et-al.pdf

Find out more about VOICES: https://www.voicesofstoke.org.uk/

For further information, please contact Bruno Ornelas at VOICES: Bruno.Ornelas@voicesofstoke.org.uk

Endnotes

1. The Care Act brought together and updated older laws to create a single, consistent route to establishing entitlement to public care and support for adults. The Act set out a new legal duty for local authorities to meet an adult's care and support needs. Local authorities have a duty to carry out needs assessments to determine eligibility. A person may be eligible if they have care and support needs as a result of a physical or mental condition that results in significant impact on their wellbeing. For further information see the governments' Care Act Factsheets https://www.gov.uk/government/publications/care-act-2014-part-1-factsheets/care-act-factsheets#factsheet-3-assessing-needs-and-determining-eligibility

CASE STUDY #2

Fulfilling Lives Newcastle and Gateshead's Respond training

What was the problem?

> For me, it's actually being on the receiving end of bad treatment by quite a few of the blue light responders.

The emergency response to someone having a mental health crisis – be that police, paramedic, or other service called to the scene – is crucial in ensuring the safety of all involved. Ongoing learning from Fulfilling Lives Newcastle and Gateshead (FLNG) has highlighted that the response to people with mental health needs in a crisis situation could be better, especially service understanding of the lives of people experiencing multiple disadvantage.

Discussions were already underway in the North East about what could be improved to ensure that people having a mental health crisis got the help they needed.[1] While multi-agency working was perceived to be relatively strong in the region, it was felt that blue light responders sometimes needed further awareness raising of the role partner agencies played and how the system should work together to respond to a person experiencing a mental health crisis.

How did the partnership address it?

Organisations from across the North East and people with lived experience of mental ill-health co-produced a simulation training package. The aim was to "improve the efficiency of the care pathway to reduce wasted time and provide a better experience for the service user."[2] Three mental health crisis scenarios (on a bridge, in a private dwelling and on a secure ward) were filmed for the training. These were co-produced with Experts by Experience to ensure that they were as true to real life situations as possible. Training sessions are held focusing on one of these situations, with the scenario revealed bit by bit throughout the day. Participants are encouraged to think about what they, and other responders, should and could do to help.

Key features of the Respond training include:

- People attend the training in plain clothes, so do not wear organisational badges or introduce themselves. As a result, all attendees are unaware of who they are working with. This allows all to contribute on an equal basis thus reducing power imbalances.
- People with lived experience join the training sessions, again without introducing themselves, and share their story and experiences. This ensures that the lived experience perspective is included in the same way as other voices in the room.
- There is no PowerPoint presentation or directed learning – attendees are encouraged to take responsibility for their own learning.

What sets Respond apart from other multi-agency training is the central role that people with lived experience play and the impact this has on attendees.

> **"The unique selling point of Respond is that Experts are involved... there's somebody in the room with that lived experience, sharing that with their peers, and that's the difference with Respond. That's what makes it special.**

The training programme is managed by a steering group, made up of partner organisations involved in actively responding to mental health crisis situations in the region.

What difference did it make?

Improved understanding of the roles and responsibilities of different agencies

Those who attend sessions gain a deeper understanding of the role of professionals in other agencies and how the system works (or hopes to work) when responding to a mental health crisis. Expectations are adjusted as professionals realise what other roles can – and perhaps more importantly, cannot – do in a crisis situation.

> "I left [the training] with the much better understanding of a person in a mental health crisis, and a much better understanding of the services and their roles to support that person.

Professionals report being better able to work with other agencies following the training.[3] In encouraging professionals to modify not just their own response to a situation but also the way they work with others, Respond has the potential to change the systemic response to a mental health crisis.

Professionals take their learning back to their organisations and pass this on to colleagues, formally and informally, further sharing their insights.

Improved preparedness for crisis response situation

Feedback from professionals attending the training suggests that they are able to respond better to the needs of people in a crisis situation. It was certainly hoped that the knowledge gained through the training would better prepare professionals for these situations and improve the interaction for all parties.

> "I would hope that the next time somebody responded to a mental health crisis, no matter where it was, they would see the person. Have more of an understanding of their multiple complex needs and sort of the complexities of that person.

The training increases awareness and empathy for a person experiencing the mental health crisis. The role of the Experts by Experience in Respond training is believed to be key to this. The training helps to improve the way participants work with people experiencing a mental health crisis, and thus work towards an improved patient experience and safety.[4]

> [I got] an up-to-date understanding of the procedure to get somebody assessed and potentially sectioned and a better understanding of how to approach, to deal with the individual.

Impact on Experts

The training provides Experts by Experience with the opportunity to influence the system and ultimately improve the way that people are treated in a crisis. Key benefits for Experts include:

- Increased understanding and empathy for professionals and how difficult their roles can be
- A sense of belonging from being involved in the team that contributes to the Respond sessions
- Acquiring new skills and confidence in making presentations and facilitating discussions, and
- The transformation of traumatic experiences into something of value.

> The experience that I had, which was terrible and traumatic, becomes transformed into a useful thing where I'm being validated and listened to and people are listening to me and it gets transformed into something useful.

Feedback has shown that sessions have met or exceeded Experts' expectations.[5]

Learning from experience

Embed co-production from the start

Experts by Experience have been involved throughout the development and implementation of the Respond training. The training scenarios were co-produced with people with lived experience. This is key to scenario authenticity and therefore the impact on professionals. Experts were not just consulted but were fully involved in the design stage, and continue to work with the steering group on the design of future potential scenarios.

