Independent review of drugs: part 2 – prevention, treatment and recovery (call for evidence)

Expert Link submission – July 2020

Introduction

1. Expert Link is a peer led organisation championing the voice of people with lived experience of multiple disadvantages, including homelessness, mental health issues, substance misuse, offending and domestic violence and abuse. We advocate for a world where people with lived experience of multiple disadvantages are treated as equal partners in decisions made about our lives.

2. We have a national network of people with lived experience of multiple disadvantages, using their wisdom to influence local and national policy. Our network is diverse, brought together by a programme of strengths-based training which supports people with lived experience to be involved in service development and to demonstrate to service providers and commissioners the power of involving them.

3. This submission has been developed by our National Advisory Panel, made up of people with lived experience of disadvantages from across England, all of whom are closely linked to the communities we're serving. Membership spans across Bedford, Blackpool, Croydon, Durham, Exeter, Fareham, Hertfordshire, Leeds, London, Sheffield and Stoke. Many of our Panel have experience of accessing or working within drug treatment services, and have particular expertise in relation to how services work for people experiencing multiple disadvantages.

4. Our submission focuses on preventing problematic drug use, the lived experience of accessing drug treatment and the effects this has on engagement, recommendations for change within the workforce, and positive practice that has taken place during the response to the COVID-19 pandemic. **We would welcome elaborating further on any of the information provided.**

1) What interventions are the most effective at preventing problematic drug use? Answers can relate to universal or targeted interventions for both adults and young people. Please include any good practice examples

5. Many of our Panel have experience of accessing or working within drug treatment services, and have particular expertise in relation to how services work for people experiencing multiple disadvantages.

6. In our experience, any intervention relating to drug use must be **community based**, **trauma-informed** and **personalised** to the individual. According to Hard Edges: Mapping Severe and Multiple Disadvantage in England, 85% of people who have experience of multiple disadvantages have experienced adverse childhood experiences. If interventions do not recognise this, and are not delivered in a way that is trauma-informed, it is unlikely that they will be accessible to people who need them. They also run the risk of re-traumatising individuals and thereby compounding disadvantage.

"Policing out and medicating out has never worked - you need community." ***Member of National Advisory Panel***

7. Our evidence also suggests that appropriate education is a key preventative intervention, and we believe this needs to start at a young age when people are curious about using drugs.

8. In many cases, current interventions in this regard need to be improved, moving away from an approach that is frightened to talk about the dangers of drug use to one based around honest conversations. Different settings and mechanisms may be required to ensure different communities are reached (e.g. the BAME community, where in some instances drug treatment is seen as a taboo).

"People shouldn't be frightened to talk about the danger of drugs. You need honest conversations with people." ***Member of National Advisory Panel***

"I think they're a bit soft with kids. The people who are good at educating, they can't glorify, you have to know how to present it." ***Member of National Advisory Panel***

"There's a taboo that's in BAME communities about treatment and drug use, and there's no education there for communities to understand and prevent drug use. It's been an on-going theme, especially in the Asian community. It's worth educating local community centres, and maybe young offenders." ***Member of National Advisory Panel***

9. People with lived experience of substance misuse have played a vital role in providing educational interventions in some areas, for example Blackpool. **This effective practice should be scaled up across the country.**

"The best are the guys that have been through the journey." ***Member of National Advisory Panel***

"(We need) lived experience going into schools, colleges, community groups etc." ***Member of National Advisory Panel***

14) Why do some drug users who need treatment not access it?

10. In our experience, either of attempting to access services or of working in them, there are a number of reasons why people do not access treatment.

11. In some areas there is a **lack of knowledge** amongst people experiencing disadvantage of the services that are available.

"A lot of work needs to be done on informing. People don't know how to access support services – sometimes there are too many services." ***Member of National Advisory Panel***

12. Some services can also be inaccessible due to **delayed, infrequent appointments at fixed times,** which put an unnecessary level of burden on the individual. This is particularly problematic given the number of other responsibilities that people experiencing multiple disadvantage may have e.g. appointments with Jobcentres, sourcing income, appointments with key workers and local authorities. Further, travelling to appointments may require funds which are not available.

"Too many barriers to appointments - the times and (physically) getting there. Services need to be more flexible!" ***Member of National Advisory Panel***

"The services aren't flexible." ***Member of National Advisory Panel***

"…And they can only see them once every few weeks for half an hour!" ***Member of National Advisory Panel***

13. There can also be little choice relating to support that people can receive. For example, in some areas support currently only focuses on prescribing and group activities.

