



## Listening to people with multiple needs and those who support them

Making Every Adult Matter Coalition Clinks, DrugScope, Homeless Link and Mind

## Multiple needs and exclusions

People facing multiple needs and exclusions are in every community in Britain. They experience several problems at the same time, such as mental ill health, homelessness, drug and alcohol misuse, offending and family breakdown. They have ineffective contact with services, and are living chaotic lives.

## **Making Every Adult Matter**

Making Every Adult Matter (MEAM) is a coalition of four national charities – Clinks, DrugScope, Homeless Link and Mind – formed to influence policy and services for adults facing multiple needs and exclusions. Together the charities represent over 1600 frontline organisations working in the criminal justice, drug and alcohol treatment, homelessness and mental health sectors.

MEAM works across the country to help local areas improve support for people facing multiple needs. Using the MEAM Approach, we help local areas to design and deliver better coordinated interventions and to measure their impact. We also provide support to twelve areas across the country as part of the Big Lottery Fund's Fulfilling Lives: Supporting people with multiple needs programme.

Through Voices from the Frontline, the four MEAM organisations are seeking to bring the voices of people with multiple needs and those who support them to the heart of the policy debate.

Find out more at www.meam.org.uk



## **LankellyChase Foundation**

The LankellyChase Foundation works to bring about change that will transform the quality of life of people who face severe and multiple disadvantage.

It focuses on the persistent clustering of social harms such as homelessness, substance misuse, mental and physical illness, extreme poverty, and violence and abuse. LankellyChase also wants to drive systems change in order to radically reshape the services designed to reduce these harms.

The Voices from the Frontline programme at MEAM is generously supported by the LankellyChase Foundation.



## Introduction

People with multiple needs live in every community, but often fail to get the co-ordinated support they need. The way services are set up means they fail people facing complex problems – which may involve mental health issues, substance misuse, homelessness and offending.

Most of us agree people should be involved in decisions about the services they use or the work that they do. Many local services do everything they can to actively involve people from their communities.

However, when it comes to the big policy decisions that are being made now around health, welfare and social support, frontline voices are rarely heard.

Better policy for this group needs to start with a conversation between:

- people experiencing multiple needs;
- · those who work with them; and
- national and local decision makers

Over the next two years, we aim to engage policymakers in these conversations and show exactly what the voices from the frontline have to offer.

This booklet includes findings from a survey of over 140 services working with people experiencing multiple needs. The full results and methodology are available in an accompanying report, *Evidence from the Frontline*, available at www.meam.org.uk/publications

We brought together over 50 people from across the country: some were currently engaged with services, others worked in frontline roles.

A range of organisations across homelessness, mental health, substance misuse and offending hosted the conversations. These included residential services, drop-ins and specialist centres working specifically with women and young people.

Rather than ask people lots of questions, we had an open conversation about their experiences, what's changed, and how it has affected them.

Read on to find out what they said.

## Why do services fail people with multiple needs?

People told us that living with multiple needs can be tough. Getting help with one issue can be hard enough, but for those who have many at the same time, it becomes much more complicated.

Our support system treats people based on what it considers to be their primary need, be that mental ill-health, dependence on drugs and alcohol, homelessness or offending.

I found the problem [with the service was that] if they couldn't pigeonhole you then that was it. You know what I mean? The fact that they couldn't say 'well, you've got this personality disorder or you've got that personality disorder...'

## Life sequences of people with multiple needs

In 2010, a team at Heriot-Watt university looked at the sequence of events in the lives of people with multiple needs. They found four broad phases:

- **1. Substance misuse:** Experiences of abusing solvents, glue or gas; leaving home or care; using hard drugs; developing a problematic relationship with alcohol and/or street drinking.
- **2. Transition to street lifestyles:** Becoming anxious or depressed; survival shoplifting; engagement in survival sex work; being the victim of a violent crime; sofa-surfing; spending time in prison; being made redundant.
- **3. Confirmed street lifestyle:** Sleeping rough; begging; and injecting drug use. Being admitted to hospital with a mental health issue; becoming bankrupt and getting divorced.
- **4. 'Official' homelessness:** Applying to the council as homeless, and staying in hostels or other temporary accommodation; being evicted or repossessed and the death of a partner.

Source: Fitzpatrick, Bramley and Johnsen (2012) *Multiple Exclusion Homelessness in the UK: An Overview of Key Findings*, www.sbe.hw.ac.uk/documents/MEH\_Briefing\_No\_1\_2012.pdf

Because people with multiple needs do not fit neatly into a single category, it's rare that a single service can meet all their needs.