> "It was definitely a really early decision, [the steering group] decided that they really wanted to make sure that the training involved the Experts from the word go.

Make clear expectations about Expert involvement and what it entails

Lived experience involvement can be a learning curve for some organisations, particularly the amount of work needed to manage and maintain genuine involvement.

> "To do [lived experience involvement] well requires a lot of support and effort [...] and the temptation for organisations is to take the benefit of involving people with lived experience and not want to share some of the difficulty, challenge and cost of it.

There can be differing expectations about what genuine lived experience involvement looks like, how it is managed and the extent to which this can be at the core of a programme. Lived experience is crucial to the success of the Respond sessions, and partners need to be committed to this. Expectations should be established and formalised at the outset of a project to ensure that all partners are aware of what is involved and the commitment required.

Consider the best way to get Expert input on project governance

Expert involvement should include lived experience at the project governance level. The FLNG Experts by Experience Network is currently represented on the Respond steering group by the FLNG System Change Lead, but there are plans for an Expert to sit on the group as a step towards the gold standard of co-production. Sitting with professionals in a formal setting and being expected to contribute can be intimidating so care is needed to make sure that both the Expert and the rest of the group are fully aware of each other's roles and responsibilities and what is expected of them.

> "It's not just Fulfilling Lives responsibility to facilitate that Expert voice on the steering group. It's the steering group's responsibility to make it accessible to that person.

Manage and support Experts throughout their involvement

Experts by Experience are in recovery and need to be protected to ensure, as far as possible, that they do not suffer setbacks from having to revisit difficult times in their lives. It is important that Experts are in the right place in their journey (as co-determined by them and the Co-production team) and are appropriately trained to make a positive contribution and not feel disempowered. The nature of the Respond training can require Experts to discuss negative experiences. They may find themselves in a room with professionals linked to these experiences. This needs to be carefully managed through ongoing support and reflective practice.

> "We still have a very, very significant duty of care for our Experts, and it's managing and balancing that for everyone [...] Experts might present confidently and be mistaken for paramedics etc. in Respond sessions however the Experts are people in recovery and it is vital we have regular check-ins to ensure their recovery journey is not being impacted by being part of Respond.

During Respond sessions, Experts are aware that they can take time out if needed. Experts may find it hard to admit when they are finding things difficult – hiding relapses or problems they are having, and wanting to put on a brave face. Again, this needs to be considered when managing their involvement.

The Respond training provides the potential for a progression pathway for Experts: from volunteering to attending sessions, to facilitating, to contributing to programme governance. If managed well, this provides a valuable opportunity for people to gain vital skills and experiences that contribute to a person's ongoing recovery.

Get multi-agency buy-in from the start

The Respond training was instigated through a collaborative process. This ensures that it is not perceived as one agency imposing their ways of working on another. The steering group is made up of the local police force, the regional NHS Trust, local councils, blue light services and Fulfilling Lives Newcastle & Gateshead.[6] Key agencies were involved from the start which ensured buy-in from across the sector.

> "It's the fact that all the organisations have come together and said, 'We need to do something like this,' and I think it's that that makes the difference, that makes it so special.

This should extend to the training sessions themselves, as it was seen as a strength of the programme and a way to ensure that the whole system benefits from thinking differently about the response to a mental health crisis.

> "It works, because it's too easy sometimes, some agencies or all of us to go, 'well, that's not a police issue,' 'that's not a mental health issue,' 'that's not a medical issue.' It's actually, it's all of us, we're all part of the solution, and it's a case of not all of us just going, 'somebody else needs to deal with this.'

Taking it further

Respond is now an award-winning training package and has attracted the attention of other local authorities, NHS trusts and emergency services. There is the potential to offer the training to many more professionals, within the North East and beyond. The challenge is to ensure that the core features of Respond, which make it a success, are retained. There is a particular need to ensure that Expert involvement follows a similar trauma-informed process; ensuring the safety of Experts remains integral to the Respond offer. There are also plans to increase the number of scenarios offered. The fourth scenario will focus on a mental health crisis in an A&E department, as suggested by an A&E doctor who attended the training.

Find out more

Read more about Respond and download evaluation reports at: https://www.ntw.nhs.uk/resource-library/respond-multi-agency-mental-health-simulation-training/

Find out more about Fulfilling Lives Newcastle and Gateshead: http://www.fulfillinglives-ng.org.uk/

For further information, please contact Claudene Cetinoglu at Fulfilling Lives Newcastle and Gateshead: Claudene.Cetinoglu@fulfillinglives-ng.org.uk

Endnotes

1. These discussions were prompted by the Crisis Care Concordat, a national agreement between services and agencies involved in the care and support of people in crisis. It sets out how organisations will work together better to make sure that people get the help they need when they are having a mental health crisis. For further information see www.crisiscareconcordat.org.uk
2. Academic Health Science Network (AHSN) North East and Northumbria (2017a). *Respond Training: Mental Health Simulation Training. Feedback from Experts by Experience*. https://www.ntw.nhs.uk/content/uploads/2019/06/Respond-Training-Expert-by-Experience-Feedback-Report-Final-1.1-.pdf
3. Academic Health Science Network (AHSN) North East and Northumbria (2017b). *Post impact and summary of findings following the evaluation of the RESPOND multi-agency mental health simulation training, November 2016 – March 2017: Executive Summary*. https://www.ntw.nhs.uk/content/uploads/2019/06/Evaluation-of-RESPOND-mental-health-simulation-training-Executive-Summary-Final-Nov-2017.pdf
4. Ibid.
5. AHSN (2017a)
6. Ibid, p.10

CASE STUDY #3

Opportunity Nottingham's specialist mental health workers

Opportunity Nottingham is the Fulfilling Lives partnership for Nottingham City. Framework, a homelessness charity with hostels across the city, are the lead partner.

