Lived Experience Report

WORKING WITH EVERYONE

NHS addictions provider alliance

Foreword

Addiction is a highly stigmatised condition, largely due to ingrained perceptions and misconceptions in society, its complex effects on the behaviour of individuals and the fact that it is frequently seen as a 'choice'. However, it can affect anyone regardless of their background, and the stigma it comes with is even more widespread, impacting families and communities as well as individuals.

Far from a choice, addiction is a mental and physical health condition that can sometimes be linked to past trauma and adverse experiences. Treatment can help people to recover from addiction, and also address the acute physical and psychological needs that it is associated with.

However, stigma and discrimination can make access to treatment very difficult, due to the constant barriers they present, many of which are outlined in this report. Fundamentally, we all deserve to be treated as citizens, and we all deserve equal access to services that help us to get well, and stay well.

This report was commissioned by the NHS Addictions Provider Alliance (NHS APA) and begins to open a window into the world of addiction, the stigma people experience, and the impact of that stigma on accessing services, and ultimately on recovery.

The lived experiences explored by Working With Everyone in this report undoubtedly reflect the experiences of people all over the country and shine a light on the barriers faced by people with addiction every day of their lives.

The NHS APA is committed to addressing the issue of stigma and working in partnership with others in the sector, to combat the stigma surrounding addiction. We are hopeful that by doing so, we will start to see positive changes in society that enable more people to access the help and support they need to recover.

About the Addiction Providers Alliance

Since its inception in 2016, The NHS APA has strived to make a positive difference to the addictions treatment and support sector and its service users.

The NHS APA membership:

- **Provides drug and alcohol services in 35 local authority areas nationally**
- **Provides drug and alcohol services in 43 prisons nationally**
- **Employs 1933 staff nationwide working in addiction services**
- **Provides 4 Inpatient Detox Units serving the most vulnerable and complex patients**
- **Gambling Services receive approximately 900 referrals working with most complex clients in the gambling treatment system**
- **Has over 200 volunteers supporting NHS APA member addiction services at any time**

Aims of the Lived Experience Research Project

To consult with current and former drug users across NHS APA community drug services to gain insights into their experience of stigma in relation to their engagement with health and social care services.

Who Are WE

We are a Not-for-Profit Company that prides itself on being independent. All of our directors, employees and volunteers have lived experience of social harms and marginalisation.

All of those who are part of WE are selected for their personal, professional knowledge and expertise. Each individual involved in the company has their own lived experience of social harms and marginalisation. We believe that each individual experience is equally as valid and valuable as any other. We have an exceptional level of in-depth knowledge and expertise.

Why WE Exist

- ✓ **WE are experts by experience**
- ✓ **WE believe multiple and complicated needs can be effectively addressed**
- ✓ **WE each make our own choices**
- ✓ **WE support the choice of others**
- ✓ **WE believe that each choice matters**
- ✓ **WE believe every journey is unique**

Making an Impact

We believe that we will make the most lasting and positive impact on the greatest number of lives by changing attitudes, behaviour, decisions, policies and practice. We seek to influence those individuals, organisations and systems that have the biggest impact on the lives of those affected by multiple needs.

We pride ourselves on being independent and evidence based. We are committed to partnership working and we work in a collaborative and productive manner with a range of organisations to share experience and knowledge in making the greatest collective difference.

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Methodology

This research was designed to consult with current and former drug users across NHS APA community drug services to gain insights into their experience of stigma in relation to their engagement with health and social care services.

Participants were recruited through posters in APA services, support from existing user groups and LEROs and by contacting people who used drugs that have taken part in other projects with WE. It was decided to concentrate on the stigma relating to the use of illicit drugs in this project, as due to the low numbers, it is possible that the workshops would not be able to separate the experiences of stigma relating to drugs and alcohol, due to low numbers.

Potential participants were asked to text their phone number to WE and a member of staff called them back. During the call the project was explained and participants were screened to ensure that they had a history of using illicit drugs (with or without alcohol use). Participants were then sent a link to a survey to complete (using survey monkey). This enabled us to gain written consent and to capture basic demographics.

Participants were then sent a link to the workshop of their choice. All participants were offered the opportunity to attend a one-to one Zoom session to practice using the technology. All participants were sent a reminder text the morning of the workshop. Five focus groups were planned that would be open to both male and female participants who have experienced stigma relating to drug use, with between 6 and 8 participants per workshop. Only adults (age 18+) were recruited. Due to COVID-19 restrictions, all of the events were conducted by Zoom. All participants were offered a £20 voucher, to thank them for their participation.

A sixth focus group was planned for female participants only, who were recruited from those who had participated in the first five workshops. All participants were offered a £20 voucher, to thank them for their participation.

The facilitators and note takers had personal experience of stigma relating to drug use. The facilitators all completed the sign-up survey and participated in one workshop, no attempt has been made to separate their experiences from the experiences of other participants.

After the workshops were complete, six individuals were identified by the facilitators to be interviewed on a one-to-one basis to develop case studies.

We then conducted a poll asking participants:

Do you think drug use is stigmatised?

All of the participants and facilitators answered yes.

All participants were offered a £30 voucher, to thank them for their participation. 35 individuals signed up for the workshops. 30 logged in to the session, 3 did not complete sessions due to connectivity or needing to leave for work/personal reasons. Due to the low numbers recruited, this research cannot be generalised more broadly and should be treated as insight.

The content of the survey and workshop were coproduced with APA staff, to ensure that the right questions wereasked to achieve the objectives. Polls were conducted as part of the workshops and the results were collated. Polls were also used to provide a fast data capture and to facilitate discussion. The questions for the sixth workshop were developed after the first five workshops were completed.

Findings

We opened the workshop by offering a definition of what it meant to stigmatise someone.

This is the definition we chose to use:

If you stigmatise someone you have given that person a (negative) label that is limiting in some way.

We then asked further specific questions around stigma in different situations, with the prompt:

We are now going to ask if you think this stigma has impacted your interaction with various people and services. We want to know if you feel the fact that you have used drugs means you get a different service to people who have never used drugs.

We are looking for specific examples of stigma you have experienced and the impact this has had on your behaviour.

It may be that there was a single experience that caused you to feel in a certain way.

It may be that there were a series of experiences that caused you to feel this way.

It may be that there is no specific experience, but that you were worried about how you might be treated.

Under each subject there was at least one Zoom poll, usually asking participants to rate whether they agreed or disagreed with a statement on a five-point scale, and a guided discussion. For full details of the polls, their results and the discussion prompts, please see Appendix II.

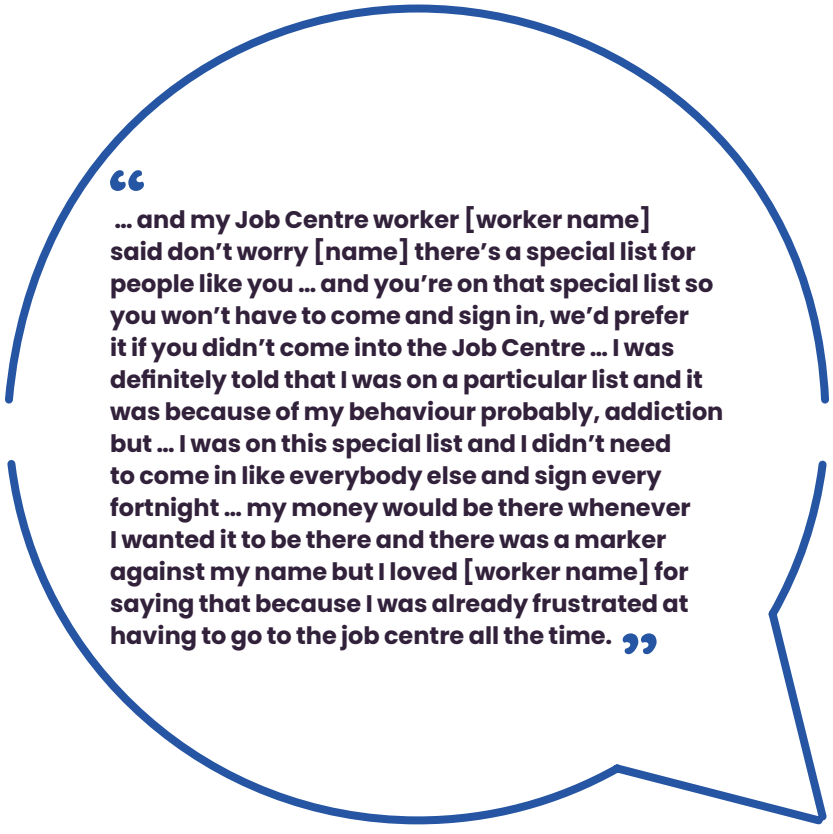
It became apparent that whilst all participants felt that people who use drugs are stigmatised, and had examples, that stigma was not homogenous and was not experienced in the same way by all of the participants. For example, one person may have felt stigmatised by their family, whereas another may not have or may have found disclosing to their family a positive experience.

The first part of the report is looking at the way participants experienced these different types of stigma.

The second part of the report looks at the characteristics and contexts in people's lives that create additional stigma.

The third part of the report contains six individual case studies that highlight the impact of stigma, including multiple stigmas on people's lives.

The presentation that we gave the NHS Addiction Providers Alliance Conference in October 2021 (recording available here) looks at the effects that stigma has on people's behaviours.



Types of Stigmas

It also became apparent that there were different types of stigma and/ or discrimination that were being experienced.

We conducted a thematic analysis of the workshops and conducted a (very brief) literature search to identify the types of stigma that had been experienced by participants, these are:

- **Discrimination which is defined as the behavioural result of prejudice**
- **Experienced stigma, which defined as the experience of being stigmatised by others**
- **Social or public stigma, which is defined as the prejudice and negative attitudes held by members of the public and/or society**
- **Anticipated stigma, which is defined as the expectation of bias from others**
- **Self-stigma, which is defined as the internalisation of prejudice and discrimination from social or public stigma**
- **Perceived stigma, which is defined as the perceptions of how the stigmatised group is treated by others, regardless of any behaviours of the others**

Discrimination

Discrimination is the behavioural result of prejudice (Corrigan and Bink 2005) and the majority of participants felt discriminated against because of their drug use, many also felt that they were discriminated against in drug treatment because of other characteristics or because of other characteristics (gender, race, culture, ethnicity, parenting status, autism, or mental health).

A number of participants mentioned that they thought part of the discrimination in society about drugs, as opposed to alcohol, was due to their legal status and that this impacted on them being able to access treatment after being discharged as drug free:

> **"...I think the fact that heroin and crack and that's illegal is something to do with it and I think the fact that alcohol's legal makes it a whole different ballgame, I mean the revolving door just spins twice as fast I think for the alcohol users... and I think it's easier for them to go back into treatment. I think as heroin addicts and that if, you've been through the treatment, got off and then you have to go back ...I think it's a bit more, it's harder because people expect you to just get over it because you've had to go out and look for your substances it's not sort of in your face, I do think there are big differences and expectations on us as well..."**

Participants reported that there seemed to be a hierarchy of drugs. With one participant feeling that they were discriminated against by both treatment staff and or service users, because their drug of choice was cannabis:

> **"Yeah, definitely in my experience I used to smoke cannabis and it was not taken seriously at all in groups I was in, it was just seen as a bit of 'puff' and not a real drug or problem and I was made to feel like I shouldn't be there" [when prompted] "yeah, the staff and other people using the service... they just didn't see it as a problem..."**

Experienced stigma

Experienced stigma is the experience (or experiences) of being stigmatised by others (Stangl et al. 2019). It is likely that participant's experience of stigma, of which there were a lot, led to them internalising stigma, anticipating stigma and perceiving stigma.

One participant reported feeling stigmatised in a private [drug and alcohol] residential service:

"I was in a residential treatment, it was private, and I felt extremely outcast I was the only user of crack in the group...to me it was cast as a dirty drug and... nobody seemed to be able, I know it was a twelve-step programme but nobody seemed to direct me in the appropriate way ... so I found it extremely difficult being that I was the only [crack] user there"

More than one participant mentioned being stigmatised by their family:

"I think what was interesting was everyone [in my family] pretty much stopped talking to me and I didn't really see anyone for about fifteen years... and then when I finally stopped taking drugs I tried to rebuild family relationships: two of my immediate family have said to me 'Oh we thought you were dead or in prison.' ...And it took ten years for the obvious reply to kind of go from my brain which was 'You didn't come and find out did you?'. So I often think they just couldn't decide how to deal with it and therefore it was just better to pretend I didn't exist and that was that..."

A female participant felt that they had been stigmatised over using alcohol, domestic violence and losing custody of their children, they didn't want to add any stigma relating to drug use on top of that:

"Mine was alcohol years ago and I got married young and had children and the relationship broke down there was violence, and I lost my children over the alcohol. I had to leave the house and go back to my parents, and they were disgusted I lost my children. So the truth is I don't know what they'd think about the drugs cos they were disgusted by the alcohol but I've not spoke to them so they don't know so I can't be sure"

Participants mentioned that they were stigmatised by medical professionals, particularly when asking for support with their mental health or pain management:

> **"I just feel like any help with like medication and stuff they don't really want to give you any medication once they know you've taken drugs... so it's really quite difficult to get your mental health seen to cos, say you're not sleeping or you're really depressed, they're really very dubious about giving you anything to help with that... because I feel like they just think you just want a free fix to be honest."**

This was felt to be true, even when the participant didn't actually want opiates:

"I found in the past a lot of doctors ... wouldn't give me painkillers because they assume I want opiates and in fact I didn't! I learnt a long time ago that no opiates are going to help me with pain I'm better off with paracetamol or something cos my opiate tolerance is too high ..."