"There's no choice, it's all about prescribing." ***Member of National Advisory Panel***

"*You need rehabilitation – at the moment there's just groups on reducing motivation."* ***Member of National Advisory Panel***

"4 years ago it was you have to join a group. People can't handle groups! Then it moved to NHS model of care, where you treat them as patients. There is no feeling! It's never "Have you had a traumatic experience?" Treatment is the whole person, it cannot be broken off." ***Member of National Advisory Panel***

14. In many areas the support that is available is dehumanising, focussing on 'deficits' of individuals rather than the strengths and goals that individuals have. An unnecessary focus on commissioned outcomes can also lead to support focussed solely on levels of drug use, rather than on treating individuals holistically.

"It's punitive. It's controlling. You do as you're told, or you're not getting your meth script." ***Member of National Advisory Panel***

"Support meetings are too structured, just focussed on reducing drug use, not around addressing trauma. There's a number of mitigating factors." ***Member of National Advisory Panel***

"There's not a lot of choice around it. People won't go back into treatment and be spoke too like a child." ***Member of National Advisory Panel***

"I was in a massive hostel. I wanted to stop injecting heroin and crack. They're plan for me was go to a place in [Location]. Take a ticket like at a cheese counter. Expected to do it every day. Why do it when I can go out and beg for £10? … In the end I just reduced… (I thought) "I'm not being humiliated like that!"" ***Member of National Advisory Panel***

"I want to be treated with dignity. …I am not a number." ***Member of National Advisory Panel***

*"You're treated like a ****. Daily pick up. Pharmacies calling your name out. Breaching your rights."* ***Member of National Advisory Panel***

*"There was no system that was going to tell me to stop doing drugs… Every time I engaged with the system it was a ****ing nightmare."* ***Member of National Advisory Panel***

"There is an over obsession with data. A lot of assessment forms are tick boxing, and forms shape the conversations." ***Member of National Advisory Panel***

"Commissioners have a set budget and providers force the service to fit into that budget, forced into being 'cost effective.' Commissioners have a duty to look at service… it can be done in a more compassionate way." ***Member of National Advisory Panel***

"It's outcome focussed, it's not person focussed." ***Member of National Advisory Panel***

"It shouldn't be about case notes and risk assessments. It should be about care for people." ***Member of National Advisory Panel***

"Recover can be anything that a person wants. Treatment can be whatever a person needs. But we (staff) believe we have to meet outcomes. But you have entered ***into a relationship****."* ***Member of National Advisory Panel***

"Recovery is a lifelong journey." ***Member of National Advisory Panel***

15. Evidence from our Panel also suggests that in some services staff attitudes, amongst frontline workers and commissioners, leads to stigmatising approaches and un-even power dynamics between worker and 'service user.' This in turn facilitates a lack of honesty and accountability within a service, and a lack of engagement from people using drugs.

"Staff are the biggest issue." ***Member of National Advisory Panel***

"The way commissioners spoke about people!" ***Member of National Advisory Panel***

"Non-judgmental comes from within. You have to bring your heart into the job." ***Member of National Advisory Panel***

"A lot of professionals think they know better." ***Member of National Advisory Panel***

*"I know someone who would come all the way in, and say **** it (and leave), given that some member of staff was on."* ***Member of National Advisory Panel***

"Prescribers prescribe in regimented way. It needs to be cohesive, joined up, and about care… If you have no understanding of human beings, you can't do the job." ***Member of National Advisory Panel***

"You need to feel like you can speak to the worker… I spoke to the person who helped with the job stuff etc." ***Member of National Advisory Panel***

"They recommission services every year. All these services change, but the people [staff] are the same. They've been there for years, haven't, or can't change their ways. Don't care. You can recommission services, but you've still got all these people in services that work the same way they did 20 years ago." ***Member of National Advisory Panel***

*"When I was in treatment, I just wanted a script. Yeah, probably sold it. I was in treatment for about 18 years, got the script and toddled off. Left. If you wanted to see a drug worker, you had to go somewhere else. Now you haven't got a separate person to speak too, someone to say that you ****ed up etc… The drug workers have control of the script. Everyone is lying so they get the script."* ***Member of National Advisory Panel***

"People need to be held to account so if they talk to people like shit or treat people like shit. But at the moment, if you speak someone, they're holding your script, so they're not going to do something that risks that." ***Member of National Advisory Panel***

16) How could the capacity and competence of the drug treatment and recovery workforce (both providers and commissioners) be improved?