What was the problem?

> I can remember, numerous examples where we had what we thought were very, very ill, very chaotic people and when they would have chances where they would come into contact with [mental health] services and we would think, 'Brilliant, this will get them in,' and they would actually be told there's nothing wrong with them.

Opportunity Nottingham saw the mental health pathway in the city as failing to meet the needs and behaviours of people experiencing multiple disadvantage. As a result, beneficiaries were often denied assessments and were unable to access treatment services, despite partnership staff concerns over their mental health.

Whilst there are some counselling services available for people with multiple needs in the city, staff felt that waits for treatment would be too long or that their beneficiaries would be considered as too complex. These perceptions are supported by the experiences of other partnerships. Further, a lack of specialist mental health staff able to work with people experiencing multiple disadvantage means that people are often labelled with inaccurate 'diagnoses'.

> I think in the homelessness sector, people are working with virtually no information. It's what you can get from the person, often it's unreliable, so for example I regularly see split personality disorder written as a diagnosis which isn't a diagnosis but it's something that someone's self-reported because they've either interpreted what they have been told in that way or that's what they believe they've got.

How did the partnership address it?

> We've actually stepped in to commission or provide things ourselves because we can't get it within the pathway.

Framework created two roles to help fill the gaps in mental health services they identified: a CBT practitioner and a Band 8 clinical psychologist.

The mental health lead worker undertook training in cognitive behavioural therapy (CBT) so they could offer this in-house to beneficiaries. The CBT was initially run as a pilot service and after six months of successfully working with beneficiaries this was integrated into the usual service at Opportunity Nottingham.

> We know now everybody's got severe trauma [...] we were certain there would be lots of people who would probably benefit from [CBT] and it was a quick way of getting access to that and delivered in a format that [beneficiaries] could cope with.

Personal Development Coordinators (PDCs), who work directly with beneficiaries, discuss with the CBT practitioner whether someone might benefit from therapy. The CBT practitioner then meets with the beneficiary to chat about what the programme entails. If everyone agrees it would be useful, treatment can go ahead.

The clinical psychologist was employed to carry out in-house needs assessments, provide direct support to beneficiaries, improve working practices across Opportunity Nottingham and Framework and connect with wider primary and secondary mental health services in the city. The psychologist was seconded from the local healthcare trust for a fixed-term two year contract.

What difference did it make?

The combination of having a CBT practitioner and clinical psychologist meant that a range of mental health needs could be addressed in-house. In addition, the specialists acted as a bridge between the partnership and statutory mental health services. This had a positive impact on beneficiaries as well as internal and external staff and the wider system.

Providing CBT that would not otherwise be accessible

Having a CBT practitioner within the partnership has enabled people with experience of multiple disadvantage to access treatment that might not otherwise be available to them. This is particularly the case for those with co-occurring mental ill-health and substance misuse issues. It is clear that for many people Opportunity Nottingham work with, the traditional treatment pathway and approach to working with individuals is unlikely to work.

Providing CBT in-house has enabled the partnership to work with clients in a much more flexible way that is more suited to their experiences, needs and current situation. This has led to successful engagement with the CBT programme.

> "[The CBT] fits around the beneficiary. I meet them where they want to meet, whether it's out in the park, whether it's here [at Opportunity Nottingham] or whether it's in a coffee shop, it doesn't matter. It's to benefit them because by making it easier for them means that they will meet with me and it works.

Enhanced beneficiary progress

Opportunity Nottingham report that beneficiaries who undertook CBT with them made better progress in reducing levels of risk and need than those who did not.[1] They also made greater progress towards self-reliance over time working with the CBT practitioner.[2] An evaluation of eleven CBT clients also showed an improvement in a number of psychological measures after three

months, including remaining calm when facing difficulties, an ability to ask for help if needed and being confident to cope with unexpected events. This evidence was used to support the decision to maintain the CBT role beyond the initial pilot period.

Improved access to assessments and mental health services

Having a clinical psychologist within the team who can undertake specialist assessments has meant beneficiaries can get a diagnosis.

> I've done, for example, an assessment of somebody who we were pretty sure had intellectual disabilities but he hadn't got a diagnosis. He's in his fifties, that's not necessarily unusual within ID [Intellectual Disability] services, we would sometimes see people a lot further down the line, so doing an assessment and giving him a diagnosis, and then connecting him into ID services for longer-term therapy.

Needs assessments can then lead to referrals into secondary health care services. Staff gave many examples of how beneficiaries have been able to access mental health services since being assessed and supported by the clinical psychologist.

The views of a Band 8 professional add weight and credibility to referrals made by frontline staff, making them more likely to be successful.

> Sometimes I make phone calls and I say the same things that hostel staff say, but it's just seen to have more weight, which I think is a real shame because I think the hostel staff often know the person way better than I do.

Knowledge of the system is essential in being able to effectively advocate on behalf of beneficiaries. The clinical psychologist has brought in-depth knowledge to the team, has helped staff to better understand beneficiary rights and relevant legislation and how to use this when appropriate.