Participants also reported that they felt their health concerns were dismissed by clinicians because they were using drugs. Participants felt that this was true for both physical and mental health. One participant speaking about mental health:

"they were too busy putting everything down to drink and drugs, there was other stuff in my past before I ever even picked up a drink that they never even bothered looking at and then, actually they still never have ... I had a four year argument with the psychiatrists and then they sent me a psychologist and the diagnosis was I had behavioural and personality disorders caused by substance misuse... but I think the personality disorder was there long before I picked up a drink or a drug"

And another speaking about physical health:

"I was going the toilet about twenty times a day, couldn't eat, passing blood and they didn't even take a stool sample they just put it all down to alcohol ... and I could have cancer, but they'd never know cos they don't see past it [drug and alcohol use]"

Social or public stigma

Social/public stigma is the prejudice and negative attitudes held by members of the public and/or society (Corrigan and Bink 2005). Participants reported feeling stigmatised by professionals, as well as other people around them, such as neighbours.

Participants also reported being stigmatised by their peer group, other people who used drugs. Participants reported stigmatisation between users of different substances and others reported being stigmatised when trying to access drug treatment, which meant leaving their peer group.

One participant felt that there were assumptions made about them purely on the fact that they used drugs. They felt that people always assumed that the fact they used drugs led people assume that this was a problem in their life:

"...because I used drugs people assumed I needed treatment... so like every G.P. I've ever spoken to since 1990 ,as soon as I mention the fact that I use drugs, they just, they're like alright [this project] or this treatment place and I'm like no, no, no, [laughs] I just use them I don't abuse them, and they could never get their head around that..."

As can be seen in case study one, the assumption that drug users behave in a certain way and have certain characteristics, can lead to a denial of service for those that don't fit the stereotype of a drug user:

"They wrote in the notes [that] 'he came very smartly dressed', or something, 'in a suit'. Which I, just, my naivety, was to go there and impress them and their whole attitude was just judging me..."

There are also societal assumptions made about different substances, even from people who use other substances:

"...I lived in a huge block of flats and the amount of people who and like at one point said to me 'smack heads eugh, eugh... crackheads I'd never be one of them eugh, eugh,' and... nobody liked a smackhead or a crackhead but it was perfectly alright to be doing speed every night or pills every day or MDMA all the time..."

This 'hierarchy' of substances was also apparent amongst peers in drug treatment:

"When I was in treatment there was a guy there, he'd say he was a junkie and he hates alcoholics because they've got the disease and a cool name alcoholism and it used to be the junkies look down at the alcoholics, the alcoholics look down at the junkies, and everybody looks down at the crackheads, so there's a hierarchy of everything, everybody dislikes everybody..."

Some participants societal context was their peer group when they were using and that they were stigmatised by other users when they accessed drug treatment services, with a view to giving you taking drugs..

> **"... No stigma from accessing services ... more from my friends, from the people around me who were doing the same drugs and didn't think I had a problem..."**

As can be seen the social/public perception of people who use drugs in society, presents in different ways in different contexts:

From neighbours, from professionals and from peer groups, but that it served to isolate people and prevent tm getting appropriate treatment. One participant described the effect that societal stigma had on them:

> **"All those years I was tried to be made into this normal thing in society, which is why I had to take drugs in the first place, I completely self-medicated, ...the only time I was able to knock the cannabis, the this, the cocaine... the ecstasy, crack binges, was once I realised: Oh okay I've got post-traumatic stress disorder because of how society views me, not how I view me..."**

Types of Stigmas

Anticipated stigma

Anticipated stigma is the expectations of bias from others (Stangl et al. 2019) and this expectation of bias prevented people from disclosing their drug use, both to family and to health professionals.

One participant described the fear they had of their family finding out that they used drugs:

> **“For me, for me it was the double life thing I mean I was so intensely worried about what my family would say, with going out at different times, aliases on phones, pipes hidden. It was absolutely horrendous because of the fear I had of them finding out and they knew anyway because I’d be out, and I’d come back in and it just went bad from there, so I was extremely worried about my family.”**

Another said that they felt drug use was an alien concept to their family and they, therefore, had no idea how they were going to react:

I didn’t come from a family that were using drugs, I probably came from quite a different family actually, it was a very alien concept to be using drugs and stuff like that so I had tremendous anxieties around disclosing to family that I was using drugs”

Another participant described being reluctant to tell their employer because they were worried their judgement would be called into question and that they would have been exposed to stigma:

> **“I wouldn’t have dreamed of telling my employer that I was using drugs, never in a million years… my personal judgement would have been questioned, and all sorts of things, all stigmas would have come out.”**

Anticipated stigma led to participants delaying health care or not accessing it at all:

One participant described their reluctance to access medical treatment because they expected poor treatment. Stating that they would only go to the doctor if they felt really unwell and that this had caused risks to their health:

“I once dropped a desk on to my foot … I hurt my toe. And I wouldn’t go and see a doctor about it, and it was only about a week later my toe started to swell up and I poked it with my finger and all this gangrene started to come out … so I finally went the doctors and just said ‘I think I’ve got a problem’ and he said ‘I’m really glad you came … give that another three days you would have had your toe amputated. So I think it did impact me in I would go if I had to but I wouldn’t go to check something out … I’d only go if I felt really unwell”

Another discussed the fact that it prevented them accessing help for their mental health: *

> “I’ve been depressed but I’ve never bothered seeking treatment because I knew the response I’d get from doctors and counsellors, so I just didn’t even bother … I’ve no personal experience of this you could just say I never ever started looking for treatment, which says something, cos I knew what was going to come with it.”

They then went on to acknowledge that they knew the fact not disclosing their drug use to medical professionals could negatively impact the outcome of their care: *

> “I only mention it [to doctors] when I have to which is very sad because obviously it does impact treatment … I mean basically we’re in a sad situation: we’ll only talk about it if I absolutely have to and it shouldn’t be like that. It’s bad for my health and their service but it’s the way it is …”

Types of Stigmas

Self-stigma

Self-stigma is the internalisation of prejudice and discrimination from social/public stigma (Corrigan and Bink 2005) where people begin to believe societal views of themselves. This led to people having a negative view of themselves. Participants reported that this prevented them asking for help and that, pretty universally, made them reluctant to complain when they received a poor service.

One participant stated that they felt they would be looked down on for using drugs, based on the way that they had seen other people treated:

"I think more than anything I stigmatised myself and I just…I feel like other people out there stigmatise other people that have taken drugs, like it's really looked down on and that might not even be the case that might just be based on me stigmatising [myself]"

Another participant mentioned that although their employer had a good reputation for dealing with people who used drugs and alcohol their own sense of shame and self-stigma had prevented them from disclosing:

"I wouldn't tell my employer, strange enough I worked for [name of employer] back in the day, and they had a really good treatment programme for drug addicts and alcoholics, and I wouldn't tell them because I was too ashamed…yeah self-stigma …"Many participants stated that they felt unable to complain about poor treatment, in different settings, because they felt it was pointless and they wouldn't be listened to because they used drugs:

With one participant reporting that they had surrendered to this view:

> **"I've never, you know with my issues and mental health and stuff, I've always just sort of surrendered and thought I wouldn't be heard… so yeah, I stigmatised myself really."**

And another not bothering because they felt they knew what the outcome would be:
"I stigmatised myself actually as far as I was concerned I was a junkie, I was like a Millwall fan of society, everybody hated me and I didn't care, so it never occurred to me to put in a complaint because I automatically assumed I'd be knocked anyway so I never bothered you know. Who the hell's gonna listen to me? So I think I actually stigmatised myself, it wouldn't have occurred to me to complain because I automatically assumed I knew what the answer would be …"

As can be seen internalised stigma not only prevented people complaining, it also led them to assume that they were hated and to pre-empt a poor outcome:

"I think I stigmatised myself. I thought of myself as a junkie that was my sense of self definition and I assumed that everybody absolutely hated the sight of me … therefore it would have never occurred to me to complain, because I'd already decided what the outcome would be … So I've no idea whether the outcome would have been negative because I never made a complaint, because I already decided I wouldn't get anywhere with it."

Types of Stigmas

Perceived Stigma

Perceived stigma- perceptions of how the stigmatised group is treated by others (Stangl et al. 2019) it is wholly subjective and is characterised by being worried by what others might think, regardless of the actual beliefs or behaviours rendered by others.

One participant reported being worried about how their family perceived them:

"... my mum saw me out on the road and she came up to me in front of all of my friends and said I know you're smoking the hard stuff you look so bloody thin and that's what made me stop smoking crack basically, that my mum realised ... she turned round and said to me she knows what I'm doing, like I've always smoked weed, I've always drunk like blah, blah, blah ... but for my mum come up and speak to me in front of my friends it made me realise ... but for her to come up and say that to me it did put something in my mind and I thought yeah I've got to stop ..., I was worried about how my family perceived me, saw what I was doing, it did affect me my recovery"

A participant from an Asian background reported staying away from their family, because of what others in the community might think:

"My solution to feeling embarrassed. [both] myself and my family ... cos I'm from India and as Asians, it's very much about what the neighbours think, that's more important ... so my solution basically was to stay away from the family and get out of communication ..."

Another participant reported feeling that health professionals didn't want to look after them because their problems were seen as self-inflicted. This person felt that this hadn't been true in drug treatment services:

"I didn't feel stigmatised in the [drug] treatment centre or the [drugs] services I engaged with, but I did however feel it when I was in the hospital ... I just got the sense that the people didn't want to look after me because I was in there ... through self-inflicted, you know, abusing substances ...I really felt it in the hospital, but not the treatment services themselves, you know they couldn't have been any nicer with me"

Participants were split about whether drug use counted against you when applying for a role in the drug treatment field or not. It was felt by participants that it might depend on the role they were applying for and what their Lived Experience was and on how recent the Lived Experience happened. With one being worried that Lived Experience would count against them:

> **"I've actually got to the point where I don't mention it [my Lived Experience] on C.V.'s and stuff ... when I write personal resumes I don't actually mention that because I know it would count against me ... and I know friends that are like that too ... I'd love to be able to do that [mention my Lived Experience] but it's a way of formulating the experience so it doesn't actually come across as a person with lived experience ..."**

Another participant felt that if they disclosed their drug use that it would make it difficult to rent a property and that they would need to hide their drug use from their neighbours, for fear of being evicted: *

> **“ … there are an awful lot of private landlords who won’t hire [sic] to drug users and on top of that we haven’t mentioned the other big decider in housing which is the neighbours, the local community, they can have a say if you stay in a house or not and if your behaviour is too far out of the norm they will make sure you move … ”**

Another participant felt that they should assume that everyone thought they were an idiot for using drugs and that this made things difficult for them when accessing services or complaining about poor services:

> **“ … always assume that people think: because you’re an addict, you’re an idiot and, you don’t know what you’re talking about, and you can’t back it up … so everything was a fight for me … you couldn’t just put a complaint in … everything was a fight … ”**

Identifying other stigmas

For many participants stigma was experienced across multiple areas of their lives.

These areas could be related or unrelated, they were certainly cumulative. To the person experiencing stigma it didn't really matter what the cause was:

> **"It was about it all ... If my criminal record wasn't going to be a barrier then certainly my race and culture would have been, or if my race and culture wouldn't have been then it would have been my criminal behaviour, criminal past. So, on all fronts."**

These areas included:

- **The use of different substances**
- **Gender**
- **Domestic Abuse**
- **Parenting status**
- **Familial and Social Context**
- **Socio-economic class**
- **Criminal record**
- **Race, ethnicity, and culture**
- **Autism**

Participants also agreed that they found it difficult to access mental health treatment if they were currently using drugs. They also reported finding it difficult to access pain relief.

Please see the above sections on discrimination and experienced stigma for examples relating to mental health, drug use and stigma.

This list only contains the stigmas that were identified, without prompting, during the workshops. It is likely that there are other stigmas related to identity and experience that could easily be added to the above list.

Identifying other Stigmas

The Use of Different Substances

Participants agreed that users of different substances were stigmatised in different ways. Many spoke of a hierarchy; this was not only apparent between users of different substances but also within drug treatment.

From a participant who used party drugs and presented to treatment for ketamine use:

"I was part of the rave culture so at that point I felt stigma but from other users and also the drug treatment service because they didn't really know what to do, ketamine was fairly new on the scene…"

A participant who felt that they had been stigmatised, by both drug treatment staff.

"Yeah, definitely in my experience I used to smoke cannabis and it was not taken seriously at all in groups I was in, it was just seen as a bit of 'puff' and not a real drug or problem and I was made to feel like I shouldn't be there" [when prompted] "yeah, the staff and other people using the service … they just didn't see it as a problem …"

Please see Case Study One for examples of stigmatisation faced by someone who does not present to drug treatment in a way that was expected (driving a car, wearing a suit, etc.) and was told that they didn't meet the criteria for treatment.

