

# COMBATING DRUGS PARTNERSHIP

LIVED EXPERIENCE REPORT

APRIL 2024



## Introduction

Over the past decade, an increase in drug usage combined with cuts in government funding has resulted in increased deaths and harm from drug and alcohol misuse. The West Sussex Combating Drugs Partnership, a government initiative set up in in 2024 to review relevant local data and put an action plan in place to inform priorities moving forward, has commissioned a number of local expert organisations to undertake research for these priorities.

CAPITAL Project Trust was commissioned by the Partnership to examine and present the unique views of those with lived experience of addiction across West Sussex, in order that commissioners, managers and specialist key workers might better understand the problems and challenges that users face on a daily basis.

The recommendations in this report will be used by the Partnership to plan and deliver new services and ways of working that better support those currently or formerly in addiction on their recovery, to improve their general wellbeing including housing and finances, and educate young people on the dangers of drugs and alcohol. Additionally, the report findings will be used to develop staff training and support systems.

## Project Overview

‘The past decade has seen a rise in overall drug use, a rise in drug related deaths (61% between 2010-2019), and increased harms from drug and alcohol misuse<sup>1</sup>. A review for the Government showed that funding cuts have put strain on drug and alcohol treatment providers, partnerships between agencies, and that vital services have been cut back<sup>2</sup>.

In response, the Government published it’s 10-year drug strategy, *From Harm to Hope*, and mandated local authority areas to establish a local Combating Drugs Partnership (CDP)<sup>3</sup>.

Key responsibilities of the West Sussex Combating Drugs Partnership include an ongoing review of all relevant local data and intelligence, a local plan of action, and an understanding of any relevant local issues relating to drugs and alcohol.’ (WSSCC Service Specification Lived Experience Project, Jan 2024)

<sup>1</sup> Office for National Statistics. Deaths related to drug poisoning in England and Wales: 2020 registrations. 2021.

<sup>2</sup> Home Office and Department of Health and Social Care. Independent review of drugs by Professor Dame Carol Black. 2021.

<sup>3</sup> HM Government. Guidance for local delivery partners. From harm to hope – A 10-year drugs plan to cut crime and save lives. 2022.

In order to gather feedback around substance misuse issues in the community which will be used to inform the combating drugs partnership priorities and development of a countywide action plan for 2024/25, West Sussex County Council (the Council) has commissioned various partners and local groups, including CAPITAL Project Trust.

CAPITAL was formed in West Sussex in 1997, as a result of mental health services not having an understanding of the experience of users of local services, or as people with lived experience of mental health issues. The Charity was established to challenge and change that experience, and set lived experience at the core of all activities. Since then it has:

- Become the voice and independent representation of the community of mental health service users to change services in West Sussex
- Developed training by people with lived experience to mental health staff, working together with professionals
- Initiated and led self-help projects in the area
- Championed the power of peer support locally
- Led peer support research and taken part in national and international evaluation
- Provided independent and academically accredited peer support hospital in-reach services
- Set up monthly peer led Patient View Point forums
- Developed a charter for service user involvement in West Sussex

Over 200 people are current members of CAPITAL, and are offered shared learning, training, workshops and community meetings – where people with lived experience lead our work.

In 2022 CAPITAL was commissioned to develop and lead co-production within the West Sussex Mental Health Community Transformation Programme. The Charity set up a new independent network: LEAG (Lived Experience Advisory Group), and is working on a vision for local mental health services as part of the priorities of the NHS Long Term Plan.

CAPITAL was specifically commissioned by the Council, through the Combating Drugs Partnership, to host focus groups in key locations across the county, bringing together those who have or continue to use drug and alcohol services to examine the issues and challenges relating to drug and alcohol use in West Sussex.

The Council is also interested to learn how the attendees feel services currently offered by the Council could be improved upon, as well linked services including outreach, peer support and work/training opportunities.

## Research Conditions

CAPITAL hosted six groups in five locations across the county between March 14<sup>th</sup> and April 11<sup>th</sup>, which 58 people attended. Groups were hosted at different times and on different days in order to include as many people as possible. Initially, the team also hoped to host two online meetings; however, after some initial challenges relating to location verification of sign-ups, it was decided to focus only on in-person groups.

Each attendee was asked to provide details of:

- age
- gender
- ethnicity
- any disability
- sexual orientation
- location
- carer/service user

*(see Appendices 1-7)*

Each group was given the same questions to answer to ensure parity. Attendees were encouraged to give their own opinion and views in an open forum, and all answers were recorded using both audio and written formats.

## Findings

### 1. *What caused you or the person you care for to use drugs or alcohol?*

*(see Appendix Eight)*

Main themes:

- Trauma
- Self-medication
- Peer pressure
- Loss of family members and close friends
- Loneliness and high emotion
- Curiosity

### Trauma

A number of attendees noted that childhood trauma led to their substance use. One stated 'abusive parents gave them alcohol and drugs to make them sleep and keep them quiet from a young age'. Another was moved away from family and friends by the authorities, and they began to use drugs and alcohol as a coping mechanism. A third reported that they hid their childhood trauma due to a lack of available help, and used substances as a result.

Others reported adult trauma being the catalyst for their substance issues; domestic abuse being the main theme here.

### Peer pressure

Peer pressure to start taking drugs and alcohol was another significant theme.

Most participants stated that the peer pressure came from friends, but some noted it was within their family network. They talked about alcohol being passed around at parties, and they drank some; 'not knowing that children weren't supposed to drink'. Others stated that they copied their friend's behaviour (drinking) in order to fit in.

Some noted that their activity began when young and living at home, and in a couple of instances under the guidance of parents. Attendees gave examples of copying parental behaviour, one being asked to pour drinks for their parents 'who were always drunk' which gave rise to beginning to drink alcohol themselves, being normalised behaviour, and another stated that they saw their parents using drugs and alcohol, so they copied. One attendee stated that their substance activity began when in prison.

It was also noted that the area in which an attendee was brought up had a significant impact on them beginning to use drugs and alcohol.

### Loss of family members and friends

A number of attendees commented that the loss of family members and friends, and/or the break-up of a marriage, led to a destabilising effect in their lives and meant that they were more vulnerable to taking drugs and alcohol. It has not been noted whether these attendees had a history of using drugs and alcohol and this loss led to a relapse, or if the usage was a new form of coping strategy.

### Loneliness and high emotion

Attendees cited loneliness specifically, and then a range of other emotions and emotional challenges such as depression, lack of self-esteem and confidence that led to them using drugs and alcohol.

### Curiosity

Some attendees stated that they began to take drugs or drink alcohol as a choice, 'I chose to try drugs, and enjoyed it' and 'enjoyed my first time, did more, and then needed to take them regularly'. Others reported impulsivity, going to parties/raves and trying there, and watching others imbibe so deciding to copy.

### Other

Comments noted in the Other category included:

- Boredom in prison
- No idea of the consequences of taking drugs

- Addictive personality
- Lifestyle choice
- 'Fuck it' syndrome

2. *What do you think are the priority areas related to drug and alcohol harm that the West Sussex Combating Drugs Partnership should focus on over the next three years?*

*(see Appendix Nine)*

*Main themes:*

- Peer support
- Training for key support staff
- Education/training for users
- Signposting
- Education for young people
- Changing laws and regulations
- Local authority intervention

*Peer support*

Attendees felt that peer support, particularly focused on community peer support, with one person mentioning the usefulness of a peer supporter working in council offices, would be instrumental in improving services across the county. Signposting to other services, whilst mentioned separately for the purposes of the report, would also fall under the remit of peer support work and one could argue that education and training (both for key support staff and young people) could be offered by peer support workers, through CAPITAL and its wider service offer.

*Training for key support staff*

Comments made by attendees in terms of the support they received from key support staff (doctors, nurses, council workers, Job Centre employees etc.) relayed a deep dissatisfaction and concern around this issue.