> I think it does take support from PDCs and sometimes from me to challenge Trust decisions, or even to know what the options are [...] Sometimes those people have then been banned from services, as well, so actually their rights aren't upheld, or the Mental Health Act is used only to control them, rather than to support them.

Improved understanding of multiple disadvantage

The clinical psychologist has worked with Opportunity Nottingham and Framework staff to help them understand the psychology behind behaviours and the benefits of adopting a psychologically-informed approach to working with people with experience of trauma.

> There's a lot of learning about people's backgrounds, it benefits us in terms of understanding how they're behaving, why, and what might work [...] there's [someone] in particular whose formulation meeting I sat in on. It was really helpful about understanding their childhood and the impact, and how it's shaped their view of services, and actually, where a lot of their anger comes from.

This knowledge has helped all staff members develop appropriate responses to behaviour and understand how best to work with people who many would find challenging.

In addition, the clinical psychologist is providing training in psychologically informed environments (PIE) and trauma-informed care. Opportunity Nottingham staff think this has had a positive impact on the way services understand, respond to and work with beneficiaries.

> I think [the biggest success has been] the concerted effort towards developing PIE and TIC [trauma informed care] services. [...] I think we're, kind of, seeing that paying off, really, in terms of the approach that people take [...] just increasing, really, the person-centred nature of the work.

Supported staff wellbeing

The clinical psychologist offers psychological consultations to Opportunity Nottingham staff and this is considered hugely beneficial in helping staff deal with the challenges of their work and encouraging them to switch off, limiting burnout and other consequences of the intense nature of working with people affected by multiple disadvantage. The provision of Critical Incident Stress Management debriefing has also helped staff deal with traumatic events such as the death of a client.

> When you work Monday to Friday, it blows your brains, absolutely. I couldn't switch off at weekends. I think I got to a point where all that week was stuck in my head, I had nowhere to take it and that's where [psychologist] come in who taught me, 'Look, on Friday, go on your computer, reflect on how your week went, put it to bed'.

Supporting staff in this way ultimately benefits them and the clients they work with. Consistency of keyworker is important to beneficiaries and will be enhanced if staff welfare is improved.

Improved cross-agency relationships

Both the CBT practitioner and the clinical psychologist have been able to build relationships with local services. This has helped improve understanding between services. Getting access to services can be dependent on having relationships with key individuals, so building these relationships is of benefit to clients.

> [The CBT practitioner's] been really good in liaison building with mental health services. Going onto the wards and making those contacts, and it's that thing that we always find, if you get to know staff and services, and see how they work, that kind of helps.

A key part of the psychologist's role has been to improve multi-agency working across the city. One aspect of this is setting up formulation meetings. These meetings bring various agencies involved with an individual together to understand more about the person, their background and behaviours, with the aim of being able to support them better.[3]

Learning from experience

It is possible to provide mental health support to people experiencing multiple disadvantage

Successfully supporting Opportunity Nottingham beneficiaries with CBT has demonstrated that even those with chaotic lifestyles can be supported and respond to this type of work – which is contrary to how secondary services often respond to people affected by multiple disadvantage.

> **"What we're challenging is the belief that you can't deliver therapeutic interventions for this client group, and through the work we're doing, we are going to be saying, 'Yes. Yes you can. You just have to do it this way.'**

Adopt a flexible and personalised approach

As a major benefit of having a CBT practitioner in-house is the ability to design a person-centred way of working. This should be built in to any service for people experiencing multiple needs from the start. The therapy provided by Opportunity Nottingham has been successful because it has been built around the needs, lifestyles and experiences of the beneficiary. The approach has a number of features which differentiates it from standard delivery in secondary mental health services:

- Delivered in a non-clinical environment, where the beneficiary feels comfortable
- Appointment times to suit beneficiaries, often the afternoon
- Appointments on the same day every week to avoid confusion
- Structured meetings going at the beneficiary's pace
- No time limit on therapy – beneficiaries can continue to have appointments as long as they are useful
- No waiting time for therapy
- Flexibility to take a break from therapy and return without the need for a re-referral

Opportunity Nottingham stress the importance of structured support and consistent messages – ensuring that the client knows what is expected of them, while also being realistic and not ending treatment if someone does not attend a session.

> If a client misses [an appointment] with me, it doesn't matter, we can catch-up the following week but I do make it quite clear that, 'If you're going to miss a few weeks, this isn't going to work.' It's about that structure and being continuous.

Be clear about roles and boundaries

Bringing mental health support services in-house requires a clear understanding from the start about staff roles and responsibilities, and the boundaries around the role.

> We had to sit down from scratch and draw up [a job description] to say what [the CBT practitioner] would and wouldn't do, and how referrals would be made, and what the expectations were. So, it was being really clear about what she was offering and the levels of therapy, almost as much what she's not offering.

It is also important to ensure that other staff know the boundaries of the specialist roles, what they can and cannot do to avoid inappropriate referrals.

Allow time to integrate different ways of working

While changes in beneficiaries have been observed, it is more difficult to judge the impact on the wider system. This is because it takes time to shift ways of working across organisations. Approaches such as PIE require ongoing training, time for reflection and adjustments across all aspects of working with people experiencing multiple disadvantage.