Speaking about the hierarchy of drugs between users of different substances:

This 'hierarchy' of substances was also apparent amongst peers in drug treatment, from one participant:

"and it used to be the junkies look down at the alcoholics, the alcoholics look down at the junkies, and everybody looks down at the crackheads, so there's a hierarchy of everything, everybody dislikes everybody"

From another participant, speaking about how this hierarchy prevented them accessing drug treatment:

> **"When I did first go into treatment I thought I wasn't as bad as everyone else…it took me a lot to go to a treatment centre because I thought the other drugs that were out there were worse than what I was on … there's always someone worse off than me"**

A number of participants mentioned there being a different stigma between alcohol and illicit drugs as well as between different drugs, this was based on both legal status and wider societal views:

For some this made accessing treatment for alcohol difficult:

> **"I went to my G.P. and said you know I think I'm an alcoholic and … the problem was he was one too and … he didn't really accept that my drinking was a problem"**

And a view from someone who used drugs about alcohol use:

> **When I was using, I looked down at alcoholics cos they weren't hard enough to use proper drugs...**

From a participant speaking about Monkey Dust and how this has changed the hierarchy:

> **the 'dustheads' as they're called are the new smackheads so now heroin's changed in the, like we've said this hierarchy because now nobody wants to admit to taking dust.**

Participants mentioned that routes of administration were stigmatised differently, even when the substance was the same:

> **Even say with opiates, people who smoke heroin are looked upon differently by the people that inject, I think people that smoke look down on people that inject ...**

With another participant highlighting the way that they felt crack and cocaine were viewed in society and by Children's Services in particular:

"Children's Services and the courts still don't know that it was crack cocaine that was my habit cos every time I did a test it come up that it was cocaine ... and they kind of accepted that a little bit more than what it would be for crack cocaine"

With one participant observing:

"Somewhere between grim irony or deep sadness that substance users who have a lifetime of stigma to look forward to actually stigmatise each other as well"

Identifying other Stigmas

Gender

In the women only workshop we identified a number of themes related to gender and stigma:

> **"I think cos perhaps going a bit old fashioned you know the men can go to work and have a drink and what not, but the women have got to be the ones that keep the family together."**

Participants felt that this view extended to drug treatment, please also see Case Study Two:

"I think the expectation are higher on the female clients and even today … because we are the parents and the carers in the family, I think the expectation is put on us a lot more whereas the men just sort of come and go, shout out, get their script and pee off …"

The female participants felt that men who used drugs treated them differently. These comments produced a chorus of laughter and agreement:

"So, for example me and a guy's gone halves on half a sixth of crack, he gets the pipe firs. Why? Why? And takes his time, why?

This was regardless of who had paid for the drugs:

"… but at the end of the day it's not always his money, it could be my money or the other girl's money but the men think …"

Women that used drugs felt that they were seen as sexually available. This led to one participant being raped, the justification used by her attacker was that they assumed that was what she wanted because she took drugs:

"… I was raped and I was raped by somebody who felt that, well I was actually asleep, I know that sounds mental but I was asleep in a friend's house and we had all taken drugs consensually, and the next morning when I was like: 'Oh my god!' He said, 'well you take drugs and I just assumed that's what you wanted …"

There was also an assumption that women were Sex Workers, even if they weren't:

> **"I think there is just a natural assumption that even if you're not a sex worker that you would 'suck cock for crack' basically there were no morals and do anything for crack – that you were basically a dirty slutty whore."**

This assumption was a large part of the reason the woman in case study three began sex working:

"Well it was assumed of me, I was already dirt … why not, why not prove them right? And be damn good at proving them right and be, the best prostitute, the best pole dancer. That was what I had in my head; if that's what you think of me, you're not going to believe me, so I might as well do it …"

Identifying other Stigmas

Domestic abuse

All of the women present in the women only workshop (n = 10) reported being survivors of domestic abuse. There was no surprise and the feeling was resigned, as if this was what they expected because they used drugs. From two separate participants:

> **"I thought it was quite normal, but it was a D.V. situation..."**

> **"I found that people thought that the domestic violence was okay because I was like on drugs so I kind of caused it on myself."**

All of the women reported experiencing physical abuse and emotional or psychological abuse (including gaslighting) in a relationship. 80% of the women reported sexual abuse and financial abuse in a relationship. One reported stalking after the conclusion of a relationship. All of the participants felt that the fact they used drugs prevented them asking for help:

> **"I thought me being an addict, him being who he was, I'm not going to get any help, so I'm not going to call, and I was very anti, extremely anti police..."**

For further discussion of domestic abuse, please see Case Studies Two and Three.

Identifying other Stigmas

Parenting Status

Participants felt that their parenting status meant that they were treated differently by drug treatment (see gender above). They felt that the drug treatment they received wasn't for their benefit that it was for the benefit of the child:

"…. to be fair I've never had the right help it's only now because my girlfriends having a bairn that I'm even having any support at all and it's not about me it's about the bairn … and although I understand child protection is important it's not even here yet … but they don't care about me I've been drinking for years, and [other workshop participant] said the same …"

And another saying that they felt all help was withdrawn, from both social services and other wrap-around support, once they no longer had custody of their children:

"Yeah, but they leave you alone as soon as you haven't got your children … [they] don't wanna help you then …"

Participants felt that Children's Social Workers didn't assess them on their parenting, but were only interested in their drug use:

"… I was the best mum and as soon as they found out about the drink and the weed, as soon as they found that out I was suddenly a bad mother who couldn't cope …"

The women felt that they were judged more harshly as parents than men:

"…You're a mum, it's disgusting that a mum should feel that way [take drugs or have problems with their mental health]. A mum should be … it's very old fashioned, nurturing and all this stuff and if you are one degree out from that, because perhaps you're an addict … even if you're doing everything really OK, providing good care for the child …. The fact that you are on drugs, just instantly, it's like 'you should be ashamed of yourself it's disgusting, you shouldn't even have children' you know judgement, tongue clicking, especially from social services … really fucking nasty unkind personal stuff … "

Participants reported little or no understanding from Children's Services about Domestic Abuse:

> **"I don't think much of them because I don't think they gave me much help and they let the man that beat the hell out of me keep my children… "**

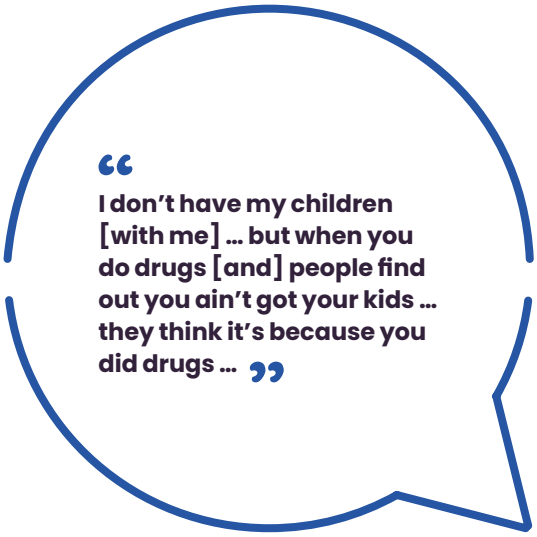
The women in the women only workshop felt that it didn't particularly matter whether they had given up drugs or not, the judgement about their parenting ability was still there:

"I've made all of these massive improvements, I've moved areas, I've changed my circle, I'm volunteering in the services … my life is dedicated in my recovery at the minute, so I've got all these positives but yet they still wanna drag up my past from like three years ago …"

Participants felt that there was an additional stigma in being a parent who had their children removed from their care and that this was a traumatic experience with one participant when speaking about people they had met:

"The way [parents who have had their children removed from their care} talk you would think they are talking about the death of their children, but it's not, it's because social services have taken those children …"

And that there was an assumption that even if your children were no longer in your care for another reason, such as domestic abuse, that drugs must be the reason:



The women in the women only workshop felt that mothers who have had their children removed from their care are judged more harshly than mem who have had their children removed from their care:

Familial and Social Context

Although many participants reported feeling stigmatised by their families and / or friends, this depended on their family's attitude to drug use:

"I didn't mind at all about my family finding out but that was just because that's the sort of upbringing I had, surrounded by drugs, my mam used to sell drugs, I used to deliver them for her, so it was sort of the expected thing so, no I wasn't worried at all ..."

Others saw it as a normal thing to do:

"Yeah ... I did it with my family from young, it was absolutely normal thing to do and my first spliff was given to me by my mum and so I wasn't scared to tell my family, they just didn't see it as a problem ..."

Others mentioned drug and alcohol use as being normal in their cultural/ social context:

> **"Mainly for me I'm a Geordie and so drinking from young is in my culture and I've been drinking for years ..."**

From another participant:

"The stigma came more from my family ... they didn't think I needed help because it's part of my culture, everyone smoked cannabis ..."

Another was surrounded by people who were using drugs and saw it as perfectly normal:

"I was very naïve, I didn't really understand what illegal meant .... To me it was just there ... most of the people that I met who were taking drugs were famous musicians ... so I didn't really think that it was a negative thing at all ... it was just something that I did"

One participant highlighted the stigma between different substances, within their own family:

"... but they were sniffing coke but because I was on crack and heroin ... it was different ... because I was a crackhead and they were a social cokehead ... so that also made it very difficult ..."

Another mentioned that they felt that a family member had changed their views on drug use based on becoming abstinent:

"My family, some of them used drugs a lot, my mum used to deal ... and then she gave up ... she was really self-righteous around the rest of us, [she thought] that we should all give up, which seemed double standard to me ... I remember what you did when we were kids and now you're telling us not to do it."

Another reported facing stigma from their family when they wanted to stop taking drugs:

> **"... I think it was harder when I tried to stop taking drugs that was an alien concept to my family and so ... yeah ... it was a little bit backward."**

Socio-economic class

Some participants felt quite strongly that attitudes about drug use were class based:

"Is it something about social class where wine's acceptable but Special Brew isn't, cocaine's acceptable but crack isn't because crack is the hardcore inner city poverty thing and cocaine's seen as the city thing ...I don't know or is it just that everybody wants somebody to look down on ..."

Others found that class assumptions prevented them from getting help:

"When I came out of rehab I had a dual diagnosis worker come and I said I wanted to move house, I'd been in the same house about twenty five years I've used drugs here, I'd sold drugs here I wanted a new environment and they said to me '[name] it's like this you are white, you are male, you are single and middle class you are fucked. Whatever you do not try and move house, stay put ..."

Criminal record

Participants mostly mentioned criminal record in the context of employability, where they felt that it was a significant barrier to future employment:

With one feeling that (with their history) they would be unlikely to be employed within the prison estate whilst serving a custodial sentence, with the implication being that no-one would employ them now they had been released from prison:

"I can't even get a job as a cleaner in prison ..."

Another mentioned that they didn't think they would be able to get any job because of their criminal record:

"... I can't get a job in McDonald's .... I can't get a job in a local newsagents ... I think I'd struggle to get a job as a paperboy if the local newsagents wanted to employ me as a paperboy because of my history ..."

Although they were optimistic about being able to work in addiction services, where they felt their criminal record wouldn't be held against them and that their Lived Experience was an asset:

"... I think it is easier someone from my experience because I've lived a life, I've been involved in crime, I've been involved in drink and drugs and I've come out through the other end. That experience is extremely valuable to people who are beneficiaries of the addiction services. I'm hoping that my experience can obviously benefit others ..."

Race, ethnicity and culture

Participants felt that drug use (particularly heroin use) had been seen as a problem specific to a particular ethnicity (white):

> **"... when I first started using, heroin was definitely a white drug I knew very few people who weren't white who used it years before that ..."**

This meant that drug treatment was 'set up' for this demographic and participants felt that this didn't meet the needs of those who weren't white heroin users.

For the impact of race, ethnicity and culture on someone from a British Asian background, please see Case Study Five. It is likely that this is true for people who identify as being from other ethnic backgrounds as well.

Autism

Autistic people face difficulties when accessing or engaging with drug treatment. For the impact of autism when accessing drug treatment, please see Case Study One. It is likely that this is true for other neurodiverse people and those with Learning Disabilities as well.

Other characteristics

As has been stated above these were the additional stigmas that altered or added to the stigma associated with using drugs that were identified, without prompting, from a very small sample. It is likely that there are additional stigmas associated with sexuality, disability, gender identity, HIV status and caring responsibility. It is also likely that there are other aspects of identity and experience that impact on how people who use drugs are stigmatised within differing contexts.

Case Studies

After the workshops were completed, six participants were re-interviewed and individual case studies were developed. These individual narratives highlight the types of stigma that have been experienced, the intersectionality of additional stigmas and the impact that this has had on the people involved.


Case
Studies

Case Study One

He is an autistic man in his fifties who very articulately explained the confusion he felt when trying to deal with drug treatment services and other people he met in drug treatment and peer support services.

He attempted to access drug treatment a number of times, but unsuccessfully. He eventually attended residential treatment and now considers himself to be in long term abstinence-based recovery.

He received a diagnosis of autism as an adult:

"... It was diagnosed and then it was kind of explained to me and then I really understood why I was feeling socially excluded and pretty marginalised a lot of the time."

He described himself as not understanding the rules and finding them inconsistently applied. He felt that he was unable to read subtext and had not received appropriate care and support from drug treatment, at least in part, because his autism was poorly understood and when he didn't present or respond in the same way as other people, he was stigmatised.

"I didn't even realise that one of the traits of autism was not knowing how to react in social environments ... [what] I figured was my brain maybe just copied because it didn't know: should I be sad? Should I be happy? Should I be angry? So if I just copy you ... that'll be great."

The first time he approached a community service, around 25 years ago, he presented in tears and with a history of suicidal ideation and suicide attempts, asking for help to detox. He was referred to a detox service, where he felt he was stigmatised, because he didn't present in the way they expected. He turned up driving a car and smartly dressed:

"They wrote in the notes [that] 'he came very smartly dressed', or something, 'in a suit'. Which I, just, my naivety, was to go there and impress them and their whole attitude was just judging me..."