Statements within this theme included: 'GP's actually giving out information and not fobbing off because they are addicts'; 'train doctors in how to actually give help and support'; 'more consequences for doctors who don't look after addicts properly' and 'train doctors to recognise over-prescribing'.

*Education/training for users*

A theme within this question was that of education and training for users. Attendees mentioned the need and desire for not only education around drug and alcohol addiction ('creating awareness around drugs and the effect on your body and life'; 'recognising what causes addiction, helping people before they get to a point of no return', and 'an explanation of what will happen when you get proper help and stay clean') but also general life skills – financial budgeting, hobbies and other more productive uses of time that will help people trying to stay clean.

### Signposting

Attendees comments under this theme were consistent with the need for greater information around the availability of help and support. They included 'making it easier to find support', 'inform people about the services available', 'create a website or place at the council offices to make it easier for users to access help'.

This is something that, as previously mentioned, is linked to peer support workers, who would have immediate access to the information required.

### Education for young people

There appeared to be a consensus amongst attendees that better drug and alcohol education for young people could be a deterrent. Comments included 'target the younger generations from early primary school' and 'educate young people on what happens to their bodies and mental health when they drink and take drugs'.

### Changing laws and regulations

Attendees had a range of ideas for changes in law and regulations that could improve local services. These included 'legalise cannabis and tax it like tobacco', 'control drug use by using pharmacies to give them out', 'make alcohol available only from behind the till, like tobacco, also making it more difficult to steal', 'limit the amount of alcohol that can be sold at one time', 'reduce the amount of cheap alcohol', stop pubs, clubs and restaurants from advertising cheap drinks outside', 'less alcohol advertisements', and 'make it compulsory to give ID for alcohol purchase, no matter the age'.

### Local authority intervention

Attendees suggested the following ways that local authorities could help to improve substance misuse services and, therefore, users themselves.

'Safe spaces (not A&E)'; 'places for addicts to go and check-in'; 'longer term rehab, more rehab places and assisted living places; 'translators to help other communities', and 'clearer and more effective priorities'.

### Other

Other suggestions for improvement of local services, not included in the main themes, included:

- breaking the cycle of homelessness
- not putting people with different addictions together
- giving long term help
- finding ways to 'invest in people to break cycles

### Respect

This theme is not shown in the bar graphs, but it was so consistently mentioned throughout the answers to this question, that it was deemed important enough to draw the Council's attention to it.

Many attendees complained of a lack of respect given to them by key support workers, both in the way they were treated and the decisions made on their behalf. Alongside the obvious issues brought up in the Training for Key Support Workers theme, additional comments included 'stop punishing people for admitting they have a problem', 'treat people equally', 'stop ignoring people who ask for help', 'treat people equally', and 'actually listen to people'.

Attendees noted that being treated with respect encouraged them to find the support they needed, as well as to see themselves in a more positive light; leading to more consistency in working on their addictions.

It is becoming clear from the responses to this question that attendees are describing a joined up service of peer workers and support on the ground in easy to access locations (council offices, hospitals, doctor surgeries etc.) that they feel would be an improvement upon, and an addition to, the current offering.

### 3. *What would make it easier for you to access all the support that you need (e.g. substance misuse and mental health, physical health, social care etc...)?*

*(see Appendix Ten)*

Main themes:

- Signposting to services
- Peer support
- Education for users
- Training for key support staff

#### Signposting to services

There were a number of comments throughout this question from attendees asking for better signposting for services. Suggestions ranged from 'a road map to services' and 'an app/website similar to 111 for addictions', to 'joining up of services' and 'linking everything like Pathfinder does'.

Attendees also noted that they were looking for a one-stop shop/one point of contact for support where all resources were joined up.

#### Peer support

Attendees specifically noted wanting more peer support. Additionally, they asked for services such as 'a hub run by peers that can help point people in the right direction', and 'more places like Open House'.

#### Education for users

Attendees mentioned the need for education once more, citing services such as 'sessions for things like help with benefits, housing etc.', and 'education for everyone from primary school to adults'; suggesting that a number of attendees had not been/were not aware of what services were available for them or their family members/friends. They recommended that education with respect to the services available and how those services could help users would make it easier to access support needed.

#### Training for key support staff

In common with attendees noting in question two that further training is needed for key support staff in order to improve substance abuse services, attendees also stated that key support staff require further training with reference to the complexities of addiction and the support available to users.



Alongside stating that they felt ‘a list of places for referral or self-referral’ would be helpful and could be given by key support staff signposting or peer support), they also noted ‘being asked if you want/need support at doctors/hospital appointments’ and ‘knowledge of what/where any help is’ could be pivotal to them keeping addictions under control.

### Other

Other suggestions made by attendees relating to what would make it easier for them and others to access all the support they needed, included:

- improving communication
- safe places to go
- something to help replace the addictions
- rehabs for parents
- a bit of kindness

It can be seen that should signposting be improved upon – perhaps delivered by peer support at strategic locations – and better training is given to key support staff relating to where this support can be found (delivered by peer support and/or those who initiate the signposting project), a large proportion of the suggestions given by attendees would be implemented.

## 4. *How can housing services better support you/those you care for to feel safe and secure?*

(see Appendix Eleven)

Main themes:

- Better support from Council
- Safer recovery
- Housing security

### Better support from Council

Attendees had a range of suggestions for ways that the Council could better support them to access and maintain safe and secure housing. They noted that these included looking at individual cases ‘properly’ and better assessing user needs before placing them into homes. They also had points to make regarding the financial side of council support, suggestions such as making rent payments directly to the landlord instead of the addict and investigating whether more support could be given to live-in carers regarding rent payments.

### Safer recovery

From drug safes and a pharmaceutical machine that dispenses prescription drugs at certain times of the day (filled only by a pharmacist), to putting addicts into a recovery safe house, and putting people in recovery in different accommodation, rather than with current users; attendees felt that there were a variety of ways that the Council could investigate that would aid their recovery, and therefore make it more likely that they would be able to keep a safe and secure roof over their heads.

One attendee also commented that it would be helpful if the Council were able to give people with medical conditions (using equipment that needs electricity) priority for overnight housing (homeless).

#### Housing security

Attendees noted a variety of practical and hands-on ways that the Council could help them, which related to the theme of housing security. One mentioned improvements to general housing security, such as proper security locks on doors and windows. A few suggestions were made with respect to management support that attendees felt would be helpful to them in keeping their homes. These included greater council and tenant contact so that support could be given at the earliest stages so that steps can be taken sooner to ensure that they are coping well generally, that they are keeping up with rent and other payments, and that any possible instances of cuckooing can be identified and dealt with quickly.

Attendees were also concerned about landlords either refusing to give recovering addicts housing, or evicting them once they found out, and felt that the Council might be able to do more in this respect. Allied to this was a comment regarding utilising empty housing stock.

Finally, one attendee stated that they felt recovering addicts should be given help to move away from toxic people in their lives.

#### Other

An additional suggestion from an attendee was to better educate people in the different housing services available. This could easily be included in the signposting and training support themes mentioned in previous questions.

### 5. *How can you/those you care for be better supported to get back into work or education?*

*(See Appendix Twelve)*

Main themes:

- *Better training for Job Centre staff*
- *Appropriate learning opportunities*
- *Personal support*

#### Better training for Job Centre staff

Attendees were very clear on ways that they felt that Job Centre staff could help them not only get into work, but stay in it too. This was a popular theme with attendees stating that they would be able to stay in work that they enjoyed much easier than something they didn't, so support in this would be very helpful. They also noted that being constantly in and out of work had a negative impact on their recovery.

One attendee commented that they felt the Jobcentre could be more open about what they could actually help people with, such as training and getting back into suitable work. Another simply asked for 'encouragement with no discrimination'.

