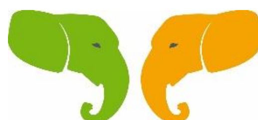
Birmingham Changing Futures Together

Service Users' (Multiple Needs) Perspectives

Study Number 2

(FINAL) Report

Produced by Peer Researchers in conjunction with Clever Elephant



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Birmingham Changing Futures Together

Service Users' (Multiple Needs) Perspectives Study Number 2, 2017

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Service Users' (Multiple Needs) Perspectives Study Number 2, 2017

EXECUTIVE SUMMARY

Chapter 1: Introduction

Birmingham Changing Futures Together (BCFT) is a £10 million programme funded over eight years by the Big Lottery Fund (BIG). Launched in 2015, it is one of twelve locations across the country taking part in *Fulfilling Lives: Supporting People with Multiple Needs.* All the areas are exploring new ways of working with adults with multiple needs, also known as HARM needs (homelessness, addiction and problematic substance misuse, risk of reoffending, and mental ill health).

The whole purpose of the Service Users' Perspectives Studies is to let the voice of the service user into the programme's research. In 2015 Experts by Experience said they wanted researchers to tell everyone how it felt to be on the receiving end of services, whether for good or for bad. By listening to these voices, decision-makers and providers can see what works and what doesn't and to listen is critical. The study reflects BCFT's position, that it is not individuals with multiple needs that make problems for service delivery, but the other way round: the way in which services are delivered can make already difficult lives impossible.

The Service Users' Perspectives of services is a key part of BCFT's local evaluation. A series of studies, it will take place over the lifetime of the programme. The first study was completed in 2016. This, the 2017 study, is the second in the series. The two most significant differences have been the introduction of Peer Researchers, information about which can be found separately, and increasing the number of people with multiple needs as interviewees. We strongly recommend that the current study is read in conjunction with its predecessor, in order to follow change as it happens in real time.

Chapter 2. Methodology and Approach

The Service Users' Perspectives Study reports the first-hand experience of people who use services. The services studied were: housing, substance misuse, mental health, health, help to stop offending, training, volunteering and employment, and BCFT's Lead Worker/Peer Mentor project.

Two researchers were involved in each interview, the interviews were qualitative and thirty interviewees participated. The interviewees broadly reflected the profile of the programme's participants overall.

From the interviewees' comments, it was clear that they weren't used to being asked for their opinions, so they welcomed the chance. They valued the opportunity to make things better for others and altruism was a strong motivator for participation: "Fingers crossed this helps". They particularly enjoyed sharing their experiences with Peer Researches who understood their world first- hand.

There are five chapters in the report:

- Introduction
- Methodology and Approach
- Findings (in interviewees' own words)
- Learning from the study, organised thematically, then consolidated into these overarching lessons:
    - User Centred Services
    - A Stable Starting Point
    - Personal Support
    - Added Value of Lived Experience
    - Appropriateness
    - Attitude
- Recommendations and future Service Users' Perspectives Studies.

Chapter 3. The Experience of using Services

This chapter presents the interviewees' first hand experiences of services in their own words

3.1 Housing and Accommodation Services: every interviewee spoke about housing at some stage during their interview, and it was by far the priority issue. Comments mainly concerned: perceived ineligibility for social housing, few options for permanent accommodation, difficulty in using the council's computer-based application system, the stress attached to being in temporary accommodation, and hostel accommodation alongside people engaged in antisocial behaviours, particularly after detox or at a vulnerable point in life. Regular, reliable, all round support from key workers was highly prized and helped them to keep people on track with their housing issues. Among the many positive interventions made by key workers were: navigating IT based systems, budgeting and resolving benefit issues affecting rent, and accessing appropriate health care. Knowing that there was someone empathetic to turn to helped to maintain equilibrium. Housing services received a mixed report, with some improvements, particularly if interviewees had experienced coordination between different types of services.