During the assessment he was asked about support networks and he replied that he was in contact with his family and had a supportive partner and had a stable place to live.

"...that really held against me and then she gave me this speech about there are more serious cases, they have no-one, they're homeless blah, blah, blah."

When speaking about his experiences of trying to access drug treatment, he says:

"... They wasn't informing me or empowering me, it was just another barrier, another barrier"

His worker then advised him:

> **"... probably not a good idea to mention the girlfriend ... we just have to be selfish here and get you in somewhere ..."**

On another occasion he accessed community drug treatment in the hope of being referred for residential treatment; he described a conversation between himself and a key-worker, where they were explaining that because he didn't inject, he wasn't considered to be at a high risk of overdose:

"I said to her 'what do you mean I don't inject' … this was shocking it was in about the 9th week of her seeing me…. she said 'you never mentioned it.' I said, 'You never asked me' …. She said, 'well, most people mention it'"

He was confused by the fact that the worker hadn't asked him, if it was important:

> **"Why would I possibly think that they want to know if I'm injecting it, if I'm sniffing it …?"**

He felt that he didn't understand the reasons that he hadn't received help and that he had to modify his behaviour and the way he presented, in order to receive help.

"Then by the fourth time [I applied to rehab], I was an expert …"

When asked directly if he felt that he was treated appropriately as an autistic person, he spoke about how important time-keeping was to him:

"What used to disturb me was even once they knew I was autistic and what the problems were dealing with autistic people …. If you say 4:30 for an appointment and then it's late [an autistic person's] world will end if the appointment is at 4:31 or a minute early … my brain couldn't comprehend this so I'd get more frustrated …"

"I always noticed the emotions coming after the frustration … losing trust, losing self-efficacy, being ignored, so when these feelings … if you're making me feel like this, I'm just going to give you lot a hard time. I'm going to shout at you lot, have a go at you lot … that would just dragon to getting bans …"

Another thing that he mentioned was confusion relating to asking and answering questions, the fact that he would only answer the things he was asked about and that he would answer questions exactly.

He also spoke about the fact that he followed instructions exactly and described a particular incident in rehab, where he was particularly hurt about the lack of awareness/understanding of autism:

"All my life I couldn't understand why when people asked me to do something and I did it exactly … it really hurt me In rehab … she [the worker] gave everyone a stone, she said you've got 5 minutes to put this stone anywhere you want … everyone put it down on the carpet somewhere … all I did … I put it on the table … I didn't think anything … she said '[name], can I ask you a question? … just because of where you placed your stone: do you think you're better than everyone else?' … I was really shocked … I didn't think that the stone was a representation of anything … I just thought you asked me to place the stone anywhere you want …"

He also described having difficulties in social situations:

"In any social situation I got that reputation … 'look at that guy he's aloof, he looks down on people.'"

Other people would try to prompt him to make him fit in:

"In social situations nobody understood me at all, I could not fathom out the purpose of saying 'hello', 'good morning' or 'good afternoon' – after a while people kept telling me … they'd nudge me saying 'say it now, say it now … '"

This difficulty in social situations meant that he found peer support/mutual aid very difficult:

> **"… [The rest of the group] they were horrible to me, they used to hate me because I talked too much."**

> **"All these strangers that are coming to me and saying hello and hugging me …. it has no purpose; they don't mean it."**

In fact he described being forced to take part in some of these interactions as making him sick:

"The group leader used to say 'get up everyone and hug everyone.' They knew I would turn my back and stand in a corner.

My body language was absolute that I'm telling you whatever you want or not that I don't want to touch you, that I don't want to hug anyone. I told them thousands of times that this hugging business is making me sick … because they hated me so much they would purposely come and grab me and hug me and keep holding me … to them it was just a bonding gesture."

As can be seen he felt that drug treatment and peer support/mutual aid were very difficult for him to access due to his autism, and that he had been unable to access the treatment he needed because he did not present in a way that conformed to expectations for behaviour and social circumstances.

Whether this is due to stigma, discrimination or a lack of education or understanding about autism, it is hard to say. He felt that he had to change his behaviour to what the services expected from him, in order to receive the support he needed.

"I'm autistic and it's really difficult for me to lie … but the intense pressure … they [drug treatment] made an autistic person become an expert liar."

He described this as having a direct effect on his mental health:

"They distorted my mental health."

Case Study Two

She is a woman in her mid-forties, who had a difficult childhood and used lots of different drugs to help her cope. She is a survivor of domestic abuse and has a long-term mental health condition.

She considers herself to be in long-term abstinence-based recovery and is now volunteering in a treatment service.

Her mother had a long-term mental health condition whilst she was growing up:

> **“My mum’s not very well, I didn’t realise at the time, and she’s a bit of a dreadful person… it’s not her fault, but she just doesn’t care, she just doesn’t have the empathy levels that most people do.”**

This has left her with low self-esteem:

“[as a child] you 100% internalise it and you just grow up with low self-esteem and believing that you are, not just, not loveable, but that you are hateable, nobody will ever care about you and you will not …. you’re not worthy of anything, don’t even try, just keep out of everyone’s way because people hate you and want to punch you.”

She feels that her childhood contributed to her having poor mental health as an adult:

> **“I basically had PTSD symptoms for years, until the terror goes, you don’t realise you’ve been living in terror for years …”**

As a child she began to pull her hair out and eventually (as an adult) received a diagnosis of trichotillomania:

“Trichotillomania (TTM) – it’s a lovely word – with the word mania in it, just to make you feel even more special …

My goodness, I was so disturbed and upset and just suffering from the effects of constant trauma which built and built. That this impulse control disorder of TTM was something that was so normal to me … it doesn’t hurt, it’s a comforting thing”

She was really worried about approaching her doctor (or anyone else) for support with her mental health because of the treatment her mother had received and felt that the only option for treatment was in a hospital:

"I was terrified of going to the doctor with any mental health symptoms, because my mother … was section 2ed and section 4ed and would spend six months at a time in [name of hospital].

My grandparents would take me to come and take me to visit her every couple of weeks and it was a really insane place … I was really so terrified of being sectioned I didn't really want to tell [my doctor] anything … I was like 'please don't lock me up,' I thought they were going to lock me up. I didn't want to be locked up … A lot of horror movies and horror stories based on these places … for good reasons"

She eventually felt that she needed some help to manage her behaviour:

> **"I asked the doctor for help because I'd been doing it since I could remember … and I felt such a disgusting freak for doing this … I mean, I don't want to pull my hair out, nobody wants to …"**

When speaking about domestic violence, she described herself as thinking it was quite normal and felt that her husband's professional status in the community and the fact she was a drug user meant that she wouldn't be taken seriously

"I thought it was quite normal, but it was a D.V. situation and I thought me being an addict, him being who he was, I'm not going to get any help, so I'm not going to call and I was very anti, extremely anti police …"

She also felt that when she did call the police that they treated her badly and didn't believe her because of the drug use, this didn't surprise her:

"There was an incident where I did actually call 999 to get safe and protection and, this wasn't a shock to me at all, the police separated us … they'd clearly done a background check on the spot and they challenged me saying 'you are not who you say you are, you're a methadone addict' now they didn't say methadone patient, methadone user, they said methadone addict, the way it was spoken was with contempt … and I could hear the other officer saying to my husband, 'say the word and we'll get rid of her…'"

She disclosed another incident of serious domestic violence where she required medical treatment for her injuries:

> **"… I remember a time where I had my front teeth knocked out and it split my lip all the way up into my nostril and I had to have it stitched together and I ended up having a bone graft to put my gum back and put my tooth back …"**

She had expected that the health professionals would ask about the source of her injuries and had been prepared to lie, a behaviour that she had learnt during her childhood:

> **"That was the really weird thing, because I was like, preparing myself to lie, like I used to with my mum when I was a child … when I had scratch marks and missing teeth …"**

She felt the need to protect her partner, the same way that she had protected her mum, because she felt that he was all she had:

> **"…you want to protect that person in your life because, they might be crap, but they're literally all you've got. You are nobody, nothing without that person … you will protect them at all costs."**

But although she had been prepared to lie to protect her partner it didn't matter because nobody asked anyway:

> **"I was kind of preparing myself to do the same thing, just automatically … but it didn't matter, because they didn't ask anyway."**

She also felt stigmatised by the community she was living in at the time and that she felt the stigma around drug use was worse, because it was a small community, where everyone knew each other, and her husband was well respected:

"… You can imagine … one of them villages and the rumours went from methadone addict … to drug dealer … to prostitute. You know, just ridiculous … everything, absolutely everything and I thought 'fucking hold up here!' … just the assumptions and the rumours …"

She felt that there were defined gender roles within the drug using community and that these roles persisted into recovery:

"There were defined gender roles in the drugs scene … all the way through to recovery"

She has acted as participant, facilitator and co-facilitator in a number of groups, including peer support and mutual aid:

"In groups where I've been a facilitator… always… it's almost like observational comedy … we're talking about the group boundaries …every time without fail would say 'no swearing because there's ladies present' all the girls are looking at each other like 'Fuck off you dickhead!'"

And that she felt men in treatment and peer support treated women differently to how they treated each other:

> **“It’s automatically sizing you up and thinking ‘oh, I can take the piss here a bit – I can either flirt my way out of this or threaten my way out of this’ ”**

She described the men talking to each other during breaks:

“You hear them [the men] talking and you overhear little snippets of conversation … ‘phwoar she’s fit!’ … ‘I would’ or even worse that person [woman] is completely written off because …. ‘They’re not fit… they’re fat’ … ‘bet they’ve got a cheesy fanny’ …. That really upsets me, and I don’t even know who they’re talking about”

Talking about leadership roles in the recovery movement:

> **“In my experience, ALWAYS men … it’s rare, but you might get women in a women’s role treasurer or something like that … you might get one that’s in charge of the coffee … and you might get someone if it [the job] is a bit of a ball ache … a bit of argy-bargy with the people you’re renting the hall from, then ‘we’ll put [women’s name] in charge, she can do all of that shit, we can do all of the glamorous, sexy roles’ ”**

“You definitely feel that even if they’re not [explicitly] saying that … it’s unspoken, isn’t it? … I’ve definitely picked up on it … ‘She can do the minutes, I can speak at the conference … ‘she can write down everything I say,’ … lucky woman! … You can be the typist, basically …”

She felt strongly that there should be targeted support for women entering treatment and safe women only spaces, particularly for those that were mothers and were at risk of having their children removed (please see main report pp 21)

Case Study Three

She is a woman in her late thirties, from a rural town, she is a survivor of domestic abuse who and has been a sex worker.

She described more than one incident of domestic violence; this was the first:

"My partner head-butted me when I was seven months pregnant and he sent me to my antenatal appointment by myself, I kept on saying that we were messing about and we clashed heads. Obviously [the midwife] didn't believe it, she rang social services and my social worker actually turned round to me and said, because she found out about my drug use I'm gonna do everything in my power to make sure [your child's] not placed with you or your family …"

When asked about why she had felt the need to lie about the cause of her injuries, she reported feeling that she needed to defend him and that she felt that it was a one-off incident:

"To defend him, I suppose, you know I really loved this guy he was the first boy I kissed and I was pregnant. I think because I'd not grown up around that I didn't know it was domestic violence, I thought it was just a one-time thing that was never going to happen again so just forget about it, let's just lie about it and forget about it."

She felt that during the assessment that her partner was seen as a risk to the child, but not to her.

She went on to describe another more recent, incident where an ambulance had been called:

"[my partner] had also knocked my front tooth out and knocked me down the stairs, he thought he'd broke my back, I was unconscious, so he had no choice but to ring an ambulance. When I come to in the hospital, the first thing I said was 'what have you done to me?' and the police arrested him but then his mum and dad said that they were there and I fell down the stairs and he was released and that was the end of it."

She went on to describe how she was treated by the hospital staff:

"Even in the hospital I was, once I'd come round and they'd arrested him and he'd gone [they] sat me out in the waiting room by myself, and at the time I was drinking, and I was covered in blood, my front tooth was missing and I was with a hospital blanket covered in blood around me and they just sat me out in the waiting room in front of everybody"

When asked why she thought that was:

> **"A number of things probably: me and my ex was put on a domestic violence order thing through the police, where the police could turn up at any time they wanted. So I felt like a bit of a nuisance that's how I was made to feel – ' oh it's just these again, fucking hell, like' "**

She felt that the police disregarded her concerns once his parents had made their statement and that, at least someone could have checked to see if she was OK:

"Like as well with the police … when that was changed [his parents made the statement] it was like, I'm not going to win this one. It was just left, like – there was no pulling to one side and asking 'are you sure [name]?' it was like OK, three against one; it's fine"

She spoke about the assumption that people had; that if she was a drug user, she must also be a sex worker and also that men felt that they could get away with more because she was a drug user:

"I used to sell my shoplifting stuff in pubs, this was before I got deeper down into the sex work but the guys in there use to ask for sexual favours, assuming that because I was a drug addict that I must do that as well …

From personal experience being a drug addict made them think they could do a lot more than what they would with somebody that wasn't on drugs, like they'd think they could get away with a lot more"

She felt that this assumption played a large part in her decision to begin sex working :

"Well it was assumed of me, I was already dirt … why not, why not prove them right? And be damn good at proving them right and be, the best prostitute, the best pole dancer. That was what I had in my head; if that's what you think of me, you're not going to believe me, so I might as well do it … and in your head, you know, it's glamourised you're going to earn all this money, you're going to have protection and it's going to be in a nice clean place …"

She mentioned that she lived in a small town and that she felt stigmatised by her family and was quite well known in the town, she felt at that time that working in a lap-dancing club was her only viable option.