#### Appropriate learning opportunities

Alongside finding work that was sufficiently of interest for attendees to be able to stay in it for the long term, thereby being able to make further positive changes in their lives and achieve security and good health, they also suggested that apprenticeship and new trade or career opportunities, weekly classes in subjects such as cooking, art, woodwork, and even support in helping recovering addicts to get a driving licence where legally appropriate would all be very helpful in their overall recovery, as well as work prospects.

#### Personal support

Additional support that attendees cited would be helpful for them to be better supported in finding work opportunities included peer support, career coaches, and specialist career officer/advisers. These could be part of a signposting hub, as previously stated, or stand-alone within the job centre.

#### Other

Other suggestions, closely related to the previous themes, included:

- ask people what they would actually like to do and support them
- educate employers

## 6. *What is your experience of treatment services, and what could be improved?*

*(See Appendix Thirteen)*

*Main themes:*

- *Respect from key workers*
- *Better support for young people*
- *More safe spaces*
- *Group support observations*
- *Peer support*
- *Holistic/natural therapies*
- *Poor communication*
- *Safeguarding issues*
- *Housing and homeless*

### Respect from key workers

Attendees had mixed responses to this theme as could be expected, ranging from experiences of doctors being rude and unhelpful, or laughing and sniggering at people with addictions, through to very positive experiences where a doctor had been 'brilliant' and helped (them) get into rehab. This speaks to previous responses in earlier questions, where attendees have suggested better overall training in addiction and addiction support for key support staff.

### Better support for young people

'No help for child addicts' and 'was told too young for support with drugs (13 yrs old)' were the stark answers relating to support for young people. Attendees were clear that this was something that needed addressing, and the need for education has been raised previously in this report.

### More safe spaces

Attendees cited the need for safe places to go to take their drugs with clean needles, as well as safe places to use cannabis. More availability of safe spaces has also previously been noted.

### Group support observations

This theme relates to attendees experience of group support. There were instances of good and bad experiences with NA/AA, with one person commenting that AA and NA don't work for everyone. Another noted that, in their experience, My Sister's House has become dangerous and is not helping people with any problems.

As expected, there were both positive and negative experiences in relation to group support offered across the county.

### Peer support

Attendees were, once again, clear that they felt peer support (formal and informal) was useful and they had some feedback on that. They found that peer support workers being open about their experiences was particularly useful.

### Holistic/Natural therapies

Attendees had some clear thoughts on using holistic and natural therapies, as well as more thoughts on cannabis (the CBD side of which is included in this theme).

They ranged from having access to mindfulness and holistic therapies to help stay clean and sober to being prescribed cannabis products. Additionally, attendees recommended that the price of CBD products be cut, micro dosing be legalised, and medical cannabis be made available where necessary.

### Poor communication

Attendees had a lot to say about the frustrations felt around interactions with key support workers that they felt were impinging on their ability to become well. They complained of being bounced around from pillar to post, being given a small amount of time to talk to anyone when asking for help and, in one instance, one attendee asked for help and didn't hear anything for a very long time.

An attendee suggested that people are given regular call backs to make sure they know they haven't been forgotten and things are actually being done to help: uncertainty and isolation not being helpful in recovery.

A final 'stop playing pass the parcel with people' is a reminder from attendees that sometimes services can become too mechanised, and that those with addictions do require a particularly personal touch in order for them to be able to come to terms with, and then overcome, their issues.

### Safeguarding issues

An interesting theme was that of safeguarding and general safety issues brought up by attendees. Attendees noted that in their opinion services need more safeguarding; another that users should be separated from current users. A further comment was that people who have been sectioned/forced into rehab, should not be allowed to leave the country for a minimum of 6 months after they get out.

### Housing and homeless

There were a final handful of comments relating to housing/homelessness and the need for improvement in this area. Attendees suggested permanent accommodation for those in recovery, and places for homeless people in recovery only being made available. One noted that they were turned away from help because they were homeless.

### Other

General observations that attendees wished to make included:

- being told that hospitals don't want to take in addicts
- told to leave the hospital because they were on crack and they didn't want to deal with it
- stop the stigma
- change the type of medications that help people wean off some drugs
- help people to feel accountable for their actions

## **Carer Feedback**

The facilitators set up a separate group for carers in order to better understand their experiences. The themes raised by them were identical to those who were using/ have used services.

One thing that particularly stood out was that carers did not want their family or friends to receive a criminal sentence for their drug of choice. There was also a lot of discussion about the difference in people's perception to alcohol and drugs because alcohol is legal.

Additionally, one carer raised the interesting point that despite having the same upbringing as her three siblings, she and one of them became carers for the remaining two siblings who have addiction problems. This could dispute the thinking that trauma or upbringing is the most likely cause for addiction in all cases.

## **Attendee recommendations**

1. Peer support services at council and other offices
2. A peer hub/one stop shop for support
3. Better specialist support made available for early stage housing issues
4. Training for key support staff in how to work effectively with those with addictions

## **Recommendations from CAPITAL**

1. Develop the commitment to co-produce solutions with people who have lived experience, placing people at the heart of plans
2. Invest in communities to lead / develop peer leadership and services
3. Develop more cohesive county wide user and carer involvement: taking a facilitated approach to co-production, building capacity of smaller lived experience groups to take more of a lead in the partnership
4. Transformation agenda: learn from mental health and take the opportunity to improve links between services (this includes one stop hub approaches and community connectors)
5. Be radical with funding and commissioning decisions to 'innovate' and improve peer approaches and services. This includes commissioning and developing more services which meet people where they are at and do not expect abstinence
6. Identify current peer leaders or support roles and develop a 'peer hub' network offering sharing learning, peer reflective practice to improve support for peers by peers
7. This is just the start and a snapshot. We noticed a considerable interest in developing this work together with people who have been part of the groups
8. Improve staff training. CAPITAL can identify and work with people with lived experience in the Combating Drugs Partnership organisations to develop and run peer led shared learning (with reference to the training needs identified in the report).

## Feedback from attendees

Attendees enjoyed being given the chance to share their experiences with CAPITAL and the Council; indeed, 85% said that they would like to be involved in similar focus groups and projects in the future.

In terms of why they were involved, almost half said that they came to the sessions in order to share their experiences and help others.

Over three quarters of attendees rated the sessions as good or very good, and only a handful had suggestions for changes including longer sessions, more groups, and an adjustment made for those who were too shy to be fully engaged.

With reference to what attendees felt they would take away from the sessions, almost a fifth said they felt validated by the experience. 14% said they learned more, and another 14% noted that they enjoyed meeting and being involved with their peers.

Some feedback from attendees:

- 'Great session, one of the best group feedback discussions I have seen, and I've seen many'
- 'Thank you for giving us the choice to be heard'
- 'Really enjoyed sharing my experience and witnessing everyone's bravery and experiences too; thank you.'

(See Appendices 14-18)

## Learning and Reflections from the CAPITAL Project Team

*Sara Shepherd, Group Facilitator*

I have been in recovery from addiction for 17 years following a long period of abusing substances from the age of 13 to 40.

I started taking drugs to self-medicate the family trauma I had experienced as a child. I kept my addiction under wraps for many years until I was ousted by a well-meaning friend to CGL (then CRI). This was very concerning to me as I had my 11-year-old child living with me. By this stage I was injecting crack cocaine and heroin, I had lost my job and was about to lose my home.

However, after reluctantly engaging with services for some time and still using class A drugs I discovered that I was meeting people just like me who had found a better existence. I no longer had to live a life centred around finding a fix to survive the unbearable emotions that I was feeling.

The support workers who told me their story were putting their jobs at risk as disclosure was not thought appropriate but instantly I wanted a life more to like them. This was the start of my recovery journey and my introduction to the power of peer support.

With support I got busy replacing my addiction with college, volunteering, organising my debts and making a secure home. For me, being believed in and trusted as a functioning member of our community encouraged me to make a complete change to a life that wasn't working for me or my family.

The most important things in enabling me to change were purpose, hope, security and building trusting relationships again. I literally started a new life and after working in substance misuse until the birth of my second child, I moved to working in mental health.