> It'd be hard to work in those hostels where you're just dealing with, you know, incidents and endless crises. It needs a real cultural shift and it needs to be embedded and it's not quick, is it? You can't just go onto training and just go, 'Right, I'm going to do PIE approach now.' You have to explore it, so it will take a long time.

Building relationships across services also takes time – there is no quick-fix for this, and it is a result of perseverance and determination.

> I think at the beginning, I didn't think that [I] was making much of an impact. I just felt as if, I was just another worker. You know, [mental health services] didn't recognise Opportunity Nottingham, they didn't really want to know. I think it was a bit later when we, kind of, carried on and carried on with it and we built that relationship up, it worked.

Taking it further

Having a clinical psychologist and CBT practitioner in-house to provide direct support to beneficiaries who are in desperate need of help is clearly beneficial. Opportunity Nottingham acknowledge that filling gaps in mental health provision by offering in-house services has been beneficial in the short-term, but is not a long-term solution and ideally, beneficiaries should be supported by the statutory mental health system to ensure continuity of treatment.

> "I am very selective in terms of who I take on because I would much rather someone was in statutory services so all their records are together. [...] So, wherever possible the first starting point is for someone to go through the [NHS] Trust for direct work.

Working outside the system will not change it. Improving access to services and encouraging a better understanding of people with multiple disadvantage is essential. Allowing the psychologist to dedicate time to this kind of systems change work has been valuable. But, ultimately, the mainstream mental health system needs to be better equipped to accept and work with people experiencing multiple disadvantage.

> "I guess having someone who can, in theory, open doors into a system is fine, but if the system doesn't work...

Find out more

Find out more about Opportunity Nottingham:
http://www.opportunitynottingham.co.uk/

For further information, please contact Mark Garner at Opportunity Nottingham: Mark.Garner@FrameworkHA.org

Endnotes

1. Based on New Directions Team (NDT) assessment scores. Five CBT clients were compared with five non-CBT clients with similar starting points and same baseline NDT assessment scores
2. Based on Homelessness Outcome Star scores
3. See https://www.tewv.nhs.uk/services/what-is-a-formulation-meeting/ for more detail

CASE STUDY #4

WY-FI's flexible psychological therapy service

West Yorkshire Finding Independence, or WY-FI,
is the Fulfilling Lives partnership for West Yorkshire.

What was the problem?

Statutory mental health services are often inappropriate, inflexible and difficult to navigate for people with experience of multiple disadvantage.

Most Fulfilling Lives beneficiaries experience both mental ill-health and substance misuse. They are often required by local mental health services to complete six consecutive months of sobriety before they can receive a mental health assessment. However, poor mental health and substance misuse are often bound-up together, with people using substances to self-medicate mental distress. As a result, few people have assessed needs.

> **We don't have a dual diagnosis worker in Calderdale [at this time]. So, it is disappointing when you've made a referral and you get somebody to assess them and then they're told, 'No, there's nothing they can do'. Although the beneficiary may say, 'I'm drinking because I'm experiencing these mental health problems'.**

Due to high demand, local mental health services have high thresholds for eligibility for services. Beneficiaries often do not meet these thresholds. But the negative impacts of their mental health problems are often compounded by the other disadvantages they face, such as trauma, homelessness, poverty and offending.

The local mental health services available tend to operate in a non-person-centred and inflexible way. The experience of beneficiaries and WY-FI navigators[1] is that the available support is often imposed – services know what's best. Furthermore, local mental health services operate in a way that is often too rigid for beneficiaries to engage with. Non-attendance, almost regardless of personal circumstances, can result in being discharged.

> **If you don't turn up then they may give you another appointment, but you really are skating on thin ice because you won't get another one after the second appointment. It is very difficult.**

It was clear to WY-FI that something had to be done to support beneficiaries who experience both poor mental health and substance misuse, and who were unable to access statutory mental health services. Beneficiaries needed help to stabilise their conditions to enable them to engage with treatment and other services. WY-FI also wanted to demonstrate that it is possible to work with this group of people if the support package is designed in the right way.

How did the partnership address it?

WY-FI commissioned not-for-profit mental health service providers Insight Healthcare to deliver a specialist service for people experiencing multiple disadvantage. This included providing mental health assessments and cognitive behavioural therapy (CBT) to provide beneficiaries with coping strategies to increase their ability to engage with other treatment and support.

> "It's teaching them strategies to be able to deal with their everyday life because that's what CBT does and having those strategies when you've nothing before, that's fabulous.

An Insight cognitive behavioural therapist was based at the WY-FI office in central Halifax, and they could also draw on other treatment and expertise offered by Insight. This allowed the therapist to work closely with navigators and selected beneficiaries to develop understanding and trust. When the beneficiary was ready, the therapist would deliver CBT sessions. The psychotherapist worked in a similar way to the navigators, being flexible and responsive to beneficiaries' needs. They accompanied navigators to visit beneficiaries in their homes to help build familiarity, trust and rapport.

> "We wanted Insight to be able to work directly with people like our navigators do, that meant person-centred, at point of need, to work flexibly with them. To go out to where they were, not just as people came in, to not worry about people not turning up.

The scheme was run as a one-off pilot between July 2017 and August 2018.

What difference did it make?

The provision of CBT made a positive differences to beneficiaries' mental health and their recovery. Furthermore, the co-location of a psychotherapist with navigators made positive differences to the WY-FI team in Halifax.