3.2 Drug and Alcohol Services In total twenty-four interviewees commented about these services. Interviewees saw the following elements as vital in any programme for substance misuse: early assessment, accurate assessment, timely access to medication, drop-in appointments; coordinated cross service packages, treatment and support packages that lasted a realistic length of time; workers who understood their reality, shared their background; clean accommodation during recovery and being treated with respect by staff. These they said would enhance their chances of a sustained recovery. Interviewees talked about their experience over what was in fact a transition period in the city's drug and alcohol services. This led to mixed reviews. Some reported frustration: others were very enthusiastic about the new programmes on offer. Levels of satisfaction may well increase as further development takes place.

3.3 Rehabilitation/Criminal Justice Services (stopping reoffending) Seven interviewees commented upon this. Comments mainly focussed on the needs of ex-prisoners. Trying to resettle after a prison sentence required the support of many agencies, and interviewees

found this difficult to arrange without key workers. Ex-offenders wanted access to support workers who could take a personal interest in them, give them support and act as alternative role models. The attitude of professionals had at times made a profound impact. Interviewees wanted personalised support programmes. These needed to address other negative aspects in their lives, in addition to their offending behaviour itself. This year interviewees talked about how having a criminal record was preventing them getting into work. They saw having to disclose their record to a potential employer as deeply hostile to their chances of getting a job. Interviewees did not seem familiar with the Rehabilitation of Offenders Act, even those with fairly minor sentences.

3.4 Mental Health Services Ten people chose to speak specifically on this topic, but mental ill health pervaded the responses of others to other questions. Whilst some had good access to help others had not: "to get onto something like that you have to try to kill yourself or someone else. That's ridiculous". Suitability of treatment was also an issue and many ended up in A&E by default. They didn't want to be slotted into inappropriate provision just because there happened to be a vacancy. Many commented on the interconnectedness between their mental health problems and their other needs. They wanted professionals to understand more about the interaction between mental health and addictions in particular, and to see this reflected in treatment packages. They thought there was little point in treating mental health in isolation. The attitude of professionals was important. To "see me as a human being", staff needed to understand how they actually lived.

3.5 Health Services Nine interviewees chose to talk about this topic specifically, four others commented at other places in the interview. There were many crossovers with mental health services. In discussing this topic interviewees talked more about mental health than any other health issue. They felt that mental health emergencies presented the most significant challenge to general health services. Many had found it difficult to access GPs and the Health Exchange was considered an effective temporary alternative. Interviewees also found it difficult to access through the phone or the internet, as many had neither. Those interviewees who had managed to get to their doctor, generally found their doctors to be helpful. Interviewees wanted serious issues affecting their health to be dealt with, as well as their presenting illness. Once again interviewees with Lead Workers had found their support invaluable in negotiating health and health-related services.

3.6 Training, Employment and Volunteering Services It is interesting that the five interviewees who commented specifically on this topic had less than four complex needs and were probably further along their recovery journey. Interviewees faced multiple barriers in the labour and training markets. These included: unaddressed personal and behavioural issues, severe and chronic health problems, substance abuse and dependency, lack of stability (especially in accommodation), lack of appropriate role models, low educational achievement, lack of information and low self-confidence. They thought that providers could help them better by working together. When ready to enter the labour market, they needed help when declaring a criminal record.

3.7. Other Services Interviewees were invited to comment on any services which they had not yet spoken about. Nineteen people did so, commenting mainly about the other services in the study. Their remarks are given in those sections. The lack of help with family issues was however raised again this year: “There's a court case coming up, and I want to get my kids back, on top of all of the other stuff. I'm scared my kids are going to go down a bad road too”; another mentioned needing support to see their family and children. Some people made service wide comments: “Agencies should all train together, so everyone has a handle on what each other is doing.” “They don’t listen”; “It’s difficult to know where to go for support”; “Because I can't use a computer”. Several stressed the massive difference that having a key worker had made to their lives.