I discovered as many people do that all along, I was undiagnosed with a serious mental illness. Again, with the support of services and my own strategies I am able to live a full life to lead by example as someone once led me.

### The pros of the focus groups

- Great attendance and passion for the subject
- Good links with local partners for further groups and signposting
- Common themes were easy to identify as many people have similar experiences
- Leading by example and people reaching out for volunteering/work
- Meeting people in their own environment, hubs, and rehabs which made it more comfortable for them
- Attendees supporting each other with signposting and advice
- People respecting each other's views
- Structure of group and group rules adhered to

### The con's of the focus groups

- Difficult client group to engage but the topic was interesting and with peer support examples this was overcome
- The building was mainly partnering Hubs for maximum engagement, but some rooms were small and not set up properly or private enough
- The on-line groups had to be cancelled as we had inappropriate attendees
- We had staff sickness but managed to recruit in time
- The timing was not sufficient to engage enough of the local community
- The topic can be triggering for the team as well as the attendees
- Male dominated groups but this is representative of the group

*Peter Young, Group Facilitator*

My background is as a well-established expert by experience working for a number of organisations including, the Care Quality Commission, The Royal College of Psychiatrists, Cygnet Health Care, West London NHS, Sussex Partnership Foundation Trust, Bedfordshire University and Kingston University.



I am a long-term service user of the forensic mental health services and have had substance misuse issues since I was a teenager. CAPITAL Project Trust asked for my involvement to co facilitate a number of focus groups on the substance misuse services in West Sussex. Sara and I agreed that we would use our own lived experiences of substance misuse as a way to encourage people to share and engage theirs in the groups. We agreed to structure the groups as an informal conversation, and it would be peer led in a relational way.

In our introductions to the group, we read from slides which included the background of CAPITAL and some information about the Combating Drugs Partnership. This included reading the aims of the partnership, and in particular the topic of 'breaking the supply chain of drugs'.

Group members felt that this is hugely unrealistic and if it wasn't for Sara and I being peers, we would have lost the groups in this early stage. When we asked what would break the supply chain, the unanimous answer across all of the groups was the decriminalisation of all drugs.

In our delivery of the groups, we found common themes relating to why people took substances. These were unresolved trauma and the breakdown of relationships; alongside a few people who became addicted from the use of cocaine and when their bodies wouldn't allow them to use it anymore (due to the damage to their nasal cavities) they started crack and subsequently heroin to help them manage the come down from crack cocaine.

People lost their housing as a result, became homeless and took drugs as a way to deal with their realities.

When people spoke of housing, when they were homeless, they were put in placements riddled with drugs and drug addicts that became a perpetuating cycle of addiction. Some people made a brave choice to remove themselves from their local area, away from peer groups to get away from drugs but found themselves in these drug riddled placements. It was universal that we all felt these people should be given better support.

There were a couple of people who planned to disrupt the groups but after Sara and I shared some deeply personal experiences of our own substance misuse and mental health, they saw we were peers and respected the groups and made some valid contributions to the groups.

I doubt that we would have received the feedback we did if we weren't peers and willing to share some of our own lived experiences in the conversation.

The goody bags and vouchers were very well received and despite there being a £25 incentive many of the group appreciated more the pens which said, 'you are worth it'. These goody bags were chosen and made whole heartedly by Tracey, a staff member at CAPITAL.

The carers provided great feedback, and their frustrations regarding the lack of support was palpable. All of the group members were in no way demanding, there was just a

general disappointment in the way services are run and the lack of support for people caught in the drugs trap.

There were also a lot of people that needed mental health support, who weren't receiving it despite asking for it.

What really stood out to me was how humble the participants were, despite having very little. In the rehab placements there was a huge peer support element, and they all supported each other even though they came from very different lives, they found a kinship in being vulnerable and trying to change. These are people who have led very troubled and often traumatic lives. These are people in our communities.

The feedback provided was as good as it gets, real people with real views who are being failed by the services but people who remain hopeful for a better future. To ignore this feedback would be an unfortunate error.

I am very grateful to CAPITAL for involving me in this series of focus groups, as it opened my eyes to this issue; it even helped me to understand my own substance issues better, and I met some amazing people. I did expect to meet angry and demanding people, but I actually saw humble human beings who didn't want free hand outs. These are genuine people with a genuine problem.

## Project learning

- Within short deadlines we were able to get up to speed to reach some successful outcomes in the project delivery and approach. Following an unsuccessful online event (we initially wanted to conduct a mixture of online and face to face focus groups) we decided to focus our attention to just face to face sessions.
- The online offer and registration link we used attracted almost 600 responses. However it was difficult to accurately ascertain the relevant status of individuals (e.g. service user, living in West Sussex etc.).
- There is an appetite for online sessions but screening technology would need to be in place (such as a system such as Qualtrics) which would incur additional costs
- Build in additional support for reflection for people attending (also for facilitators) Sharing lived experiences can be quite tough to hear and to impart – safeguarding and signposting etc.
- We offered an incentive of £25 to take part. Some feedback suggested that vouchers for food shopping would have been more welcome. (We used generic gift cards).
- It is clear that there is a lot of interest to continue to work with and alongside this community of service users and carers to co-produce plans and work toward finding solutions together with commissioners, agencies, and services.
- This seems a good opportunity to plan to transform services and improve joined up working, learning from a 'co-production facilitated approach' that is working in mental health.
- This is also an opportunity to align with plans to develop mental health neighbourhood team, working within the transformation agenda (see points above).