Improved understanding of beneficiaries' mental health needs

In total 35 beneficiaries completed a full assessment of their mental health needs with an Insight psychotherapist. Of those, fourteen went on to engage with CBT, with just under half completing the treatment.[2]

Without access to local mental health services, beneficiaries and navigators did not have an accurate understanding of a person's mental health needs. This meant that they were uncertain about the type of support needed. The provision of a full mental health assessment by Insight psychotherapists helped both beneficiaries and navigators to better understand and address needs.

Provided stability and coping strategies

The combination of CBT sessions and continued support from navigators helped beneficiaries who engaged with treatment to make improvements in self-reliance and stability. One beneficiary spoke about how he managed to complete six months of sobriety and was due to receive an assessment from the local mental health team. Before getting help from WY-FI he would get frustrated and abusive towards public service staff. With the combined support from CBT sessions and his navigator, he managed to acquire coping strategies that helped him control his emotions and behaviour around people in public services. Furthermore, while he now feels more confident and in control of his daily life, he knows that if any problems start to emerge with his mental health he can rely on WY-FI to support him.

> I'm doing a lot of stuff on my own now. I'm doing a lot of this stuff on my own, but I know that they're here. That's the thing. Sometimes I'll need to talk stuff over.

The flexible CBT service can also help beneficiaries overcome relapses and set-backs. For example, another beneficiary experienced a relapse to substance misuse while training to become a peer mentor with WY-FI. This set him back considerably. He completed a mental health assessment and several CBT sessions with the psychotherapist. This helped him to recover from substance misuse more quickly than he expected.

Better understanding and connections with local mental health services

Before Insight got involved, WY-FI staff experienced difficulties engaging with local mental health services. They either did not fully understand the referral processes or did not know the right professionals to contact. The psychotherapist worked alongside navigators when they advocated for beneficiaries in mental health services. This allowed navigators to learn correct terminologies, the right processes to follow and added health care professionals to their contacts. As a result, navigators were taken more seriously during their communications with professionals in mental health.

Learned cognitive behavioural therapy techniques

WY-FI navigators also learnt some CBT techniques that they can use when they work with beneficiaries. This has helped them to better handle situations when a beneficiary experiences problems. Moreover, Insight provided some CBT sessions for WY-FI staff and this helped them learn coping strategies with their case load.

Learning from experience

There were a number of factors that helped to ensure the effectiveness of cognitive behavioural therapy sessions for beneficiaries. These include co-location of the psychotherapist and WY-FI navigators, flexibility in the work pattern of the psychotherapist, and the importance of beneficiaries seeing the same therapist.

Co-locate therapists with outreach teams

Basing the psychotherapist at the WY-FI office made a big difference. This allowed navigators and the therapist to work closely together, to share information and understanding of beneficiaries. The WY-FI office is familiar to beneficiaries and provides a comfortable setting to introduce them to the therapist.

Co-location provided the opportunity for WY-FI navigators to learn about the therapist's practice and develop their own techniques. Navigators also learnt more about mental health services and started to make contact with key professionals.

Provide flexible appointments

Flexible appointments for CBT were important in ensuring beneficiary engagement. Beneficiaries were allotted two hours for CBT sessions rather than the usual one hour, to allow for late arrival, give time for beneficiaries to settle in and to take breaks.

> "Sessions weren't ever an hour, they were two-hour sessions, purely to accommodate diverse factors like concentration, memory, some, like [name], one of the ladies was in chronic pain, so we had to have lots of breaks due to drug use.

Beneficiaries did not always attend when expected and visited the office at other times in need of help. The therapist responded flexibly, recognising

the importance of being prepared for when a beneficiary is ready to talk. Unlike statutory services, beneficiaries were not discharged for missing appointments. This flexibility helped to build trust and was found to pay off over time with improved engagement.

> We started the pilot with really high DNA [did not attend rates] for all the assessments [...] once they were engaged in a relationship with that person and they knew they could rely on them, then the DNA rate significantly improved.

Go where beneficiaries are

Being prepared to go out and visit beneficiaries was an important element of the therapist's working practice. This would involve meeting beneficiaries at their home or at a venue where they felt comfortable, such as a coffee shop. This was particularly important in the early stages of building a relationship between therapist and beneficiary. Therapy sessions could be done either by telephone or face-to-face meeting, depending on the beneficiary's preference. Navigators played a key role in brokering meetings and helping to develop trust and rapport between all involved.

> We'd got a new referral and she was speaking to me [the navigator] about some things in her past. I mentioned to her about the CBT and asked if I could bring [the therapist] out [to her home] with me. She said, 'Yes.' And that just brought down quite a lot of barriers, because we went out into her home. She talked a little bit with the therapist whilst I was there. They took it from there and arranged their appointments.

Combine mental health treatment with navigator support

For people affected by multiple disadvantage, it's important that issues, including mental ill-health, are addressed holistically. The therapeutic

treatment was combined with ongoing support from navigators. Navigators worked to ensure other aspects of beneficiaries' needs were being addressed, such as organising suitable housing, ensuring correct benefit entitlements and helping people to engage with meaningful activities such as hobbies.

Getting a therapist with the right skills and attitude is key

Mental health specialists working with people experiencing multiple disadvantage need to be prepared to work flexibly and this may be different to how they have been trained or used to working. Several different Insight psychotherapists were engaged during the scheme and not all were prepared for the demands of working in a more flexible and responsive way. Recruiting people with not just the right skills and expertise but the right attitude was a challenge and meant there were sometimes gaps in service provision.