"my dad kept going on and on, get a job, get a job and I'd already got a name for myself in the town, it wasn't a case of just getting a job … the first lap-dancing club opened up in [name of small town] and I went there with [someone I knew] and I was going to go for a bar job and one of the owners approached me and asked me to dance on the pole"

Describing her relationship with her dad and how this affected her decision to begin sex working:

"My dad looked down on me and my drug use and he wasn't understanding at all, he just. He'd sort of walk past me in the street, not even acknowledge that I was his daughter, he'd actually look the other way"

"It was more to go like 'fuck you dad, you wanted me to get a job, well, this is the job I've had to get'"

After the lap-dancing club closed, she was approached by her regular drug dealer, firstly with the offer to marry someone he knew, so that they could get a visa, and then when she refused, the offer of a place sex-working in a house.

"[This] drug dealer he says 'oh, I know this brothel, it's really safe and you can earn money and it's clean, this that and the other…' so … in the end I agreed, and we ended up … I'd never been to London before … they actually drove me and two other girls to London … they pulled up, told us to get out the car and we weren't allowed back in the car until we'd got their money and that was my first experience. … I didn't even have condoms with me."

She then decided to work in a brothel because she felt it would be safer. She then went on to describe being raped whilst she was working there and that this demonstrated the low status of sex workers.

> **"that's how low that person actually thought of me, you know, he come into a brothel to then rape a worker …"**

When speaking about her interactions with the police, during the time she was using drugs and sex working:

"There were two certain police officers that would drive around looking for me knowing that I'd got a warrant and they used to arrest me, they knew where I'd be because [name of town] is only a small place and they'd actually come out searching for me and not call it in and offered me a bribe … if I gave them sexual favours they'd let me out the car, … at the time I was prostituting and they was aware of that. So I'd do the act, they let me out and a couple of hours later they'd be looking for me and they'd arrest me [again]"

There were a number of reasons that she didn't think of complaining, including the time it would take to put in a formal complaint, the fact she didn't feel that she would be believed and the risk of being arrested for outstanding warrants:

> **"No. because I got out. I got my fix … do you understand what I mean, I didn't have time …"**

"I spent a lot of time in police stations, in the cells and I wasn't doing that voluntarily, because it would have been my luck, I would have gone to report it and they would have had a couple more shoplifting charges to nick me with, and that'd be the issue, so no I didn't think about complaining …"

“I spent a lot of time in police stations, in the cells and I wasn’t doing that voluntarily, because it would have been my luck, I would have gone to report it and they would have had a couple more shoplifting charges to nick me with, and that’d be the issue, so no I didn’t think about complaining ...

I wouldn’t have been believed, it would have been ‘oh it’s [name] again and this is the story she’s come up with’ ... I know ... there were probably a couple of other girls they were doing it with, but that wasn’t my concern ...”

She feels that during the years she was using drugs that she was stigmatised by her family and other people in the community. There was an assumption that women who used drugs were automatically sex workers, and this directly contributed to her beginning to sex work. During the time she was sex working she did her best to hide it from the other sex workers.

“[my drug use] was something that I never really tried to advertise ... people knew enough about me without me having to advertise myself ...”

Whilst she was using drugs, she felt that professionals didn’t take her seriously when she was a victim of domestic abuse and that when she was at her most vulnerable members of the police force exploited her.

She felt that there was no pint in trying to press charges against her abusive partner or complain about the inappropriate behaviour of police officers, because she felt the fact she was a known drug user made it unlikely that she would be believed.

Since she has been in recovery she feels that it is better to tell medical professionals about her history of using drugs up front. When asked why she felt that it would be difficult to hide and that it was better to tell professionals rather than have them deduce it or read it in her medical records:

“[my drug use is] quite visible as well, like my teeth, my hair, my arms ... a professional would probably put two and two together that I’d had [drug] issues ... Because I think sometimes if you tell the professionals, in your head, you think ‘oh they’ll work with me better’ if they find out themselves and I haven’t come up front about it, they’re going to dismiss me’,”

She also felt that it was better for her to disclose her drug use rather than be questioned:

“It’s a defence to say ‘ look here you go, I’ve told you, I’ve told you the information that I know you’re going to want to know, now don’t ask me no questions .... You sort of spew it out to shut it down.”

Case Study Four

He is a man in his sixties with long term physical and mental health conditions

He first started taking drugs seriously in the 1970s in Berlin, where he was living for work. He'd been taking a lot of psychedelic drugs:

LSD, mescaline, psilocybin, mushrooms, and cannabis. This was perfectly normal to him and those around him:

> **"I was working as a music promoter ... basically, part of my job was entertaining people ... it was par for the course that I was drinking heavily and ... psychedelics were part of the scene ..."**

He first took heroin in 1981 on his return to England:

"[I started taking heroin] because I had basically blown my mind on LSD ... and the heroin ... somebody gave me a fix and it ... basically brought me back down to earth ... once you've taken one injection, it's lovely and you just carry on"

"[When I came back to London] ... I just carried on, London's a beautiful city, great night life ... I was young ... I had no family to worry about ... so I did as I pleased ... I was basically a bit of a party animal"

He then decided to travel to India, before he went to India he made an appointment with his Doctor, to get his travel vaccinations.

Whilst there she asked if he took drugs, when he replied that he did take drugs, the doctor registered him as a heroin addict:

> **"... I wasn't seeking help for it, she registered me as a heroin addict and gave me some advice about my journey to India."**

His attitude to drug use at the time was that everyone did and he saw no reason not to disclose:

> **"I was very naïve, I didn't really understand what illegal meant .... To me it was just there ... most of the people that I met who were taking drugs were famous musicians ... so I didn't really think that it was a negative thing at all ... it was just something that I did."**

He travelled to India on a one-way ticket and whilst he was there, he was robbed, he approached the British High Commission and they wouldn't give him any money or a ticket back to the UK, they agreed to contact his parents, who then declined to help:

"I was shocked [when they wouldn't repatriate me] … I just sat down on the pavement and cried … they agreed to contact my parents, I had some idea where they were, but I didn't know exactly … it took a couple of months and they both [my parents] declined to help me.

My mother … told them that I'd done that sort of thing before and that I really wasn't …. worth bothering with, that she'd buried me basically .. and the government said that if your parents aren't going to help you we're not going to help you .."

Speaking about his relationship with his parents and their attitude to drug use, he said:

"I never told them [my parents] [that I used drugs], they cut me off because they assumed that I was taking drugs, I didn't have to tell them … that was it – I was no good, I went to India … that was stepping over the line as far as they were concerned. Even though they never had any proof that I was a drug addict, they assumed … I mean they were right in their assumptions … and I was just cut off from the finances."

Despite the difficulties, he described the year he spent in India as being totally amazing. He then returned to London, where he obtained a private prescription:

"I first got into … treatment when I came back from India, because I had such a massive habit … obviously I couldn't sustain that habit and I went to a place called the Rivendell clinic, up in the West End … and I was on a methadone script, I was using methadone amps and Dexedrine … I was paying for that, that sustained me."

At the time he believed that drug treatment meant attending a residential rehab, which he didn't want to do:

> **"I had no thoughts of rehab or anything … I assumed that things like rehab were for people like the kids of rich and famous people, rock stars … it wasn't something that I thought was applicable to me."**

> **"… I didn't even give it a second thought … I had no real intention of giving up drugs, I like drugs … it was just I had a problem with the amount of drugs I was taking … the fact that I couldn't afford to keep purchasing them …"**

On his return to London, he spent some time street homeless, before finding himself work and somewhere to live. When speaking about employment, he says:

"I always worked … over the years I've always worked, because I've always needed money, I work, I do whatever I can."

Although he found it difficult to get work whilst homeless:

> **"You have to present yourself properly before you can get a job in the first place – when you've got no clothes and no money it's kind of a difficult problem … so it took me ages to get back on my feet …"**

Once he had found somewhere to live, he had a number of different jobs including working as a financial adviser in the City. At this point he felt that he would not have been able to disclose his drug use to his employer or colleagues:

"I've gone to the extremes of life, from being very poverty stricken, homeless on the streets, to having my breakfast at the Café Royale and working for one of the top companies in the City … I couldn't tell the people I was working with [in the City] that I used drugs, it would have been professional suicide! … I would have been dismissed immediately"

Since being homeless he has lived in social housing, where he feels his drug use wasn't an issue because everyone around him was using as well:

"I lived in social housing … as time went by … and crack cocaine came in and the vibe changed from being nice to being awful and …. so, I was surrounded by mayhem and chaos, so nobody cared what I did …"

Around 25 years ago he had a stroke and then a heart attack, he then developed osteoarthritis that led to him using a large amount of opioid based painkillers:

"I had a stroke … basically I had two years of hell … I was in a really serious way and … I found myself very much alone and when I talked to people, because they didn't know what I was like before … I was very much on my own and there wasn't really anybody to support me …

Fortunately, I recovered from the stroke, but unfortunately I had a heart attack … that put me back again and then, because I've got this osteoarthritis problem that I've developed, it was getting very painful and I was taking dihydrocodeine, of course my dihydrocodeine use skyrocketed."

He then attended a residential detox and accessed community drug treatment for the first time.

He states that he had been unaware of free at the point of delivery drug treatment services, although given the time scale of his drug use, it is likely that there were fewer options available when he was younger:

> **"When I was on a private script, I didn't know that such a thing existed [free at the point of delivery drug treatment]. I'm a bit naïve when it comes to state benefits [and services], I'm a person that knows nothing about them …**
>
> **Drug treatment as we know it now probably didn't exist back then … the last few years … there are a lot of things that are available now that weren't available years ago"**

When speaking about his problems with his mental health, which resulted in him being sectioned, he felt that he had been treated differently because of his drug use:

"You see if you haven't been using drugs you're a decent person and you're a decent person with a psychiatric problem. If you've been taking drugs then you're a bad person .... you're a criminal and a bad sort that takes drugs and is basically no good."

He feels that the mental health services operate on assessing risk and that drug use presents an additional risk:

> **"They do everything with risk – it's all about risk ... I think [my drug use] made their decision making difficult and I think it always forces them to take a negative stance."**

At the end of the workshop, he stated quite clearly that he now didn't disclose his drug use unless absolutely necessary and that this prevented him being stigmatised.

This is a significant change from earlier in his life where he felt that drug use was normal and that everyone around him was doing it.

> **"I don't tell them ... I just lie ... I just don't fill in that bit on the form"**

His reasoning was:

"I don't want them to have an opinion about something that's illegal anyway ... I'm a very private person, I will tell people that I already know or that I'm comfortable with but I'm not going to tell you anything that's going to give you a bad perspective of me."

Stating that he felt he would be profiled and not receive employment housing or other services if he was honest:

"Unfortunately, this is how people profile and if you think any other way you're deluded. If you take an application form and you say 'I have psychiatric problems and I use drugs', do you think you'll get a job [or housing], no, no you're not ..."

Case Study Five

He is a British Pakistani man in his late thirties who has a long-term mental health condition and has served at least one prison sentence:

When talking about his experiences of stigma, he highlighted the fact that he has experienced multiple stigmas and that he was unable to break it down:

"It was about it all. If my criminal record wasn't going to be a barrier then certainly my race and culture would have been, or if my race and culture wouldn't have been then it would have been my criminal behaviour, criminal past. So, on all fronts."

When asked about drug use and drug treatment and the South Asian community: He described there being a lot of guilt and shame associated with drug use in the South Asian community and he felt that this was a barrier to people asking for help:

> **"…. there's a lot of shame and guilt as to people's problems and issues and they definitely don't want those issues or problems being known by someone else within the community…."**

He described the community as small and felt that it was still small, even in large cities where the number of South Asian community members was higher:

"The communities can be small, but [name of large city] has pretty good big South Asian community. To be fair, it's still very small, because they tend to know the same people, tend to go to the same events, same weddings, and stuff like that. So … it's quite easy for that gossip to be passed around like Chinese whispers."

He also felt that the South Asian community viewed drug use as a private problem and community members felt that it was unlikely that they could get the help they needed:

"… The South Asian community are a lot more religious than the [other communities]. They believe that maybe religion can help them through, focusing on the religion. … So yes, I do believe that they look at it differently …I believe they look at it from the point of view that it's your problem and only you can sort it out. You will not get the support that you want so why bother trying …"

This meant that people felt worried about accessing drug treatment in case any members of their community or family found out. This applied to collecting OST in the community pharmacies:

> **"A lot of Asian lads for example, South Asian lads in [name of town], they definitely wouldn't be going anywhere near a pharmacy to collect any methadone, they'd rather just go to their dealer and collect their heroin. It's more intimate, more private."**

He said that he felt that people in the South Asian community had a fear of authority and were worried about the consequences of this were that people were worried about accessing drug treatment.

"...where people think that if they go to the authorities for help then something's going to come back at them. Or they live in fear of what could potentially happen as a result of having to go to the authorities.

They're "authorities", even that word itself is a hurdle to have to cross without your mind getting carried away with ... what potentially could happen as a result of you seeing that service ....

I think a lot of the lads think if they go to a pharmacy then their mum and dads are going to get a knock on the door by the police to say they've been using methadone, or they've been using needles."

He felt that he didn't feel welcome in drug treatment services and that this applied to other people from his community:

"... [in existing services] they don't feel welcome. I really didn't feel welcome, I still don't feel welcome at times. I have to continuously go and be a part of [it] because I know it's the best thing for me ...