## **CAPITAL Team Members**

Sara Shepherd, Group Facilitator

Peter Young, Group Facilitator

Tracey Horne, Peer Supporter

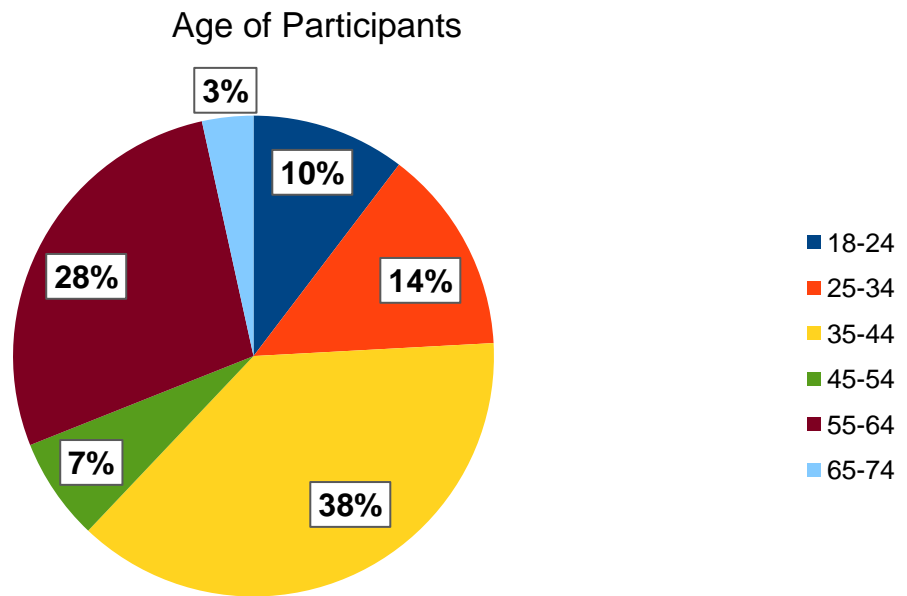
Tabitha Thompson, Note Taker

Lin Gibbs, Note Taker

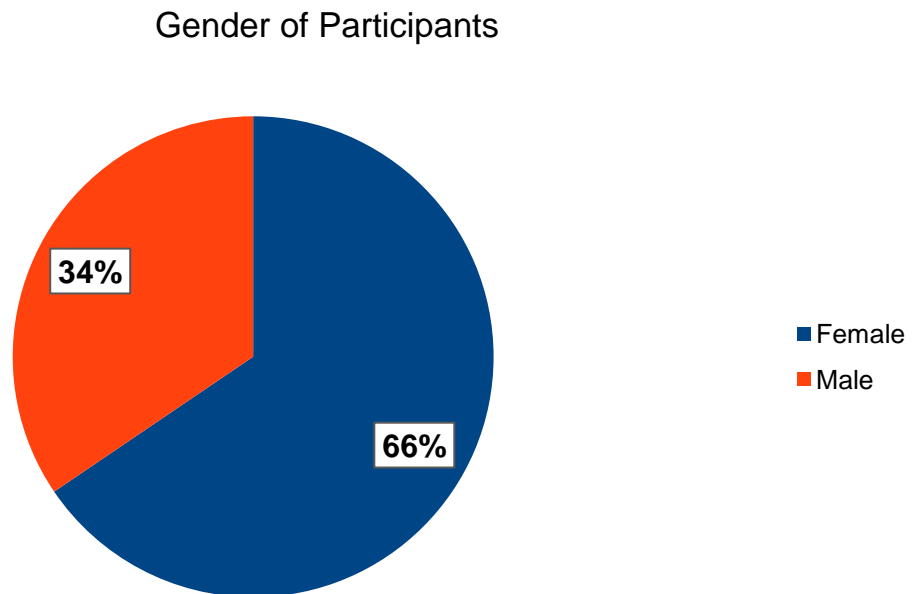
Duncan Marshall, Project Manager

# Appendix

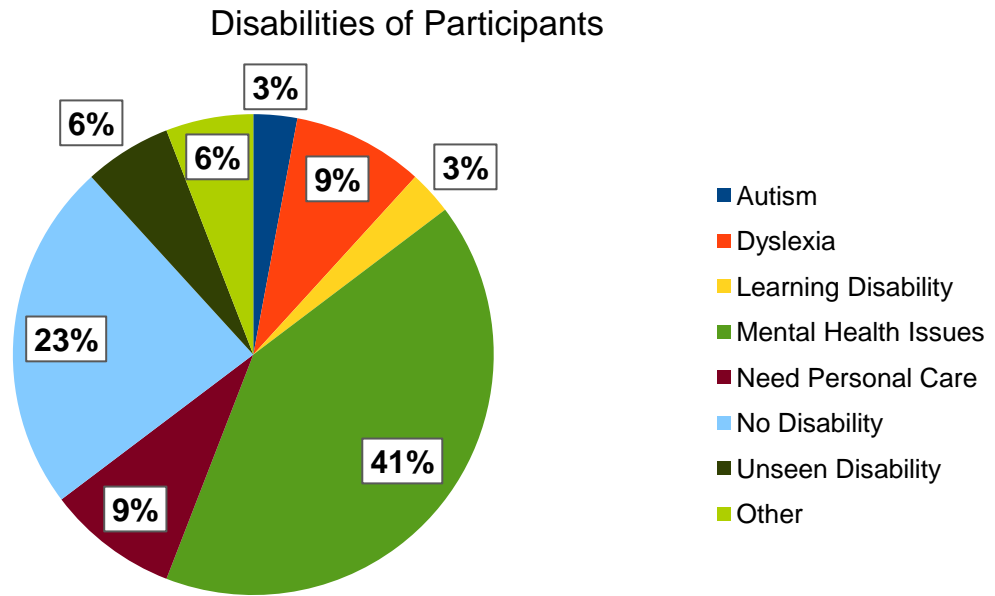
## Appendix One



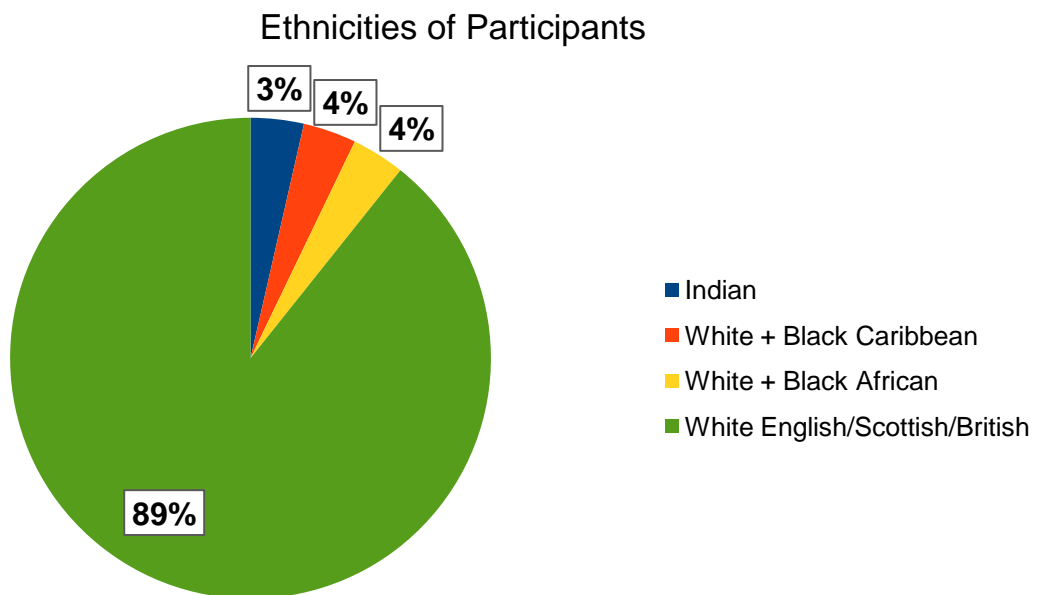