3.8 BCFT Lead Worker/ Peer Mentor Service Fifteen interviewees were eligible to comment on this service. Ten did so specifically, but many more referred to it in their other answers. Nine said that it had been very beneficial: “I would have died or been in prison if it wasn’t for (Provider)”; “If it wasn’t for the help from (Provider), I’d end up in jail”. For one person it had made little difference, as their needs were already met. Even those who weren’t in the project repeatedly said how valuable a key worker could be. The need for a key worker to coordinate service packages and to provide information ran like a leitmotif through the research. It seemed to be the one thing that everyone agreed on. Likewise interviewees wanted to be helped by people who had shared their lived experience, and truly understood their reality. In the recovery or resettlement of such workers, they found their own hope.

3.9 Summary of Experiences and Perceptions of Services Interviewees' perspectives on services have not changed significantly in the last year. The exception was the improvement reported in drug and alcohol services through a new "umbrella'd" approach. Better coordination among providers had also featured in the 2015/16 report. For those without someone to negotiate and coordinate services for them, it was frequently impossible to keep up with everything they needed to do. Providers' arrangements sometimes made demands on individuals that they were most unlikely to meet, suggesting that such demands need to be reviewed. Negative staff attitudes were also mentioned in the 2015/16 report. On the other hand there was virtually unanimous backing given to having a key worker especially one who had shared a similar experience. It will be interesting to see if any of these perspectives change in the next Service Users' Perspectives Study.

Chapter 4. Learning from the Study

The learning summary focuses on where improvements could be made, and it reinforces many lessons in the earlier Service Users' Perspectives Study: "I want people who are a bit passionate. Textbook people haven't a clue." As in the previous study, learning is organised under the following headings: suitability, attitude, timeliness, wrapped around the individual, accessibility and duration and continuity. The overarching lessons for effectively working with people with multiple needs are: provide user centred services, provide a stable starting point for recovery and resettlement (especially stable accommodation), offer personal support by a key worker (especially one who has shared and lived experience); provide appropriate and timely services, and make sure staff exhibit a positive and respectful attitude towards those with multiple and complex needs.

Chapter 5. Recommendations for Future Research

The first Service Users' Perspectives Study was a pilot. It took an innovative approach centralising and amplifying the voices of service users. The current study has continued to amplify service users' voices, and has also expanded the interviewee pool and introduced Peer Researchers into the very research process itself. The recommendations are: to

maintain this qualitative research alongside BCFT's other evaluation strands, carry out these studies regularly to get the most value from a set of sequential studies; to encourage more of BCFT's core partners to engage in the research, referring both potential Peer Researchers and interviewees; and finally to promote the studies externally with commissioners and providers. These studies have enormous value in that they both to enable and encourage the coproduction of services for people with multiple needs, by giving those people a voice. This can make for uncomfortable reading, for these studies show that it is often difficult and frequently impossible to get what you need when you're 'on the receiving end'.

Birmingham Changing Futures Together

Service Users' (Multiple Needs) Perspectives Study Number 2, 2017

CHAPTER 1 INTRODUCTION

1.1 Birmingham Changing Futures Together (BCFT)

Birmingham Changing Futures Together (BCFT) is a £10 million programme funded over eight years by the Big Lottery Fund (BIG). Birmingham is one of twelve locations across the country taking part in *Fulfilling Lives: Supporting People with Multiple Needs*. All the *Fulfilling Lives: Supporting People with Multiple Needs* projects are exploring new ways of working with adults with two or more multiple and complex needs. These are also known as HARM needs which are:

- Homelessness
- Addiction and problematic substance misuse
- Risk of reoffending
- Mental ill health.

Birmingham Changing Futures Together (BCFT) began work in June 2014, launching officially in June 2015.

1.2 BCFT Research and Evaluation

Fulfilling Lives: Supporting People with Multiple Needs is the subject of substantial national and local research. The national research will look at results from all twelve locations, identifying what works for the individual, for providers and for commissioners, and ultimately, for the public purse. The evidence will, it is hoped, lead to systems change. It

should demonstrate how services can become more cost effective and deliver better outcomes.

Birmingham's local research, including its series of Service Users' Perspectives Studies, began in 2015 and will contribute to that wider learning. BCFT commissioned the first Service Users' Perspectives Study in September 2015 as part of its local evaluation, and the first report was published in 2016. The current report is the second in the series. As such it builds on the previous study, updating the findings, the learning and the recommendations. This latest research took place in 2017, with the most significant difference being the introduction of Peer Researchers.