The key learning from this experience is to ensure that prospective candidates fully understand what the role entails and that they are willing to be proactive and work as part of the navigator team. More experienced therapists rather than newly qualified professionals appeared to be better suited to taking on the additional challenge of working in a less structured way.

> **"The attitude that you need, it's the attitude the navigators have, it's the attitude of, 'Right, anything could happen today and I'm going to be persistent, proactive, positive, optimistic.' You know? And not all CBT practitioners have that, not all therapists have that.**

Try to ensure beneficiaries see the same therapist

Beneficiaries spoke about the importance of ongoing sessions with therapists who know them and their back story. Seeing different professionals and having to re-tell their story can be frustrating, time-consuming and traumatic. If a therapist already knows their story, they can make more progress during the sessions.

> I really got on with her [the CBT practitioner]. They offered me someone else and I said, 'Look, I'd prefer to work with her, because she knows my background.' I didn't want to explain it all again. And that's what they do for you.

Taking it further

Working closely with Insight, WY-FI navigators have a direct link to psychotherapists who have a standing in local health services. This has continued beyond the life of the scheme, where navigators have been able to call upon the guidance and assistance of Insight when they encountered difficulties in accessing and engaging with mental health services. Insight have advised and assisted navigators to reach the appropriate professionals to ensure a beneficiary gets the support they need.

> Although the scheme's finished, they've just been really, really welcoming and they've said, you know, 'We'll try and push it through as best as we can', or, 'We'll give it priority', or, 'We'll have a look at it'. And yes, they've been really good, yes.

Find out more

Read WY-FI's latest briefing on the impact of mental health services: https://www.mcnevaluation.co.uk/wp-admin/admin-ajax.php?juwpfisadmin=false&action=wpfd&task=file.download&wpfd_category_id=338&wpfd_file_id=6532&token=acdf0009c1814ceac9f027b0973d4a9a&preview=1

Find out more about West Yorkshire Finding Independence: https://wy-fi.org.uk/

For further information, please contact Mark Crowe at WY-FI: Mark.Crowe@humankindcharity.org.uk

Endnotes

1. Navigators are service neutral staff members who build trusting relationships with beneficiaries and support them to re-engage with services and get person-centred help

2. Crowe, M. (2019) *Mental Health Assessment and Support Needs for People Experiencing Multiple Needs: A Report to the Calderdale WY-FI Locality Group* WY-FI

CASE STUDY #5

Golden Key's lived experience involvement in the local mental health strategy

Golden Key is the Fulfilling Lives partnership for Bristol.

What was the problem?

People with lived experience of multiple disadvantage are increasingly consulted in the design of local services, but have limited opportunity to affect broader strategic work. The strategic vision around mental health often misses the needs of people experiencing multiple disadvantage. This in turn leads to commissioned outputs and outcomes that aren't focused on their needs.

Golden Key identified a gap in mental health service provision for people with experience of multiple disadvantage, particularly between primary (day-to-day healthcare such as GPs, pharmacists) and secondary services (specialist healthcare such as hospitals, clinics).

How did the partnership address it?

Bristol, North Somerset and South Gloucestershire Clinical Commissioning Group (CCG) are writing their new ten-year mental health strategy. Golden Key Bristol have facilitated the involvement of Independent Futures (IF), a group made up of Golden Key beneficiaries with lived experience of multiple disadvantage, alongside Bristol Independent Mental Health Network (BIMHN), another group of people with lived experience of mental ill-health. Golden Key were approached by the CCG due to their broader range of experience working with people affected by multiple disadvantage and their relationships with relevant partners. The IF group are well-known in the area and members are regularly invited to meetings and consultations.

Group members have been involved in all stages of the strategy development. IF group members took part in consultation workshops with the CCG. Two workshops were run with 20 to 30 attendees, including people with lived experience. Participants contributed their experiences and thoughts firstly to contextualise problems and issues and secondly in identifying potential solutions. In-depth interviews were held in between the workshops to look at life journeys of people engaging with mental health (and other) services.

> "We spoke about what we would like to change when [the strategy has] gone through this commissioning, you know, what would we like to see different?

Following the workshops, one Golden Key beneficiary also agreed to compile and contribute some detail of their life experiences to the consultation process to bring a real and personal account of the link between early life experience and adult complexity into the strategy document.

As the strategy has developed, Golden Key and members of the IF group have been invited to follow-up meetings to test what is being written and asked for further input. The beneficiary who contributed their life story remained involved in the editing process. The role of Golden Key is not limited to providing experts but has continued in reviewing the strategy as it is developed. This has ensured that the expert voice does not get lost or diluted.

> **At these times when people are writing these big documents, there tends to be, sometimes, a bit of tokenistic consultation process. Then, stuff gets written into the strategy and then it doesn't really turn out like that, but... each time they've produced the outcome from the days, they've come back to us to make sure that they've got it right, and asked us if they think there's anything else that hasn't been included, or is there a different perspective on this?**

What difference did it make?

The strategy is still being written so any impact that Golden Key's contribution might have is solely on the development process at present.

Ensured the strategy incorporates lived experience

Genuine lived experience involvement in strategic work like this has the potential to change how mental health and related services support people with experience of multiple disadvantage. In this case the depth of involvement went beyond a token consultation and reflected a more genuine approach to co-production. It is hoped that there will be a tangible impact on the system as a result.

> Having the voice of lived experience absolutely brings home the points of the strategy. It really enhances the messaging.