## Appendix Two



### Appendix Three

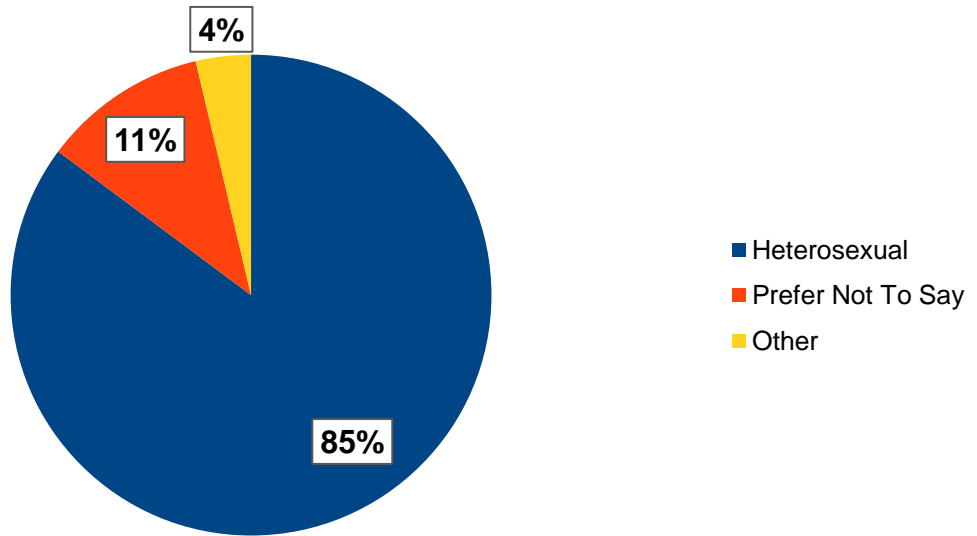


### Appendix Four



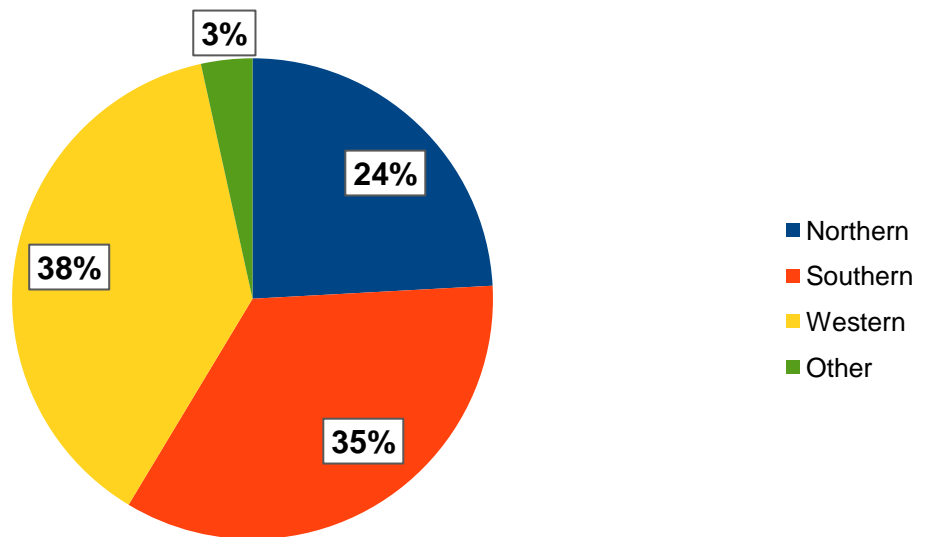
Appendix Five

Sexual Orientation of Participants



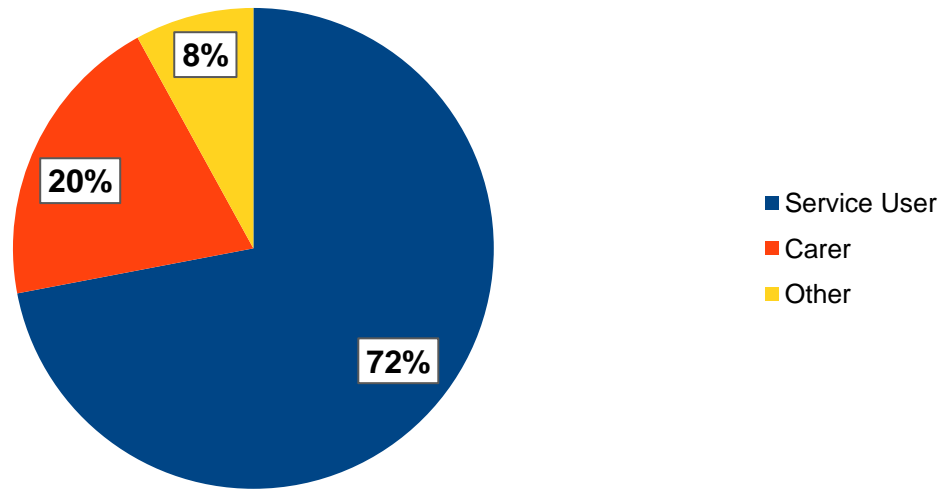
Appendix Six

Where is a Participant From?



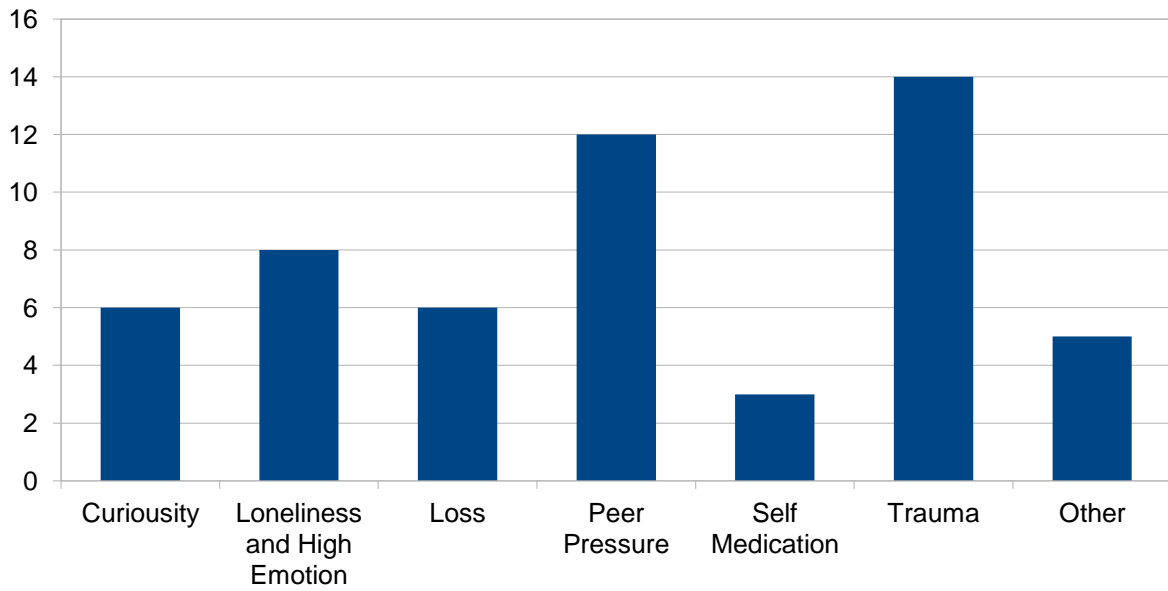
Appendix Seven

Service User/Carer?