For the South Asian community, it's not that they're not aware of the stuff, because services are very good at getting their name across and the offer of helping, however once you're actually through the door, whether they can actually help is a different matter ... "

He felt that poor experiences were common:

"It's like what they say in marketing, one person has a bad experience, they'll go and tell many more than the person who's had a good experience. I often have to console some South Asian people when I talk to them when they tell me that the services they've been to ... they didn't feel welcome. I have to try and switch it round ... until they realise that it's not about feeling welcome it's about them needing to do what they need to do to live a better life."

When asked about why he felt South Asian people didn't feel welcome in drug treatment, he said he felt it was about inclusion:

"I think it's an inclusion thing. They maybe don't feel welcome because they don't see anyone else from the South Asian community within the organisation or within the service itself, and they believe that they are going ... against their own collectiveness. It's like, one of the reasons I was so apprehensive about getting into services and following it through was because there was no one like me."

When asked to explain further, he said that it wasn't just about ethnicity, it was about an entire culture:

> **"...but genuinely in the services in [name of town], there was no one like me – not even into the same music, into the same clothes, same culture, same religion, same race. And that really made me apprehensive because I knew I needed help but I wasn't able to get the help from somewhere I thought that I would be a part of ..."**

This feeling of not belonging extended to peer support/ mutual aid in the community:

> **"I still go to NA meetings now … and don't ever see a brown face in there … and it does make me feel not a part of [it] …"**

When asked about the things he felt could help:

"Maybe relating to people in different languages would help, maybe relating to people of a similar being, similar cultures, and similar race."

But went on to emphasise how far he thought services still had to go to achieve this:

"The biggest rehab organisation in [name of town] that I know of is definitely not inclusive, it's so far from inclusive."

He was genuinely grateful for the opportunity that he had been given but described the residential treatment centre as prejudiced and racist:

"Though I'm grateful to them for giving me the opportunity … taking me somewhere where I wasn't able to score … they moved me out of the area for 56 days …

But, wow, was that such a racist, prejudiced place. It was one rule for one and one rule for everybody else."

He went on to emphasise the lack of diversity amongst the staff and the impact that this has had on his community:

> **"I find it very surprising that in the ten years that I've known about this organisation they've never had someone complete the treatment of my ethnicity, my culture … and there's a particular reason for that- there's no one of my ethnicity, my culture that works for that organisation."**

Despite all of these experiences, he is volunteering in the treatment services in his area and feels strongly that his life experiences will enable him to support others, he also speaks positively about his employment chances in addiction services:

"... I think it is easier someone from my experience because I've lived a life, I've been involved in crime, I've been involved in drink and drugs and I've come out through the other end. That experience is extremely valuable to people who are beneficiaries of the addiction services. I'm hoping that my experience can obviously benefit others.

I think it's easier for me to get a job with the addiction services based on my history than it was, for example, MacDonald's ... I can't get a job in MacDonald's .... I can't get a job in a local newsagents ... I think I'd struggle to get a job as a paperboy if the local newsagents wanted to employ me as a paperboy because of my history ...

but when it comes to the services, for example addiction services, or mental health services, it's like, 'yeah, we want you, because you've overcome that sort of thing.' I was proactive, I'm a real valuable asset ... because I work hard in everything I do."

He is hoping that by working with the local services that he can help people from his community:

Case Study Six

He is a man in his mid-fifties who describes himself as having been addicted to heroin for nearly 40 years:

> **"... and I've spent nearly 40 years addicted to heroin. 35 of which have been spent in substance misuse treatment."**

He describes people who use drugs as being one of the most stigmatised groups in society:

"Drug addicts are one of the most stigmatised groups in western society ... in fact the only group that really compares, in terms of stigma, are paedophiles!"

And goes on to emphasise that he has experienced life-long stigma in many forms:

"... so, I can honestly say, by now ... I have a PhD in stigma and it's many forms."

He stated that he was aware of the stigma inherent in using drugs, but emphasises that he was deeply hurt the first time he experienced this stigma:

"... I was obviously aware of the stigma around addiction long before becoming an addict ... but the first time it really hurt me ... cut me deep was when an old friend stopped talking to me ... when I asked, 'Why?' he told me "I don't want to hang around with junkies'"

He considers that this was the first of many things that stigma cost him:

"Sadly ... the stigma around addiction is so heavily negative .... that someone I considered a close friend was blinded to our friendship by it ... that was the first of far too many [things] that stigma cost me ..."

He goes on to list the things he believes stigma has cost him:

> **"... stigma has cost me dearly ... I've lost friendships ... jobs ... opportunities ... but It almost cost me my life ..."**

In the 1990's he was providing an out of hours peer-to peer needle exchange in [name of large city], which meant that lots of people were visiting at home, at odd hours. This caused a reaction from the local community:

"... people needing clean syringes outside of normal service hours knew they could come to my place and I'd supply them with clean injecting equipment ... this steady stream of people coming to my door at weird times didn't go unnoticed in the local community ... one night there was a knock at my door ... but when I opened my door I discovered it wasn't someone needing a bag of 1mls ...

but instead it was a delegation of my neighbours ... who informed me that if carried on dealing drugs they'd torch my home with me in it! ... they had nothing against me personally ... they just didn't believe I could be doing something positive ... and so I must be dealing ...."

He comments that it was the stigmatisation of people who use drugs, that made the community members act in this way:

> **"... their stigma was so strong ... a bunch of normal, backbone of the community types ... were prepared to kill another human being .... stigma kills in many ways..."**

He also mentions that he feels drug users stigmatise each other – based on different criteria, such as drug of choice and route of administration:

> **"But it's true, isn't it? Stigma's universal across society and it's just as alive in drug users as it is in anyone else ..."**

This is something that he finds sad:

> **"... [it's] somewhere between grim irony or deep sadness that substance users who have a lifetime of stigma to look forward to actually stigmatise each other as well ..."**

He feels that not only is stigma present in wider society, but that it is present in drug treatment:

"In my opinion you have to be in denial or deluded to think that stigma didn't exist … it's in wider society and it's most certainly in drug treatment as well unfortunately … I've been in treatment now nearly forty years and it was there the day I walked in and I fear it will be there the day they carry me out in a box …. Obviously, it comes in many forms from individual drug workers I've met … and it's also institutional in the way that services are actually set up …"

When asked about institutionalised stigma, which he feels is more dangerous than stigma from an individual:

"… more dangerous than an individual stigmatiser is institutional stigma … stigma becomes collective … a shared madness … and this can be found in just about every group …it's even present in substance misuse services who should know better …"

He feels that urine testing is a form of institutionalised stigma and sends a message that services don't trust people who use drugs:

"… every time a client undergoes urinalysis they're stigmatised. … the mass urine testing of clients is akin to telling your clients 'We don't trust a word you say!!' … try developing a therapeutic relationship in that environment!"

He feels that stigma contributes to people dropping out of treatment:

> **"… many people drop out of treatment after discovering individual and collective stigma … in one of the few places that should offer sanctuary … but actually doesn't …"**

He feels that stigma within drug treatment is increasing:

> **"…if anything stigmatisation of addiction seems to be increasing making life for a vulnerable group even more dangerous …"**

More recently, he feels let down by treatment services during the Covid-19 Lockdowns:

"…another recent example of stigma in treatment arrived courtesy of the Covid pandemic … I suspect … like many other clients … I rang my service to ask about Lockdown and how they could help me stay safe … I suggested writing lengthy scripts so I didn't have to leave the house as often … only to be told, 'I'm sorry, we never write for more than 2 weeks'! …"

He felt that the risk of him (maybe) abusing his medication was given more importance than the fact he was clinically extremely vulnerable (on the shielding list):

> **“... the fact we were in a pandemic caused by a respiratory virus and I suffer from COPD and asthma ... and [I'm] classified as clinically vulnerable didn't matter ... they were more worried about my abusing my script than the possibility of my dying. As I say, stigma kills.”**

He feels that stigma is something that has been around for a long time and will, therefore take a long time to change. He feels strongly that educations is the best way to combat stigma:

> **“... stigma has been around a long time ... longer than I've been around ... and I suspect it will be around long after me ... fighting stigma is going to be multi-generational battle ... the only way to kill stigma is to educate, educate ... and after you've done that ... educate some more.”**

Appendix One

35 participants completed the sign up process, not all of them attended a workshop.

Gender

Participants were asked to self-identify from the following options:

- **Woman (including trans woman)**
- **Man (including trans man)**
- **Non-binary**
- **In another way**

45.71% of participants (16/35) identified as a man (including trans man) and

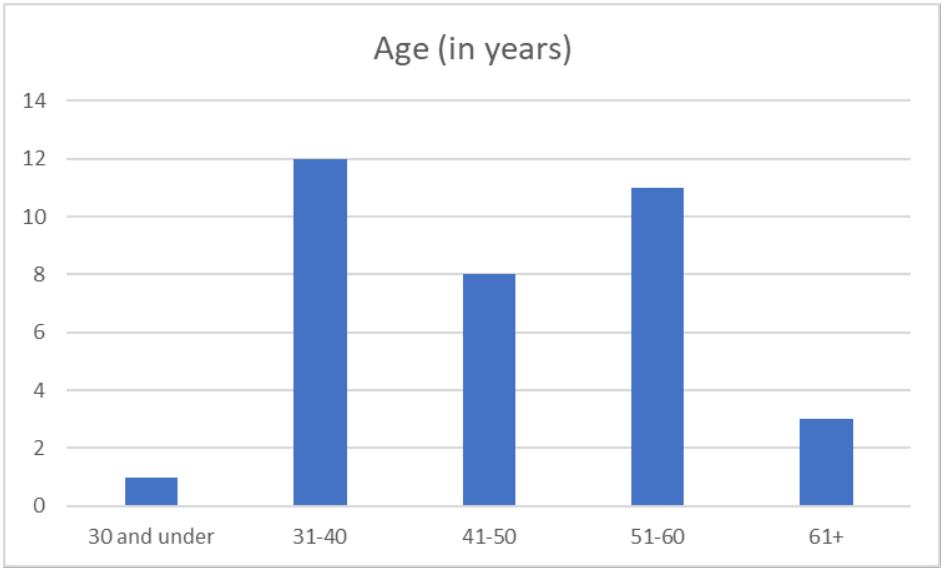
54.29% (19/35) participants identified as a woman (including trans woman). No participants identified as non-binary or other.

Participants were then asked if their gender identity was the same as the one they were assigned at birth. All participants (35/35) answered yes.

Age

Participants were asked to state their age in years. the minimum age was 28 and the maximum was 69, with a range of 41 years.

The mean age of participants was 46.83 years and the median age was 47 years, with the following distribution:



Ethnicity

Participants were then asked to describe their ethnicity. The results were as follows:

80.00% of participants (28/35) described themselves as White English /Welsh /Scottish /Northern Irish /British.

11.43% of participants 4/35) described themselves as Asian or British Asian.

5.71% of participants (2/35) described themselves as Black/Black British and 1 participant described themselves as Mixed White and Black Caribbean.

Religion

Participants were asked to identify religious beliefs. The question was about identity and made no attempt to differentiate whether were currently practicing the religion or not.

The responses were as follows:

	Number	Percent
No Religion (Atheist)	13	37.14
Agnostic	3	8.57
Christian (inc. all denominations)	12	34.29
Muslim	1	2.86
Buddhist	1	2.86
Other (please specify)	5	14.29

Other included, Pagan and Spiritualist. As can be seen the largest category was No Religion (Atheist) with the second largest being Christian (including all denominations).

Autism

Participants were asked if they were autistic. One participant answered yes. Interestingly, one participant mentioned Aspergers under "other" when asked about disabilities and long-term health conditions (see below)

Disabilities and long-term health conditions

Participants were asked if they considered their life to be limited in any way by a disability or long-term health condition.

The possible answers were: yes, limited a lot: yes, limited a little or no. 33 participants answered this question.

One of whom went on to identify one or more health conditions and has been counted when considering categories of disability or long-term health condition. The other left the entire question blank and has not been counted.

	Number	Percent
No	13	39.39
Yes, limited a little	11	33.33
Yes, limited a lot	9	27.27

61.76% of participants(21/34) reported one or more disabilities/long-term health conditions. The number of disabilities/health conditions reported by participants is as follows:

Number of Health Conditions	Number of Participants
0	**13**
1	**10**
2	**4**
3	**4**
4	**2**
5	**0**
6	**1**
7	**0**
8	**0**

And the health conditions reported as follows:

	Number
Vision (eg. due to blindness or partial sight)	**0**
Hearing (eg. due to deafness or partial hearing)	**2**
Mobility, such as difficulty walking short distances, climbing stairs, lifting and carrying objects	**7**
Learning or concentrating or remembering	**5**
Mental Health	**17**
Stamina or breathing difficulty	**5**
Social or behavioural issues (eg. due to neuro diverse conditions such as Autism, Attention Deficit Disorder or Asperger's Syndrome)	**4**
Any other impairment (please describe)	**4**

As can be seen half of all participants (17/34) reported problems with their mental health and of those that reported their life being limited by their health conditions 80.95% (17/21) reported problems with their mental health.

Approximately one in five (20.59) of participants (7/34) reported difficulties with their mobility.

Drug Use

Participants were asked to identify their drugs of choice in order of preference with there being the opportunity to name 10 specific drugs.