> I don't think there's any substitute for having people with lived experience [involved] ... I thought they brought a lot, and I think they brought a very real perspective.

Raised awareness of the contribution people with lived experience can make

By working closely with the CCG, Golden Key have demonstrated that it is possible – and beneficial – to work with people with lived experience when designing health strategies. It is hoped that this will be recognised across the area and even contribute to a shift in the way other strategies are developed.

> The work that we've been doing in raising awareness about multiple complex needs has, moved people away from apathy or ignorance to a place of urgency about the need for doing something different, and that might be driving some of the engagement with the strategy and shifts in the way behaviours are happening.

Impact on experts

Involving people with lived experience in this type of work can have a positive effect on them. IF group members appreciated being invited to contribute their thoughts and enjoyed the respect afforded to them in speaking alongside professionals, and being treated as equals.

> "What was nice about it is, when you go to the workshop, you had to sit with people that you don't know... what I like about all of this is, there's no stereotyping, and that's really important. You feel like everybody's on the same boat.

For the beneficiary who contributed their life story to the strategy, this was a positive and therapeutic process and continued involvement in the editing stage has allowed this to continue as the strategy has developed. It is hoped that when group members can see how their contribution has shaped the final strategy document this will have an even bigger impact.

Learning from experience

Although the strategy development is still ongoing, there are a number of learning points that should be considered when involving lived experience groups in similar activity.

Get buy-in at all levels

All partners involved in the strategy need to buy into having lived experience involvement and be committed to this from the start. Golden Key have a close relationship with the CCG, as a commissioner sits on the Golden Key partnership board. This has helped to build a positive relationship between them and develop understanding of what Golden Key do and the importance of involving people with lived experience.

> "There's a real buy-in to thinking differently at a commissioner level [...] and really embracing that, right down to the nitty-gritty of user-experience as well.

Bring in external expertise where required/ respect what different players bring

The consultation workshops were designed and delivered by an external company. This helped to add credibility and independence to the process.

It is also important when a range of different agencies and organisations are involved to understand and respect the strengths that each partner brings. Golden Key were involved as an organisation with in-depth knowledge of working with people with lived experience; others had expertise elsewhere and a recognition of this was deemed essential to the success of the process so far.

> "We've had quite a healthy relationship around acknowledging each-others' subject matter expertise.

Ensure good understanding of multiple disadvantage before starting work

In the early stages of the strategy development, the CCG insights team worked with Golden Key to harness what they had learnt over four years of working with people with lived experience. This ensured the CCG had a good understanding of people affected by multiple disadvantage and how best to work with the lived experience groups.

> "I guess, with anybody who doesn't really work with this client group, they really underestimate the complexity.

Ensure genuine, varied and recent lived experience involvement

People with lived experience giving up their time and energy to contribute want to know that it will make an impact. Involving people with lived experience needs to be central to the work rather than a token offer or an add-on. Golden Key felt that the CCG understood this and as a result, they could give reassurance to IF group members who were asked to attend.

> I think what [IF group members] wanted was persuading while they were there that it wasn't just going to be water off a duck's back, and this wasn't some tokenistic effort.

The partnership highlighted the value of having a diverse range of voices represented. Lived experience should also not be understood or portrayed as a generic experience, but one that is experienced differently by different individuals. It is also important to ensure that contributors have recent experience in order to be able to comment on current services.

> I would get people more with lived experience in there. People that are using the service. Like, fresh heads, not stale ones, because there's something about, you always have to be up-to-date with services to know what's going on. If you're not up-to-date with it, you can't get the right information.

Make sure contributors are properly supported

People in lived experience groups are likely to have a range of needs that can fluctuate over time. While someone might be in a good place to contribute at the start of the process this can change. It is important to manage expectations and ensure people are not asked to do too much. There is always a risk that people are adversely affected by discussing difficult experiences.

> It's really scary when you go into those places... when you go into a room, it's like, sometimes, they expect you to have all the answers because you're lived experience and sometimes, you don't.

Meetings and consultations can be intimidating. Organisations like Golden Key can provide valuable experience, knowledge and advice on how to ensure people with lived experience are sufficiently prepared and supported. But, with enough time and resource, it is possible to involve even those with high levels of need.

> It is really difficult to capture the genuine client voice of people who are at the highest level of need, [...] So, I think that seeking the guidance of organisations who work closely with people who are working with the clients, letting them lead that process and giving them enough time for that is really important.

Keep timescales realistic but swift

The consultation process, from initial planning meetings, through the workshops to writing a final draft strategy, took approximately three months. This demonstrates that the necessary depth of consultation required can be achieved in a relatively short timeframe. Keeping the work moving swiftly is efficient but also important in reducing the risk of the lived experience voice being lost in an extensive revision process.

> I feel that if the change comes from anywhere, it comes from the energy, and what we're seeing, through this bit of work, is ideas that have come from practice going to strategy, in quite a quick and efficient way. It's not got diluted through going through managers and reports and all this sort of thing.

Taking it further

Following the consultation process, the findings are being presented back to stakeholders (including people with lived experience) for final comments. Golden Key continue to be involved and are hopeful that the final strategy will have a direct impact on how services are commissioned.

Find out more

Find out more about Golden Key: http://www.goldenkeybristol.org.uk/

For further information, please contact Joe Fisher at Golden Key: Joseph.Fisher@goldenkeybristol.org.uk

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