Over 90% of all of our clients [have a] dual diagnosis that is not being met. And it really, really pisses me off, [...] the fact that you've got to have a primary issue to access services in this country. I believe everyone should be able to access mental health services, no matter what. If you self-medicate [...] you've got to come off those to go into your detox or your rehab, or a mental health service. And people can't do it.

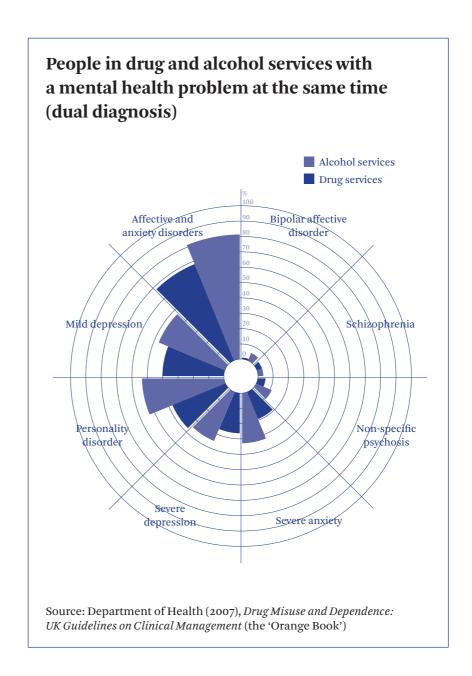
The support system is very inflexible when people do not progress in the way it expects. Sometimes they're offered support for a limited period of time, or that doesn't cover all their needs.

I don't understand why it's a one-shot deal. You only get a one-year period with the service, but yet we work with young people over a nine year span of their lives, potentially [...] So why can't they come back repeatedly, if they get a house at 18 and they struggle at 23?

When seeking support, it can be hard for people with complex needs to explain what's wrong. There are few opportunities to describe their different needs and how they fit together – especially to services that are focused on just one thing.

When you think of people with mental health needs, a lot of them come from very deep rooted issues like sexual abuse or physical violence. It's taken them a lot to come and open up [to me as a counsellor]. They're

not going to tell people within the benefits system: they don't want to share that information. [People] have no idea of that person's story, and they don't think for a minute that there might be reasons that they're like that.



It can be really difficult to navigate the system when accessing services or trying to claim benefits. Organisations seem complex and difficult to engage with.

For young people who are expressing complex needs to go through that system, they can't get their head round how the system works – so why would you engage with somebody who just talks jargon at you, and tells you to come back in a month's time to see somebody else about another assessment?

And even with the help of expert staff it can be hard to get issues resolved.

There are staff in here that will headbutt the wall constantly to help you, but [other services] won't meet them halfway – JobCentre, council, anyone.

# What are the new challenges?

The system has always struggled to help people with multiple needs, but people told us that recent changes are making matters worse. In particular, some of the things that used to help people through difficult situations are falling away.

## Pressures are increasing

The way that services are commissioned has changed a lot as budgets tighten. This means services don't have as long as they need to work with people.

The big change [is] that we only get 12 months now to work with them, whereas previously we had two years. [Where] clients we have worked with who have really complex needs have been successful, it took a year to get them to engage, and then a year to actually do something with them, and then they could move on. Whereas now we've got a year to do it all. I can't see us being able to achieve the same results.

Doing more for less also reduces the personalised support that people with multiple needs benefit from most.

To deliver, like, a personalised service is quite hard under pressure, isn't it? [...] You don't feel like you're getting a personal service – in the door, out the door, and that's it – and you're just the same as the next person, when your needs haven't been assessed.

Having a single person to work with, who is in regular contact, makes a big difference.

In here, yeah, they're really good: 'I'll put your application into this place, I'll let you know on this date'. You see them every week, so you always know from day to day what's going on.

It's also good if staff have personal experience of the issues they're helping others with.

There's some staff here that have been through this: that have lived here, been to prison, done everything that we've done, and they're the ones that I find it easy to [talk to] - 'cause they know.

## Services are poorly joined up

Often, people need specialist help from a range of services in the community, and getting access to these can be a struggle.

It's becoming harder. Where before we could access services [for] the more specialist work that was needed, it's much harder now to get them into those services, or the services just aren't there anymore. [...] You get someone on your books, and you're thinking to yourself 'this is kind of pointless, because I know I'm not going to be able to achieve with them what needs to be done'.

Meanwhile, where services do exist, they can be less open to people with a range of needs.

A resident, he's identified himself that he would benefit from a talking therapy. I've had to be explicitly clear, but without putting words in his mouth, that if he discloses any cannabis use, he is likely to be refused a service with talking therapies – because this happens a lot – and he'll be batted back to the drug and alcohol agency, which I personally don't feel he needs at the moment.

This seems to be a particularly big problem with mental health problems, which can prevent other issues being resolved if they aren't addressed.