It is advisable to read this study in conjunction with its predecessor of 2015/16. By taking a sequential approach, the reader will gain a richer perspective, on a wider range of services, over a more sustained period of time. Most importantly, they will hear from more people with multiple and complex needs.

Fulfilling Lives aims to bring about changes that are firmly based on evidence. Cultural change and service development however, are incremental processes. Witnessing change over eight years through tracking the perceptions of service users is an ambitious project. Each of the Service User Perspectives Studies not only captures what was happening at a particular time, but when the series is complete, will provide a record of when and how change occurred for people with multiple needs in this city.

1.3 Purpose of BCFT Service Users' Perspectives Studies

The whole purpose of the Service Users' Perspectives Studies is to let in the voice of the service user, and for professionals and policymakers to take heed of it. This focus was set by service users and Experts by Experience back in 2015. They didn't want any more case studies exposing their lives. What they asked for instead was that the services on offer to them be put under the spotlight. The instruction was to tell everyone how it felt to be on the receiving end, the good and the bad.

This research therefore deliberately places the words, perceptions, and lived experiences of service users right at the centre of service review and systems change. By listening to these voices, decision-makers and providers will see what works, and what doesn't work. It is critical that they listen. The study reflects BCFT's position, that it is not individuals with multiple and complex needs that make problems for service delivery, but the other way round. The way in which services are delivered often makes already difficult lives even more difficult.

1.4 Introduction of Peer Researchers

"A trained and experienced peer researcher is worth their weight in gold"

(Evaluator)

The Service Users' Perspectives Study 2015/16 was undertaken by BCFT's local evaluator, Clever Elephant. As well as producing research guidelines for people with multiple and complex needs, the evaluator also supported BCFT's ambition to involve Peer Researchers. So whilst in the first study the evaluation explored how to get the richest data during interview, the second study has gone one step further and introduced Peer Researchers. This has reinforced the centrality of the service user's voice. Bringing lived experience into the heart of the research process was a significant advance in approach.

The Peer Researchers were recruited in April 2017, trained in May 2017 and undertook fieldwork between June and September 2017, and subsequently helped with the analysis. They gave a presentation at BVSC conference in November 2017, signalling the end of their involvement in the second study.

The local evaluator trained and supported the new Peer Researchers on all the research elements. The training went far beyond the usual multiple-choice, tick box option. Instead they were trained in the whole research process, so that they understood where their work was going. They were trained to conduct quite lengthy qualitative interviews, often with

challenging individuals, and they were also responsible for taking notes and entering the interview data into excel. The Peer Researchers engaged throughout the research. The initiative has been successful, and BCFT intend to continue Peer Research in the next Service Users' Perspectives Study. Further information about this can be obtained from BCFT.

CHAPTER 2. METHODOLOGY AND APPROACH

2.1 Research Aims

These studies aim to find out about services from the first-hand experience of people who use them. The services studied were: housing, substance misuse, mental health, health, help to stop offending, training volunteering and employment, and BCFT's Lead Worker/Peer Mentor project. Two researchers were involved in each interview, one to lead on questioning, the other to take notes. These interviews form the basis of the report that follows.

Thirty qualitative interviews were completed, recorded and analysed. The interview group was different to that of the previous study. The twenty-one interviewees in the 2015/16 study all had Lead Workers, which meant they all had three or more complex needs. This time Lead Workers' clients formed only half of the interviewees. The other fifteen individuals came via three other BCFT partners as part of the No Wrong Door Network.

2.2 Profile of Interviewees

The interviewees' profile broadly reflects that of the BCFT programme. Twenty-six were male. They had an age range from 20 years to 60 years, with the highest number in their 30s. The majority were White and British, and five Lead Worker Peer Mentor clients were from ethnic minority backgrounds.

Four interviewees were female, and they all participated within co-dependent couples where their partner had agreed to the interview. In the previous study, a quarter of the interviewees were female and all came independently. The difficulty of accessing the marginalised female voice is widely acknowledged ("Where Are the Women", Sarah Robinson, October 2016). By the time this study is done again, BCFT expects that a provider of services specifically to women to have joined the partnership. This should increase the profile of women both in the programme and in the research.