- **All pharmaceutical opioids were recategorized as opiates.**
- **All forms of cannabis were (hash, cannabis, weed, etc) were recategorized as cannabis.**
- **Speed, amphetamine and methamphetamine were recategorized as amphetamines.**
- **LSD and acid were combined as LSD.**
- **Spice and mamba were categorised as SCRA.**

The criteria for inclusion in this project was self-identity as a person who uses drugs. It was explained to participants prior to sign-up that this meant drug use other than alcohol. People who identified as primary alcohol users, or who used alcohol as part of poly-substance use were eligible to take part if they also used other substances.

When the data were analysed one participant had taken part who was not eligible. Because the data were anonymised and it was impossible to remove their poll answers from the workshop data, they have been left in for analysis purposes.

The first choice of drugs amongst participants were:

Drug	Number
Heroin	7
Opiates	2
Alcohol	9
Cocaine	2
Cannabis	3
Crack	3

With 9 people identifying opiates as being their first drug of choice (7 heroin, 2 other opiates) and 9 people identifying alcohol as being their first drug of choice.

3 people identified crack as being their first drug of choice and 2 as cocaine being their first drug of choice.

3 people identified cannabis as being their first drug of choice. This question made no attempt to identify which drug(s) had caused problems for people (if any).

The following drugs were mentioned by participants:

Drug	Number
Heroin	18
Opiates	18
Alcohol	20
Cocaine	4
Cannabis	16
Crack	17
MDMA	10
Amphetamines	8
Ketamine	4
LSD	7
Barbiturates	1
Benzos	2
SCRA	1
Other (2CB)	1

Alcohol was mentioned 20 times overall. Heroin was mentioned 18 as were other opiates. It should be noted that these were mentioned by 20 separate people, with 11 people mentioning one opioid (either heroin or another opioid), 6 people mentioning 2 opioids, 2 mentioning 3 opioids and one person mentioning 7 opioids.

Cannabis was mentioned 16 times by 15 people (with one specifying two different forms).

As can be seen from the above table the majority of participants stated a preference for more than one drug. Only one participant mentioned one substance alone, and that was alcohol (see above). 13 participants mentioned 3 substances of choice and

19 mentioned more than 3 substances of choice. For distribution see below:

Number of Substances	Number of People
0	**0**
1	**1**
2	**2**
3	**13**
4	**2**
5	**6**
6	**4**
7	**2**
8	**1**
9	**2**
10	**2**

Participants were asked about their history of injecting drug use, with the following options and distribution:

Statement	Number	Percent
No, never.	**18**	**51.43**
I tried it a few times, but didn't carry on	**2**	**5.71**
Sometimes	**2**	**5.71**
Regularly	**5**	**14.29**
I used to inject but stopped because I found it too difficult	**1**	**2.86**
Other (please specify)	**7**	**20.00**

It should be noted that all of the people who ticked other disclosed injecting at least once in their life. Some mentioned that they stopped before it became difficult and others mentioned stopping because of associated health problems.

This means that 49.57% of participants (17/35) reported injecting drugs at least once in their life.

Participants were then asked if they had injected drugs during 2021. 11.76% of those who had ever injected in their life (2/17) reported injecting in 2021.

Participants were also asked about their history of drug treatment. The options and distribution are shown below:

Statement	Number	Percent
Yes, currently	**10**	**28.57**
Yes, previously	**19**	**54.29**
No, never	**6**	**17.14**

As can be seen the majority of participants had used treatment at some time in their life with over half (54.29%), 19/35 having used treatment previously and 29.57% (10/35) being currently engaged with treatment and only 17.14% (6/35) having never used treatment services. This is unsurprising given that the majority of the recruitment occurred through service providers and LEROs.

Appendix Two

This section contains the questions and prompts that were used in the first five workshops. The polls function in Zoom does not allow free text.

The questions and the answer options were co-produced between NHS APA and WE. The poll questions were mostly used to facilitate discussion. No attempt was made to differentiate between "that doesn't apply to me" and "I don't want to answer.

Because of the way the data were collected (using Zoom) and recorded (using an internet connection), the number of participants answering each question is not the same for all questions.

There were significant technical difficulties in some of the workshops, this means the data captured are incomplete.

If a participant changed their mind after discussion or reported pressing the wrong button, this was recorded manually, and the numbers were updated prior to analysis.

Because of the way questions were phrased (particularly the ones with the 5-point strongly agree – strongly disagree scale) there was some confusion amongst participants and additional help/ explanation was given.

At the beginning of each workshop the following definition of stigma was given:

If you stigmatise someone you have given that person a (negative) label that is limiting in some way.

POLL ONE

Question: Do you think drug use is stigmatised?

Options
Yes
No

All participants (n = 30) answered yes to the question.

The facilitators then introduced the topic as follows:

"We are now going to ask if you think this stigma has impacted your interaction with various people and services. We want to know if you feel the fact that you have used drugs means you get a different service to people who have never used drugs

We are looking for specific examples of stigma you have experienced and the impact this has had on your behaviour.

It may be that there was a single experience that caused you to feel in a certain way

It may be that there were a series of experiences that caused you to feel this way

It may be that there is no specific experience, but that you were worried about how you might be treated (self-stigma)"

Drug treatment

POLL TWO

Statement: stigma relating to drug use prevented me approaching drug treatment for help.

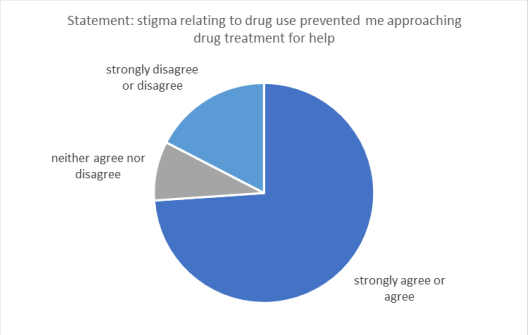
Options
Strongly agree
Agree
Neither agree or disagree
Disagree
Strongly disagree
This doesn't apply to me

The poll results were as follows:

Strongly Agree	**9**	**34.62%**
Agree	**8**	**30.77%**
Neither agree nor disagree	**2**	**7.69%**
Disagree	**2**	**7.69%**
Strongly disagree	**2**	**7.69%**
Doesn't apply to me	**3**	**11.54%**

26 participants answered this question with 11.54% (3/26) stating that it did not apply to them.

Taking the answers from the participants who felt the question was relevant to them (n = 23) and combining the categories agree and strongly agree and the categories disagree and strongly disagree, gives:



As can be seen 73.91% (17/23) of those who expressed an opinion either agreed or strongly agreed with the statement that stigma prevented them accessing drug treatment.

Then the following prompts were used:

Has stigma stopped you from receiving or accessing drug treatment?

- **Is there a specific experience that stopped you asking for help?**
- **If there is no specific experience is it cumulative or self-stigma or a combination?**

Participants were then asked:

Do you feel that people who use different drugs are treated differently?

- **By other people who use drugs?**
- **By services?**
- **By society?**

Families and family relationships

POLL THREE

Statement: I was not worried about how my family would react to finding out I used drugs.

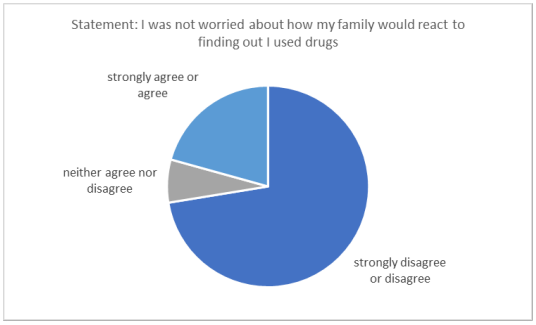
Options
Strongly agree
Agree
Neither agree or disagree
Disagree
Strongly disagree
This doesn't apply to me

The poll results were as follows:

Strongly agree	**17**	**58.62%**
Disagree	**4**	**13.79%**
Neither agree nor disagree	**2**	**6.90%**
Agree	**2**	**6.90%**
Strongly agree	**4**	**13.79%**
Doesn't apply to me	**0**	**0.00%**

29 participants answered this question, with all of them expressing an opinion (no-one answered this doesn't apply to me).

Combining the categories agree and strongly agree and the categories disagree and strongly disagree, gives:



As can be seen 72.41% of participants (21/29) either disagreed or strongly disagreed with the statement, i.e., 72.41% were worried about how their family would react to finding out about their drug use.

Participants were then asked:

Do you feel that the fact you used drugs affected the way your family treated you and/or your relationships with them?

- **Is there a specific experience that illustrates this?**
- **If there is no specific experience is it cumulative or self-stigma or a combination?**

Mental Health

POLL FOUR

Statement: the fact I am a drug user has made it difficult for me to get help with my mental health.

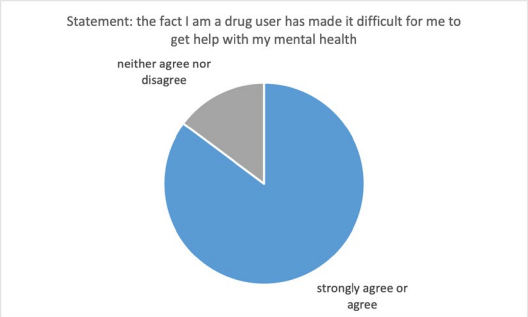
Options
Strongly agree
Agree
Neither agree or disagree
Disagree
Strongly disagree
This doesn't apply to me

The poll results were as follows:

Strongly agree	**9**	**32.14%**
Disagree	**14**	**50.00%**
Neither agree nor disagree	**4**	**14.29%**
Agree	**0**	**0.00%**
Strongly agree	**0**	**0.00%**
Doesn't apply to me	**1**	**3.57%**

28 participants answered this question, with 3.57% (1/28) stating that this did not apply to them.

Taking the answers from the participants who felt the question was relevant to them (n = 27) and combining the categories agree and strongly agree and the categories disagree and strongly disagree, gives:



As can be seen 75.19% (23/27) of those who expressed an opinion either agreed or strongly agreed with the statement that their drug use prevented them getting treatment for their mental health.

It should be noted that no participants disagreed or strongly disagreed with this statement.

Then the following prompts were used:

If you have problems with your mental health do you think your drug uses has affected your receipt of treatment?

- **Is there a specific experience that stopped you asking for help?**
- **If there is no specific experience is it cumulative or self-stigma or a combination?**

Physical Health

POLL FIVE

Statement: the fact I am a drug user has had no impact on me accessing physical health treatment.

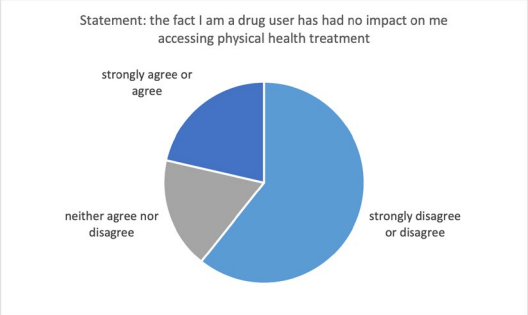
Options
Strongly agree
Agree
Neither agree or disagree
Disagree
Strongly disagree
This doesn't apply to me

The poll results were as follows:

Strongly agree	**5**	**17.86%**
Disagree	**12**	**42.86%**
Neither agree nor disagree	**5**	**17.86%**
Agree	**5**	**17.86%**
Strongly agree	**1**	**3.57%**
Doesn't apply to me	**0**	**0.00%**

28 participants answered this question, with all of them expressing an opinion (no-one answered this doesn't apply to me).

Combining the categories agree and strongly agree and the categories disagree and strongly disagree, gives:



As can be seen 60.71% of participants (17/28) either disagreed or strongly disagreed with the statement, i.e. 60.71 % felt that the fact they used drugs had impacted on their treatment for physical health.

Then the following prompts were used:

Do you think your drug use has affected your access to or receipt of treatment for physical health problems?

- **Is there a specific experience that stopped you asking for help?**
- **If there is no specific experience is it cumulative or self-stigma or a combination?**

Complaints

The following information was provided as a background to the discussion: if you receive a poor service somewhere, you can complain in various ways: to the service itself, to the organisation paying for the service (council, CCG etc) or you can complain to your MP or the local paper.

POLL SIX

Statement: I thought I wouldn't be taken seriously if I complained because of my drug use.

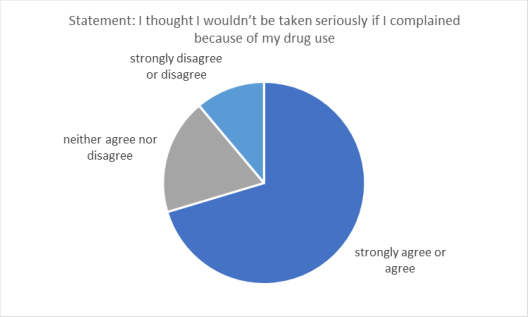
Options
Strongly agree
Agree
Neither agree or disagree
Disagree
Strongly disagree
This doesn't apply to me

The poll results were as follows:

Strongly agree	**12**	**44.44%**
Disagree	**7**	**25.93%**
Neither agree nor disagree	**5**	**18.52%**
Agree	**1**	**3.70%**
Strongly agree	**2**	**7.41%**
Doesn't apply to me	**0**	**0.00%**

27 participants answered this question, with all of them expressing an opinion (no-one answered this doesn't apply to me).

Combining the categories agree and strongly agree and the categories disagree and strongly disagree, gives:



As can be seen 70.37% of participants (19/27)) either agreed or strongly agreed with the statement and felt that the fact they are a drug user made them feel as if they wouldn't be taken seriously if they complained about a poor service.

Then the following prompts were used:

Do you think your drug use has stopped you from complaining when you received a poor service?