We're not mental health specialists. I think we're concerned that we take them on so that they don't drop between the gaps. [...] But then the other services who potentially should be picking them up will go, well, we're not because they're already working with you guys.

Having a care co-ordinator or key worker who is able to work on your behalf can help, especially if there is a trusting relationship.

You can get a key worker or care coordinator, and they will help you with your misuse and other things, but you've got to be honest with them, and tell them everything, otherwise they're not going to be able to know where to point you in the right direction.

## Welfare reforms are taking effect

There have been big changes to the welfare system, and these are having a negative effect on people with multiple needs.

## Selected changes to the benefits system

- Sanctions: since 2012, heavier penalties have been placed on people who fail to meet the conditions of their benefits.
- **Benefit caps:** from April 2013, limits were placed on both housing support and overall payments.
- Bedroom tax: from April 2013 the 'spare room subsidy'
  was removed, reducing housing support for people with
  an additional room.
- Work Capability Assessments: in recent years there have been several big changes to how people are judged able or unable to seek employment.

Sanctions have increased dramatically, and many people have had problems as a result – particularly when trying to appeal decisions that have made their lives difficult.

All you do is you get a little thing at the back of it [that] says 'if you disagree with this decision, please write to this address'. And you write the disagreement, honest to God, it takes weeks and weeks on end. Then you get asked to come into a benefits centre to talk to somebody. And then it goes another couple of weeks. By the time that's finished, your sanction's over and you're back on your Jobseeker's again!

The threat of losing benefits has an effect on people beyond their finances. For those with other things going on in their lives, it can be hard to keep on top of what's required.

Me, I'm not used to signing on, and it doesn't seem like a big deal, but it is because you've got to worry about [whether] you've done the right jobs, you've got to make sure you turn up exactly on time, otherwise you're gonna get sanctioned. Do you know what I mean? It's a lot of stress.

## An increase in the number of people being sanctioned

Between the first quarters of 2013 and 2014, the number of people on Employment and Support Allowance who were sanctioned rose by 346%.

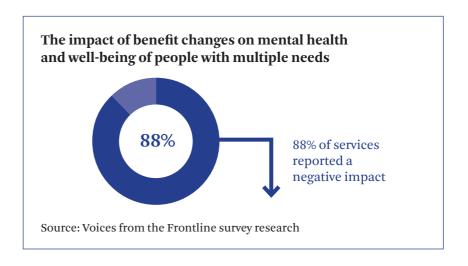
Source: Department for Work and Pensions (2014), *Jobseeker's Allowance and Employment and Support Allowance sanctions: decisions made to March 2014*, www.gov.uk/government/statistics/jobseekers-allowance-and-employment-and-support-allowance-sanctions-decisions-made-to-march-2014

79% of services reported that sanctions are affecting over half of their service users with multiple needs. Sanctions were viewed as having the most negative impact of all welfare changes we asked about.

Source: Voices from the Frontline survey research

New interviews for some benefits have also been a source of stress – for example, the Work Capability Assessment.

I've got one client and she's constantly being called in to be assessed. She's got very severe anxiety and depression, and she's had a life – a really difficult life – she can't say a sentence without having a breakdown, you know. [...] It's too much for her to even have a phone call once a week, it makes her worry the whole week waiting for that call to come in, and worry that they're going to stop the benefit again.



This is particularly true for vulnerable people, such as women who have experience of domestic abuse and may worry about the stigma of being dependent.

The anxiety of just going for the benefits and things in the first place is really huge for a lot of women. They feel guilty about having benefits, they actually want to be working. [...] The abuse that they've taken for a lot of years, that they would be scroungers, they wouldn't be able to live on their own, they wouldn't be able to live without a partner, or whatever else. All of that kind of stuff is really triggering for them.

When issues arise, people with complex situations often prefer to speak face-to-face, but increasingly are being asked to use the phone or the internet. Often, it's the small things that matter. Many people – whether claimants or support workers – loathe the JobCentrePlus hold music, which they have listened to for hours on end.

Do you know I would actually pay 50p out of my giro for them to change that. I told the woman on the phone, I said listen: take 50p out of my giro, go and buy a new song. iTunes! 99p!

In dealing with outside agencies such as JobCentrePlus, people benefit from having an advocate who can help them through the process.

There's a guy who deals with benefits in this building, and he is \*shit\* hot. He is the guy! He filled it out for me, he spoke to my doctor, he got a letter from my doctor to add to it, and he did everything he possibly could.

And where people build an effective relationship with committed staff at the JobCentre, it makes a big difference.

I think I've just been lucky who I've had ... he's went above and beyond, and when he's put us on courses and stuff, he's rang round and done a lot.