2.3 The Added Value of Peer Researchers

Peer Researchers bring lived experience to the research process. BCFT seized the opportunity to be more exploratory and innovative in its approach. Peer Researchers were fully involved and well trained. As stated above we strongly advise against limiting Peer Researchers to ticking boxes. They are at their most valuable in gathering rich qualitative data.

Given that Peer Researchers cannot be on standby one hundred per cent of the time, it is clearly advisable to have additional interviewers available: "People rocked up on the wrong day to do their interview and we didn't want to turn them away". Many in the target community find keeping to a schedule difficult. To ensure that interviewees were not disappointed, the local evaluator, a MIND worker and the lead from BCFT filled in on six occasions when no peer interviewer was at hand. Backup is strongly recommended for such contingencies. Turning people away was never considered an option

It appeared from the interviewees' comments that they weren't used to being asked for their opinions, so telling it first-hand was welcomed. That what they were saying to people would be converted into research was something quite novel. They valued the opportunity of helping to make things better for others: "Fingers crossed this helps".

Altruism was a strong motivator for participation. Equally importantly interviewees enjoyed sharing their experiences with researches who had been on a similar journey to themselves. There is considerable added value here, which didn't find its way into the data. In their interaction with the Peer Researchers, many interviewees found inspiration and hope for themselves. Some asked if they could become researchers themselves. BCFT will be taking this forward.

2.4 The Structure of the Study

This report focuses on findings about services. Like the earlier study, it presents a body of lived experience from the front line, of services being delivered here and now.

- Chapter 1 introduces the research. Understanding how 'it feels at the receiving end' can help staff and providers understand service users' reactions, both positive and negative, and help commissioners design better future provision.
- Chapter 2 sets out the methodology and approach. The most salient change from 2015 is the introduction of Peer Researchers.
- Chapter 3 gives the interviewees a voice and then sets out the findings. The chapter presents each service area studied in turn. The services are: housing and accommodation; drug and alcohol; rehabilitation and Criminal Justice; mental health and general health; training employment and volunteering; and BCFT's Lead Worker/ Peer Mentor service. Commentary on each is structured under the same headings, enabling cross reference between topics

  All verbatim remarks are indicated by quotation marks and use the actual words spoken. All reported points reflect the information or views given by the interviewees themselves. Interviewees often jumped around between topics, remembering things belatedly, distracted by other needs (needing to get a drink or a smoke), or they were not ready to disclose some key experience until enough trust had been established (the 'doorknob moment').
- Chapter 4 contains the learning from the study. It is organised thematically, using the same themes of the 2015/16 study. Over time, this approach will enable the reader to identify how services have changed as the programme progressed. The earlier study generated these themes:
  - Suitability
  - Attitude
  - Timeliness
  - Wrapped around the Individual
  - Accessibility
  - Duration and Continuity

  The final section consolidates the overarching lessons. This year's headings are:

        - User Centred Services
        - A Stable Starting Point
        - Personal Support
        - Added Value of Lived Experience
        - Appropriateness
        - Attitude
- Chapter 5 The last chapter contains recommendations on the promotion of the learning and future Service Users' Perspectives Studies.

2.5 Guaranteeing Anonymity

A major concern when reporting on a relatively small but high profile community like this, is how to ensure interviewees' anonymity. Guaranteeing anonymity was essential to building trust with interviewees, to remove any fear on their part that their providers would hear about their criticisms. The report therefore removes any specifics by which any interviewees could be recognised.

The same respect has been given to providers. Interviewees were not asked to name providers, rather to comment on their experience of service areas. Where the names of providers cropped up, these were anonymised too. No provider is named or identifiable. The aim was never to evaluate specific provision; it was always to capture the raw experience of service use.

