#### **FULL REPORT**

# Improving access to mental health support for people experiencing multiple disadvantage

#### **Evaluation of Fulfilling Lives:**

Supporting people with multiple needs





#### **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 partnerships¹ 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.<sup>2</sup> 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

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,<sup>5</sup> 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.<sup>7</sup>

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.<sup>8</sup>



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

#### **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, 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<sup>10</sup> 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<sup>13</sup> 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.<sup>14</sup> NICE guidance on people with coexisting severe mental illness and substance misuse<sup>15</sup> 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 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<sup>17</sup> 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.



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

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. 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 6–7). 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.<sup>19</sup> 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.

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. <sup>20</sup> The National Commission on Domestic and Sexual Violence and Multiple Disadvantage <sup>21</sup> 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

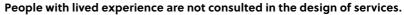


Negative past experiences can create a lack of trust in the healthcare system.

instances of mixed-sex mental health wards, which presents a risk factor for sexual safety, especially for women.<sup>22</sup>

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

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.



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.



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

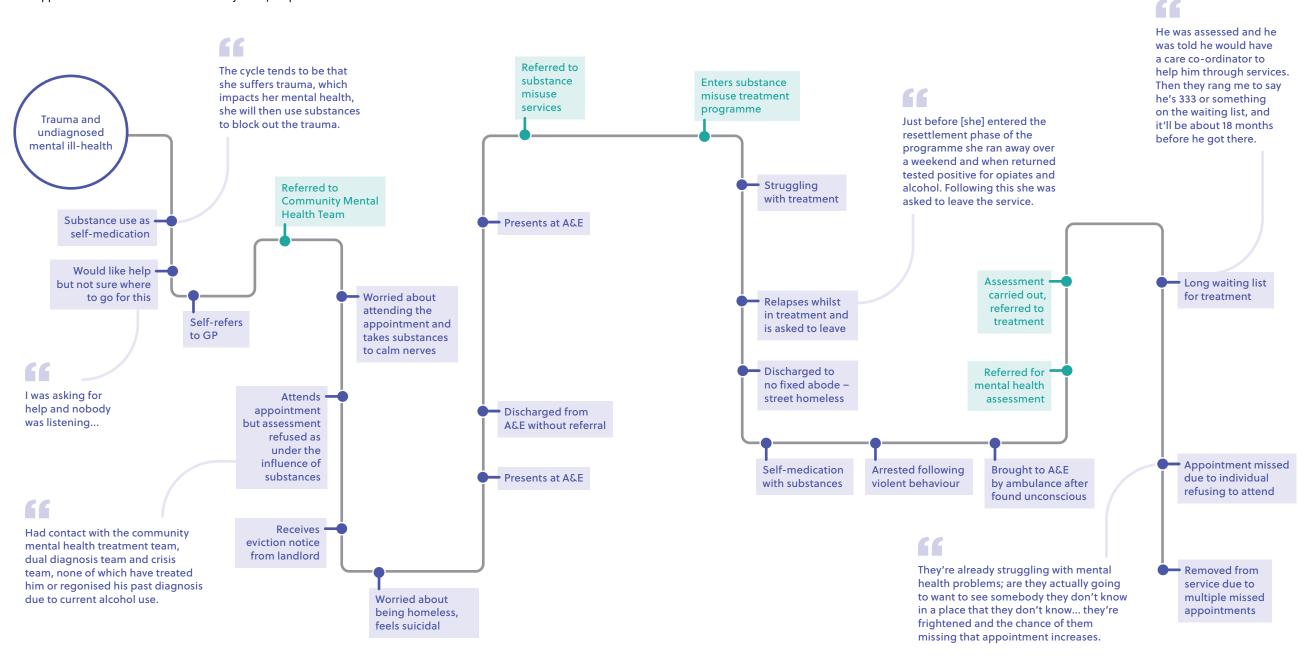
Gap between service thresholds. Many Fulfilling Lives beneficiaries are reported to be caught between gaps in the current structure of local mental health services. They are generally considered too complex for primary services (such as IAPT – Improving Access to Psychological Therapy) but are also often 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.

# KeyBarrier or negative experienceSupport 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.<sup>23</sup>

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.<sup>24</sup> 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 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



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.

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<sup>28</sup> 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.

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.



Psychologicallyand traumainformed approaches are important.



People with lived experience should be involved throughout the process.

# 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

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<sup>29</sup> 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.