# It's not just one thing

Alone, these changes would be troubling. But together, they interact in unexpected ways for people with multiple needs.

A difficulty in one part of the system often leads to a problem in another.

I self harm, and [the service] are like, no, you can't use the services. We don't want you here. And I'm like, okay then. And then that has a roll-on effect with my GP, which then was 'well, you're not interested, you're not trying'. Which then has the snowball effect that my benefits were, well, you know – 'you're not complying, you're not helping yourself.' And I'm trying to say to people, hold on a minute, it wasn't me, I turned up there and it was them that turned around and said 'you can't come in'.

These setbacks are caused not only by the practical barriers people come up against, but also their sense that the system is treating them unfairly.

When policy starts to change about the sharing, and the withdrawal of benefits to certain under-25 year olds and all the rest of it, [it becomes] frustrating for them, because they see nothing ... no prospects of a job, no prospects of a place of their own. [They think], 'well, if I'm gonna go out and have a drink, I might as well have four'. [...] No matter how much we can put sticking plasters on certain things, it becomes more and more difficult to give them a sense of hope.

The impact of welfare reforms on people's ability to engage with the job market



2% of services believed that welfare reforms were having a positive impact



55% reported they have had a negative impact

Source: Voices from the Frontline survey research

Difficulties when dealing with the benefits system can cause stress and also increase people's needs.

I've returned to alcohol now, because I'm so stressed. I've got a court case going on with my children, who are going to be removed from this country... nothing to do with me, but that's the way it's going. It's just got to the point where all of these things have just come into a massive great big circle. [...] You're banging your head against a brick wall.

People want to work, and need the right support to move towards employment. But at the moment, not everyone is getting it.

For six weeks I had to go with no money. To get to work, with no money. The Work Programme provided us with a pass, and said 'oh, we want the money back for that pass, by the way'. You know, you're telling people you want to get people into work, but you're not actually helping them, when they've got themselves a job.

All in all, there are enough challenges facing people with multiple needs: changes to the support they depend on should help them overcome their difficulties, not make matters worse.

This vicious circle, in what I call the real life – not the sugar-coated, the real life – is getting bigger and bigger and bigger, and there are not the services around to actually help people. So, it's just like, seriously, swimming in a pool with a load of sharks that somebody's just waiting to open a cage and go, there you go: bang. 

## Join the conversation

The voices you've heard from tell us about some of the things that work for people with multiple needs – and some that don't.

Usually a publication like this would end with some proposals for what the government and policymakers should do next.

But as you've seen, changes to policy interact in unexpected ways. These issues need deeper exploration, through an ongoing conversation with the people who know best what could solve them.

We're asking MPs, Peers and Parliamentary candidates to commit to listen to the voices of people with multiple needs, and those who support them.

- If you can influence policy on these issues, we're inviting you to:
- 1. Commit to listening to people with multiple needs. Spend some time at services near you, and find out more about the experiences of people with multiple needs. We're happy to connect you with organisations in your area.
- Get to know the people who can create change where you are commissioners, Directors of Public Health and officials.
   Ask difficult questions and help them to understand the issues.
- 3. Work with us, people facing multiple needs and those that support them in the run-up to the election in May 2015. Together, we'll make the case for how the next government should act on multiple needs.

Will you join us?

## Acknowledgements

Voices from the frontline – of people engaged with and working in services across the country – fill this booklet. We are grateful for their time, insight and honesty.

Thanks to all the services that worked with us, and particularly those that helped host meetings:

- Bea at St Mungo's Broadway
- · Lucy at Oxford Homeless Pathways
- Erin at Depaul Housing
- · Lisa at Brighton Women's Centre

The conversations were facilitated by the Voices from the Frontline team across MEAM:

- Jonathon Graham, Homeless Link
- · Andy Kempster, Mind
- · Nicola Drinkwater, Clinks
- Sam Thomas, DrugScope

This booklet was produced by Jonathon and Sam, with help from the team and the Voices from the Frontline steering group:

- Paul Anderson
- · Andrew Brown
- Ellie Cumbo
- Oliver Hilbery
- · Helen Mathie
- Jacqui McCluskey
- · Louise Rubin

Thanks also to Alice Evans at the LankellyChase Foundation, Nathan Dick at Clinks and Ruth Goldsmith at DrugScope for their insightful comments.

Designed by Rachel Bray at Soapbox.

## Find out more

Find out more about Voices from the Frontline on the Making Every Adult Matter website:

## www.meam.org.uk/voices-from-the-frontline

If you'd like to find out more about getting involved in the project, contact:

Sam Thomas Programme manager, Voices from the Frontline samt@drugscope.org.uk @iamsamthomas When it comes to the big policy decisions being made now, frontline voices are rarely heard. We aim to show exactly what they have to offer.