16. Given our extensive experience relating to accessing and working in drug and alcohol services, the National Advisory Panel have the following recommendations to improve the capacity and competence of the drug treatment and recovery workforce:

"It's about building up a relationship that is stronger than that with the drugs." ***Member of National Advisory Panel***

Recommendation 1: Train staff on the reasons those experiencing multiple disadvantages may have substance misuse difficulties

"Too many times we still hear that people have to deal with substance misuse and not recognising that for some it's a way of self-medicating." ***Member of National Advisory Panel***

"For them to have a better understanding of this client group!" ***Member of National Advisory Panel***

Recommendation 2: Employ and support people with lived experience of accessing drug and alcohol services throughout the workforce providing interventions.

"They should employ more people with lived experience. When you have been through the process you can understand it a bit… You just connect with people. If you haven't done it… You just feel that its them and us." ***Member of National Advisory Panel***

"Service managers should also be trained specifically in how to manage people with lived experience positively – too often those in the team who have a history of substance use are ostracised for not being hard-line enough, so their wisdom gets lost. So it's not just about employing more people with lived experience, but about ensuring that those with lived experience are encouraged to influence team culture." ***Member of National Advisory Panel***

Recommendation 3: Reduce reliance on outcomes measures and ensure staff meet a set of standards which will support recovery

"They have to ditch opiate free discharges." ***Member of National Advisory Panel***

"There needs to be training on what's no longer acceptable, like comments on people being born bad or it's a lifestyle choice. There should be a strict set of standards, and we need good staff members who know they are right in challenging these attitudes to have the information to hand on why they are right. MHCLG can have a big role on shouting loud and clear to councils on what's no longer acceptable." ***Member of National Advisory Panel***

"The set of standards should be enforced by a third party, as an organisation will be afraid of losing a tender." ***Member of National Advisory Panel***

Recommendation 4: Ensure all people experiencing multiple disadvantages receive housing as the basis of their support so they can realistically engage in treatment where they choose.

"Just giving them a roof, and free food, and not paying bills, was the biggest thing for them to stabilise their treatment." ***Member of National Advisory Panel***

Recommendation 5: Increase the choice of support available which meets the needs and aspirations of the individual. This can build on some of the positive work during COVID-19 relating to rapid prescribing, phone call engagements and outreach work (see question 24)

"Most positive is harm reduction, needle exchange on the street. It's the best intervention." ***Member of National Advisory Panel***

"There needs to be more choice, it's not all about prescribing." ***Member of National Advisory Panel***

24) What lessons can be learned from the way that drug prevention, treatment and recovery services have responded to coronavirus (COVID-19)?

17. There have been many positive developments relating to the way that drug services were delivered during the COVID-19 pandemic.

18. In some areas, rapid prescribing was offered to people experiencing homelessness, allowing them to receive support at the time when they needed it, rather than at an extended period into the future. People were trusted to receive higher quantities of prescriptions, reducing time and stigma associated with picking up prescriptions from pharmacies. Phone call engagements were focussed on relationship developments, rather than assessments for prescriptions. Services also increased their outreach, taking the support that people required to them, rather than making people fit into an inflexible appointment schedule.

"There needs to be more choice, it's not all about prescribing. People have enjoyed the phone calls [during COVID]. The workers have had time to build relationships, not just urine tests, not daily prescribing at the chemists. Drug deaths have reduced dramatically." ***Member of National Advisory Panel***

"Prescribers have been more flexible, some have been given weekly pick-ups instead of daily and has given some a feeling of being trusted where they weren't before." ***Member of National Advisory Panel***

"We wanted to prevent people using other illicit drugs, so asked for rapid prescribing – doctor wasn't happy as it meant had to turn over clients in a week! But to save pressure we wanted a week's prescription in hand. This was about looking at people's needs and looking at what was presented, they can't wait a month." ***Member of National Advisory Panel***

"We took all the drug services to them (rough sleepers in hotels). Rapid prescribing, didn't have to see a doctor, needle exchanges took to them, safe boxes for the methadone. Had to do rapid prescribing and a telephone buddy. Treat people like adults. We had two drug deaths, before that had 4 or 5 a week. We've been advocating for all that, and it's all happening now. Seems to be working so going to keep it like that." ***Member of National Advisory Panel***

19. An appropriate legacy for this work would be for:

- **Rapid prescribing to be offered to people experiencing homelessness**
- **Less stringent requirements around accessing prescriptions (with associated appropriate safety measures such as access to safety lock boxes, etc)**
- **Option for phone call engagements were appropriate and chosen by the individual**
- **Increased outreach support which take services to individuals where needed.**

We would welcome elaborating further on any of the information provided. Members of our National Advisory Panel would also be available to provide oral evidence to the inquiry where required.

Contact

Chris Brill, Policy and Communications Manager, Expert Link
Chris.Brill@ExpertLink.org.uk