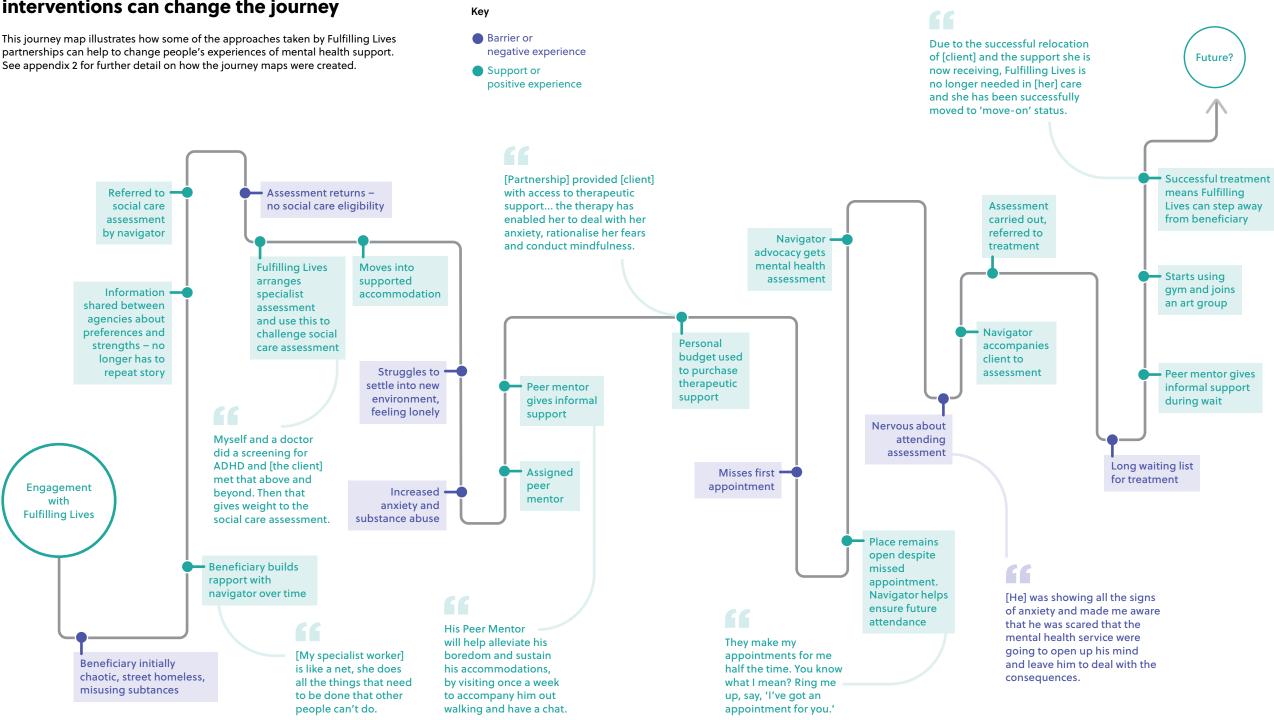
Some organisations unused to genuine co-production of strategies and services may underestimate the time and resource needed to effectively engage and support people with lived experience. There is always a risk that people will be adversely affected by discussing difficult experiences, and so it is 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

partnerships can help to change people's experiences of mental health support.





Fulfilling Lives partnerships have modelled a more flexible and personcentred service.

#### **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.

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<sup>30</sup> 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.<sup>31</sup> 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:

 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 psychologicallyand 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.

 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.

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:

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.

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**

- 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
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- Bramley, G. and Fitzpatrick, S. (2015) Hard Edges: Mapping severe and multiple disadvantage Lankelly Chase Foundation <a href="https://lankellychase.org.uk/resources/publications/hard-edges/">https://lankellychase.org.uk/resources/publications/hard-edges/</a>
- 5. Ibid p37
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- 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-makesa-difference-new-briefing-published/
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- 16. Public Health England (2017) p24

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  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-downthe-Barriers-full-report-.pdf
- 22. Care Quality Commission (2018) Sexual safety on mental health wards Newcastle: Care Quality Commission
- For example, see Emerging Horizons (2017) Lead Worker and Peer Mentor Fieldwork Evaluation
  Birmingham Changing Futures Together
- 24. See <a href="https://inspiringchangemanchester.shelter.">https://inspiringchangemanchester.shelter.</a> org.uk/gm-think
- <sup>25.</sup> '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) Crosscultural dialogues on Homelessness: From Pretreatment 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
- 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%20 briefing%20March%202017 0.pdf). Traumainformed 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?

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  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-multipleneeds-new-briefing-out-now/
- 31. For further information see <a href="http://meam.org.uk/">http://meam.org.uk/</a>

# 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™ and New Directions Team assessment²)

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<sup>™</sup> 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 <a href="http://www.outcomesstar.org.uk/using-the-star/see-the-stars/homelessness-star/">http://www.outcomesstar.org.uk/using-the-star/see-the-stars/homelessness-star/</a>
- 2 For further information see <a href="http://www.meam.org.uk/wp-content/uploads/2010/05/NDT-Assessment-process-summary-April-2008.pdf">http://www.meam.org.uk/wp-content/uploads/2010/05/NDT-Assessment-process-summary-April-2008.pdf</a>

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 35-38.

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/		0.994***	0.859**	0.186	0.557
therapies		(0.352)	(0.355)	(0.166)	(0.499)
Mentoring and befriending		-0.547	-0.954	-0.184	-0.552
and bernending		(0.554)	(0.725)	(0.218)	(0.653)
Education		-0.494	-0.899*	-0.083	-0.414
and training		(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.

<sup>\*\*\*</sup> p<0.01, \*\* p<0.05, \* p<0.1

#### **Evaluated by**