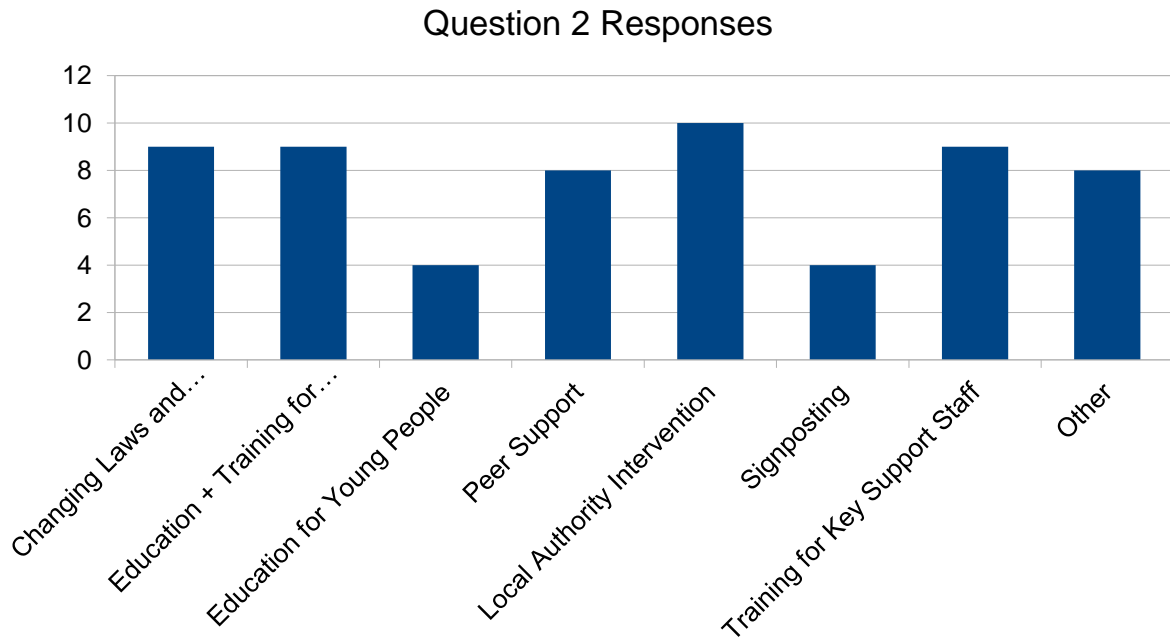


Appendix Eight

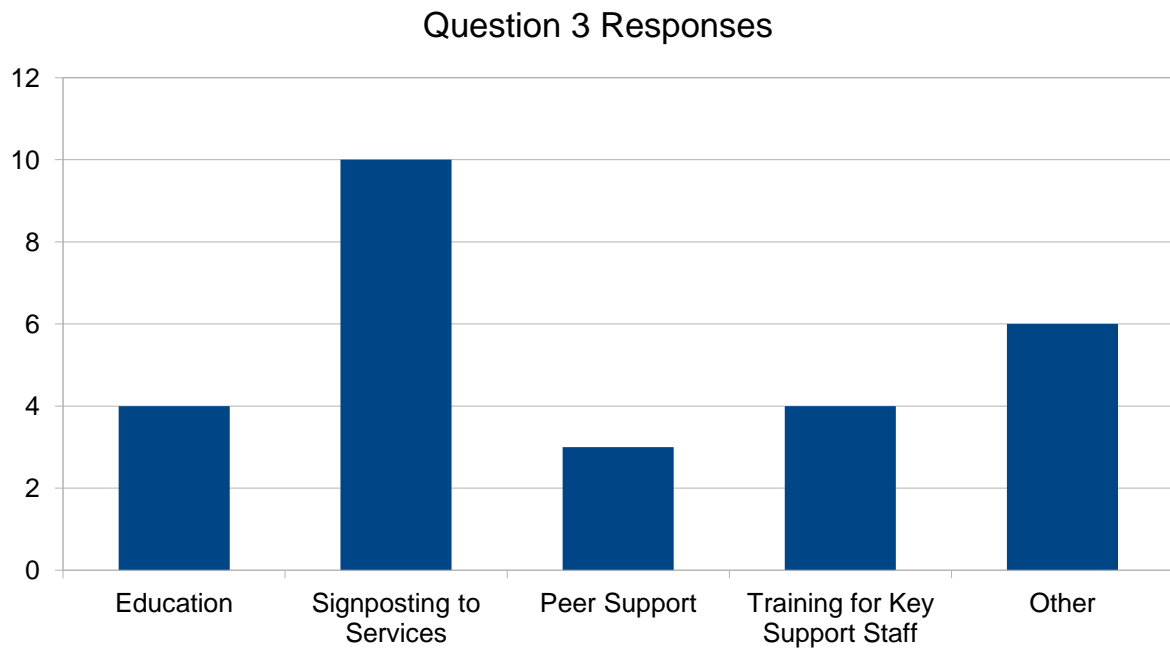
Question 1 Responses



## Appendix Nine



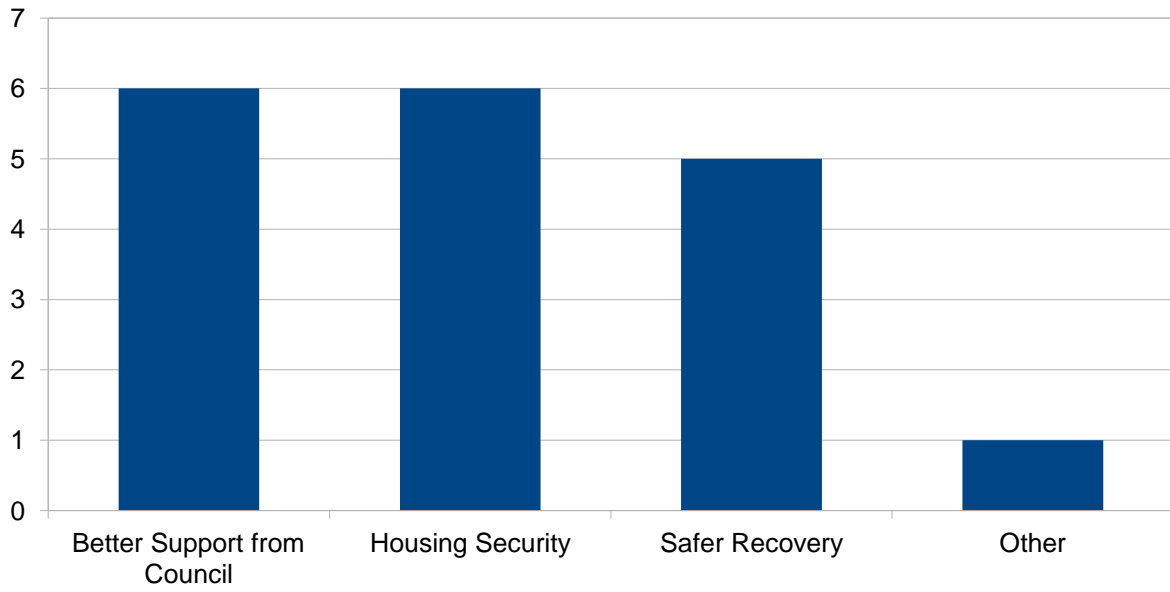
## Appendix Ten





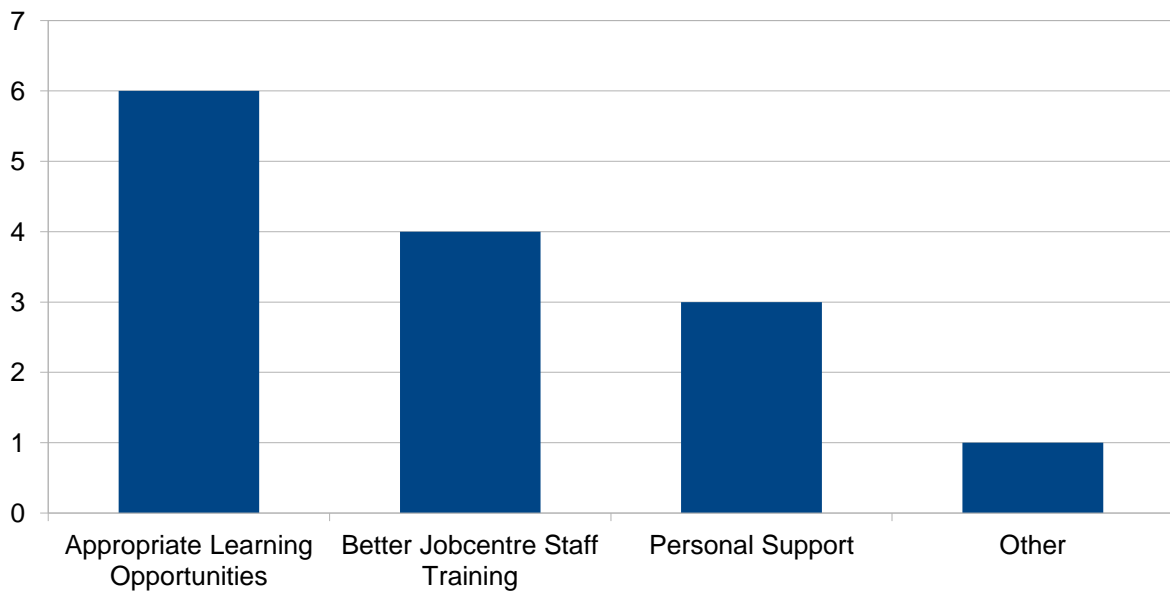
## Appendix Eleven

### Question 4 Responses



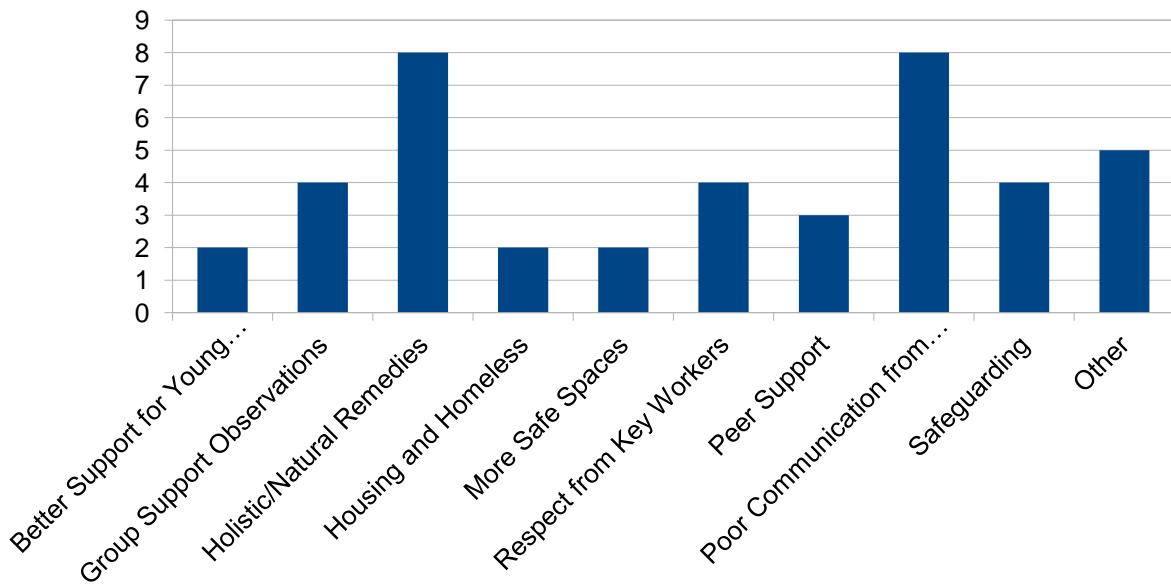
## Appendix Twelve

### Question 5 Responses



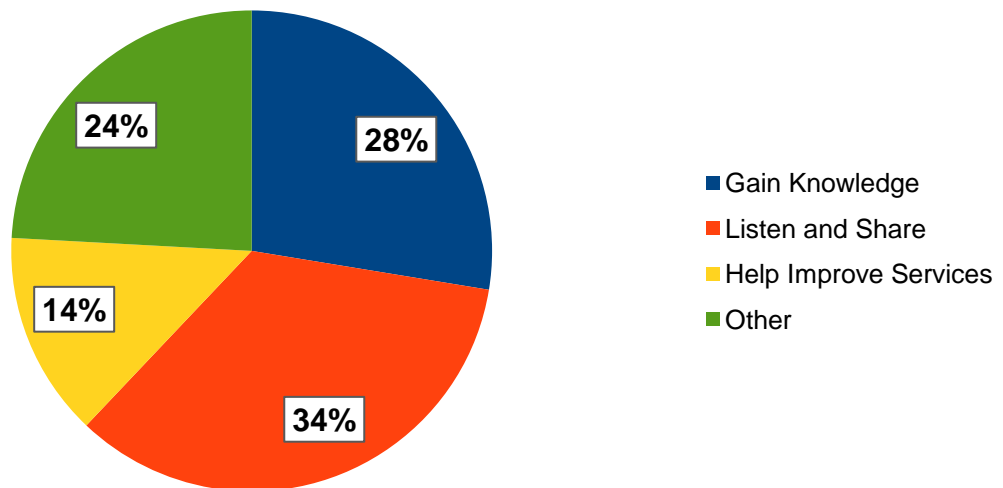
## Appendix Thirteen

### Question 6 Responses



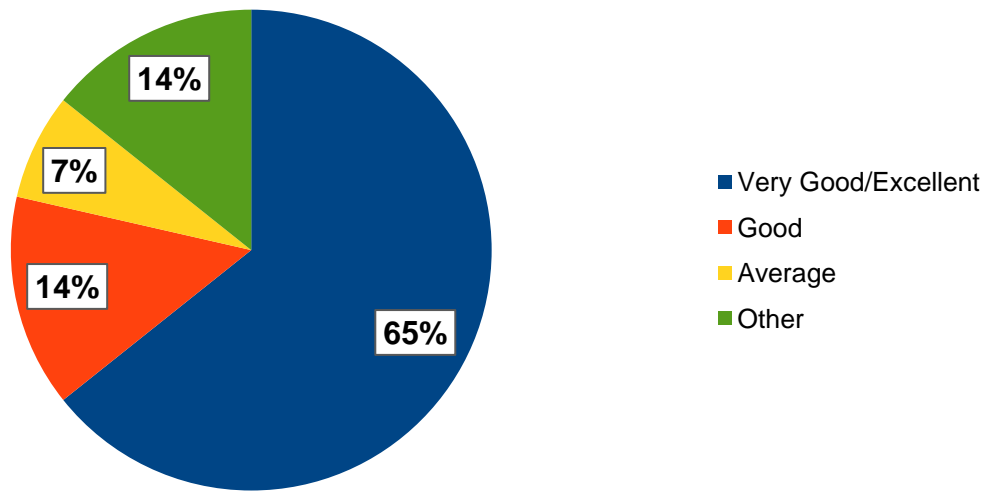