- **Is there a specific experience that stopped you complaining?**
- **If there is no specific experience is it cumulative or self-stigma or a combination?**

Employment and Benefits

POLL SEVEN

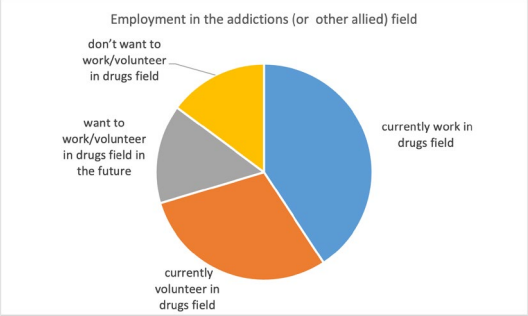
Firstly participants were asked if they worked in the drug treatment addiction field (this was extended to include allied fields such as working/volunteering in a hostel/food bank/ soup kitchen).

Options
I currently work in the drug treatment field (paid role)
I currently volunteer in the drug treatment field (unpaid role)
I do not currently work or volunteer in the drug treatment field, but I do want to in the future
I do not currently work or volunteer in the drug treatment field, and I do not want to in the future

The poll results were as follows:

Work in drugs field	**11**	**40.74%**
Volunteer in drugs field	**8**	**29.63%**
Want to work/ volunteer in drugs field	**4**	**14.81%**
don't want to work/ volunteer in drugs field	**4**	**14.81%**

27 participants answered this question.



As can be seen the majority of participants 70.37% (19/27) currently work or volunteer in the addictions field. With a further 14.81% (4/27) hoping to work in the addictions field in the future.

This means that only 14.81% (4/27) of those participating in this poll did not want to work in the addictions field in the future.

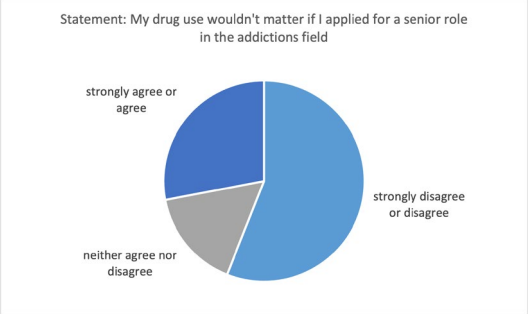
Options
Strongly agree
Agree
Neither agree or disagree
Disagree
Strongly disagree
This doesn't apply to me

The poll results were as follows:

Strongly agree	**12**	**48.00%**
Disagree	**2**	**8.00%**
Neither agree nor disagree	**4**	**16.00%**
Agree	**5**	**20.00%**
Strongly agree	**2**	**8.00%**
Doesn't apply to me	**0**	**0.00%**

25 participants answered this question, with all of them expressing an opinion (no-one answered this doesn't apply to me).

Combining the categories agree and strongly agree and the categories disagree and strongly disagree, gives:



As can be seen the majority of those that answered this question 56.00% (14/25) disagreed or strongly disagreed with this statement, implying that they felt their drug use would be held against them if they applied for a senior role in the addictions field.

There was some discussion as to what was meant by a senior role and many of those who felt that their drug use would not be held against them worked or volunteered in LEROs or small CICs within the addictions (or allied) field.

POLL NINE

Statement: I was worried about telling my employer that I used drugs.

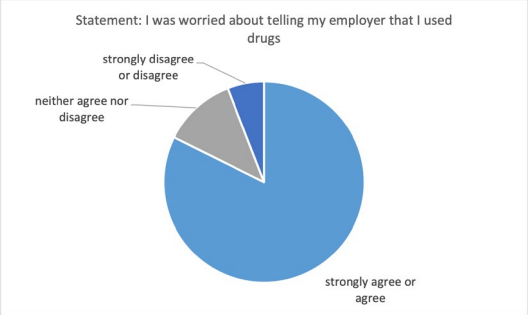
Options
Strongly agree
Agree
Neither agree or disagree
Disagree
Strongly disagree
This doesn't apply to me

The poll results were as follows:

Strongly agree	**12**	**52.17%**
Disagree	**2**	**8.70%**
Neither agree nor disagree	**2**	**8.70%**
Agree	**0**	**0.00%**
Strongly agree	**1**	**4.35%**
Doesn't apply to me	**6**	**26.09%**

23 participants answered this question with 26.09 % (17/23) stating that it did not apply to them, mostly because they had not been employed whilst using drugs,

Taking the answers from the participants who felt the question was relevant to them (n = 17) and combining the categories agree and strongly agree and the categories disagree and strongly disagree, gives:



As can be seen 82.35% of participants (14/17) either disagreed or strongly disagreed with the statement and had been worried about their employer finding out about their drug use.

Then the following prompts were used:

Do you think your drug use has affected support you received from your employer (do you think you would have been treated differently if you had a physical health condition or other support need)?

- **Is there a specific experience that illustrates this?**
- **If there is no specific experience is it cumulative or self-stigma or a combination?**

POLL TEN

Statement: the benefits system (job centre) treated me the same as everyone else while I was using drugs.

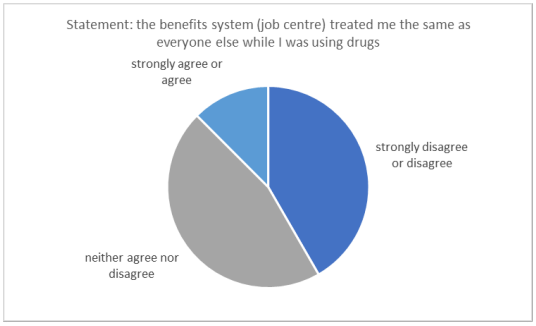
Options
Strongly agree
Agree
Neither agree or disagree
Disagree
Strongly disagree
This doesn't apply to me

The poll results were as follows:

Strongly agree	**5**	**18.52%**
Disagree	**5**	**18.52%**
Neither agree nor disagree	**11**	**40.74%**
Agree	**2**	**7.41%**
Strongly agree	**1**	**3.70%**
Doesn't apply to me	**3**	**11.11%**

27 participants answered this question with 3.70% (3/27) stating that it did not apply to them.

Taking the answers from the participants who felt the question was relevant to them (n = 24) and combining the categories agree and strongly agree and the categories disagree and strongly disagree, gives:



As can be seen the largest response category was neither agree nor disagree with 45.83% (11/24) of participants choosing this category. 41.67% (10/24) of participants either strongly disagreed or disagreed with this statement, implying that they felt they had been treated differently by the benefits system (job centre) because of their drug use.

This was interesting, because some of the people that had been treated differently because of their drug use felt that they had been offered more support. More than one participant reported being told not to bother signing-on and although in retrospect they felt that this had been discriminatory it had been to their advantage at the time. Some of the participants who felt that they had been treated the same as everyone else, still reported a poor service, they just felt that everyone received a poor service, regardless of whether they used drugs or not.

There was significant variation in reported experiences, depending on when people had interacted with the benefits system, as there have been a numbe of initiatives through the years that have provided additional support and/or a relaxation in job-seeking requirements for people who were engaged in drug treatment.

Then the following prompts were used:

Do you think that the service you received from the job centre was affected by the fact you were using drugs?

- **Is there a specific experience that illustrates this?**
- **If there is no specific experience is it cumulative or self-stigma or a combination?**

Housing

POLL ELEVEN

Statement: the fact I used drugs made it difficult for me to get or keep housing

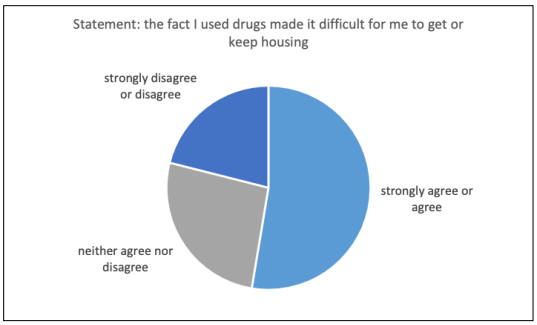
Options
Strongly agree
Agree
Neither agree or disagree
Disagree
Strongly disagree
This doesn't apply to me

The poll results were as follows:

Strongly agree	**4**	**19.05%**
Disagree	**6**	**28.57%**
Neither agree nor disagree	**5**	**23.81%**
Agree	**3**	**14.29%**
Strongly agree	**1**	**4.76%**
Doesn't apply to me	**2**	**9.52%**

21 participants answered this question with 9.52% (2/21) stating that it did not apply to them.

Taking the answers from the participants who felt the question was relevant to them (n = 19) and combining the categories agree and strongly agree and the categories disagree and strongly disagree, gives:



As can be seen just over half of those that answered this question 52.63% (10/19) agreed or strongly agreed with the statement that their drug use made it difficult for them to get or keep housing.

It is again worth noting that reported experience changed significantly over time, with participants that had been offered social housing in the 1970s and 1980s reporting a very different (more positive) experience. There also was reported variation between different local authorities, particularly with respect to keeping housing during residential drug treatment or being offered social housing after completing residential drug treatment.

Then the following prompts were used:

Do you feel that the fact you used drugs affected the way housing workers interacted with you and the housing you were offered (or the support to keep your housing)?

- **Is there a specific experience that illustrates this?**
- **If there is no specific experience is it cumulative or self-stigma or a combination?**

Criminal Justice

POLL TWELVE

Statement: the criminal justice system (police, courts, prison, probation) did not offer any help for my drug use.

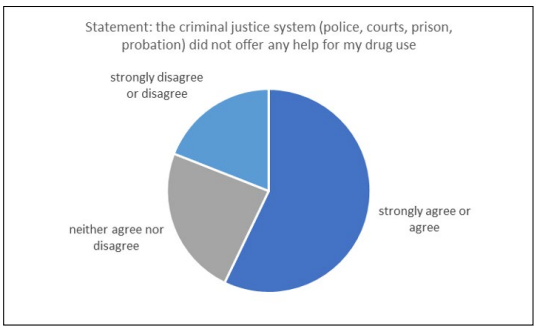
Options
Strongly agree
Agree
Neither agree or disagree
Disagree
Strongly disagree
This doesn't apply to me

The poll results were as follows:

Strongly agree	**5**
Disagree	**7**
Neither agree nor disagree	**5**
Agree	**4**
Strongly agree	**0**
Doesn't apply to me	**0**

21 participants answered this question, with all of them expressing an opinion (no-one answered this doesn't apply to me).

Combining the categories agree and strongly agree and the categories disagree and strongly disagree, gives:



As can be seen just over half of those that answered this question 57.14% (12/21) agreed or strongly agreed with the statement that the Criminal Justice System offered them no help with their drug use.

It should be noted that many of the participants who felt they had been offered no help for their drug use by the criminal justice system were speaking about historical interactions (20 or more years ago) and made this fact clear during the workshop.

Then the following prompts were used:

Do you feel that you were treated differently by the criminal justice system because you were using drugs?

- **Is there a specific experience that illustrates this?**
- **If there is no specific experience is it cumulative or self-stigma or a combination?**

General Services

(such as home help and other community support)

POLL THIRTEEN

I think people who use drugs get the same level of help as everyone else.

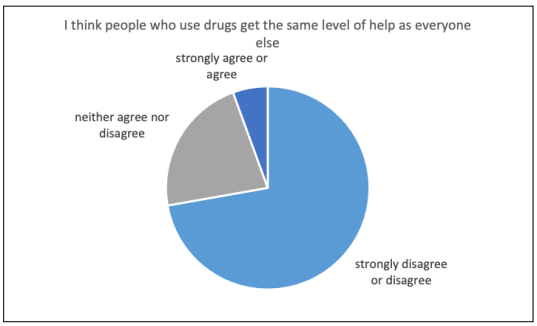
Options
Strongly agree
Agree
Neither agree or disagree
Disagree
Strongly disagree
This doesn't apply to me

The poll results were as follows:

Strongly agree	**8**	**38.10%**
Disagree	**5**	**23.81%**
Neither agree nor disagree	**4**	**19.05%**
Agree	**1**	**4.76%**
Strongly agree	**0**	**0.00%**
Doesn't apply to me	**3**	**14.29%**
Total	**21**	**100**

21 participants answered this question with 14.29% (3/21) stating that it did not apply to them.

Taking the answers from the participants who felt the question was relevant to them (n = 18) and combining the categories agree and strongly agree and the categories disagree and strongly disagree, gives:



As can be seen 72.22% (13/18) of those that answered this question) disagreed or strongly disagreed with the statement that people who use drugs get the same level of service as everyone else. It should be noted that a few participants felt that they had received better or more services than other people, because they used drugs.

It should also be noted that all of the participants that mentioned interacting with Children's Social Care (Child Protection) felt that they had been treated much worse than other parents because they used drugs.

Then the following prompts were used:

Do you feel that the fact you used drugs affects your ability to get the other help you need?

- **Is there a specific experience that illustrates this**
- **If there is no specific experience is it cumulative or self-stigma or a combination**

The NHS Addictions Provider Alliance (NHS APA) is a collective of 18 NHS Trusts working together to be more effective in contributing to the addiction treatment sector.

It works collaboratively with service users, carers and other organisations who are committed to making a positive difference to the ongoing development of the addictions field, including within drug, alcohol, gambling and gaming treatment and support.

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NHS Addictions Provider Alliance

www.nhsapa.org

Working With Everyone (we). is collective of unique individuals who have both lived experience of social harms as well as professional expertise. This offers an unparalled opportunity to improve the outcomes and levels of knowledge across a spectrum of services.

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Thank
you