## Appendix Fourteen

### 1. Why did you want to attend this group session?



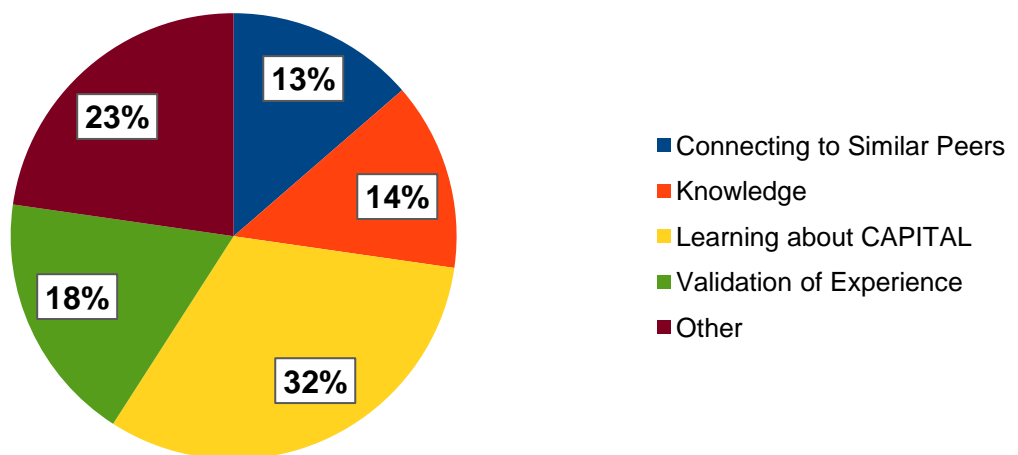
Appendix Fifteen

2. What did you think of the structure of the focus group?



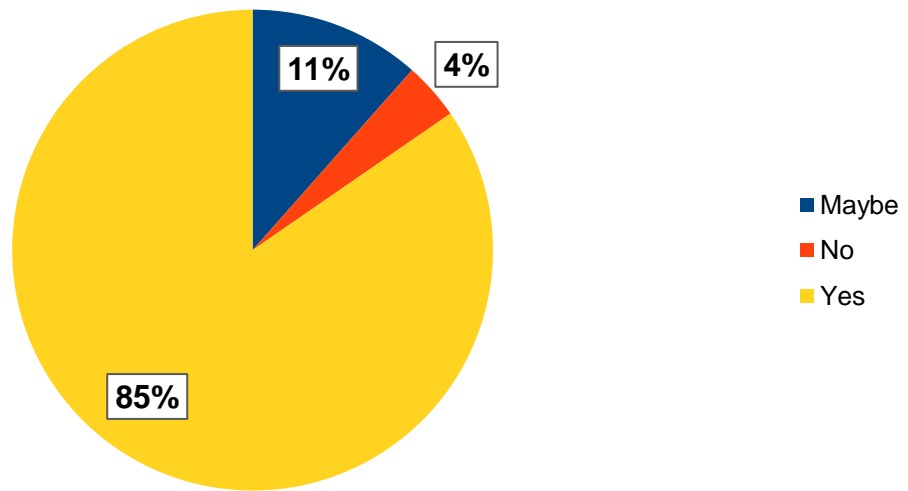
Appendix Sixteen

3. What do you think you will take away from this focus group?



Appendix Seventeen

4. Would you like to be involved in this project in the future?



Appendix Eighteen

5. Do you have any suggestions for us to improve future events?