CHAPTER 3. THE EXPERIENCE OF USING SERVICES

This chapter presents the interviewees' experiences of services. There is a section for each of the areas: housing and accommodation, drug and alcohol services, services to prevent reoffending, mental health and health services, and training employment and volunteering. Each section employs the following structure:

- How does it feel, using this service? Using the words and reporting the views of interviewees as spoken to the Peer Researchers (respecting the anonymity of both interviewees and providers). What has been helpful and what has not been helpful?
- What interviewees want, what could be improved, and what would be ideal, in their own words, accompanied by a commentary by the researchers, based on interviewees' responses to both questions
- Reference back to the Service Users Perspective Study of 2015/16
- Summary of learning points, for those interested in taking the findings forward

3.1 The Experience of using Housing and Accommodation Services

All the interviewees talked about housing and accommodation services, with twenty-one talking about it first, and many commenting at other points during the interview. Homelessness was seen to be on the increase: **"**Homelessness is exploding"; "We need more housing."

Many people commented on the pressure on housing; "There are so many homeless people at the moment". In 2016 Shelter estimated that Birmingham topped the West Midlands homelessness league with 9,560 homeless individuals. Change may come with the Homeless Reduction Act 2017 that emphasizes "prevention intervention, recovery from and exit". This is due to be implemented from April 2018 onwards, and the next Service Users' Perspective Study may record a different experience.

3.1.1 How does it feel using Housing and Accommodation Services?

"To get my own place is number one. It will be my last and only property. I will stay there. It will be the flat of all flats."

Comments on Housing and Accommodation Services that have helped

- "I find with all the agencies there's a lot more help with housing now. Lots of them have housing support services".
- Several interviewees said their social housing provider had helped them not only to keep their accommodation, but to access other services such as food banks.
- This interviewee is typical in reporting that having a lead worker had improved their access to housing services:

  > "They knew exactly what I needed and helped me get there. They went out of their way making appointments for me and reminding me of where to go. Before (Provider A) I just had to use my own knowledge of what was available and hope for the best. That's why I was two years homeless. It's so hard on your own, especially dealing with mental health issues and addiction. There's basically no help for people like me in normal services and I couldn't talk to the people in housing. I didn't know I could get food vouchers or anything before (Provider A) Tried through the (Provider B) but it was all based on set criteria and they needed to follow their own rules. There was nothing human about it and I wasn't seen as a person."

- "Birmingham Changing Futures helped, absolutely. {They} came to my flat and supported me 100%. If they hadn't come with me, I wouldn't have got help to get furniture, a grant for me. {They} helped me get gas and electricity - saved my life. {They} said come to this appointment. The practical side helps when you haven't got any money."
- Lead Worker Peer Mentor clients had benefited from this level of support: (Provider) have sorted this for me. ….. It's {the service} getting better in general."
- Having the help of support workers to negotiate the council's online housing bidding system had enabled several individuals to get over a massive hurdle: "Me and

technology don't mix". Another interviewee said: "since I am homeless I cannot access the internet and computer to bid for a flat". Such remarks were frequent.

- Fairly small service improvements had made a considerable difference:

  > "When I was homeless years ago, all we had was (Provider A) and if you went out for food or something, you lost your place and your chance for accommodation. It's much better now because you can wait at (Provider B) and sort out your accommodation there without fear of losing your place. This is a great improvement on the old days"

- The ability of some housing providers to specialise in an older age group found support amongst older interviewees, as it had done in 2015/16:

  > "There was a period where I kept getting evicted. …… It was all my own fault. I got support from (Provider). The difference where I am now is the manager is very selective on who gets in. We all get on - it's 45 years plus and the manager is great. The people are positive."

Comments on Housing and Accommodation Services that have not been helpful

- Interviewees expressed considerable frustration about the rental housing sector: "sitting on their backsides, saying no houses for a year"; "(Worker's name) has tried to get me into housing, but has hit a brick wall." "{There's} a lot of scam landlords. They get a house, fill it up. {They} get £600".
- "It's very hard to get support with housing". "Main problem is funding. Places for help have been cut". One interviewee felt that it was much harder to ask for help than ten years ago and "a lot harder to get help".
- Eligibility was mentioned repeatedly: "It's rubbish. As a single male, I get no help. (Provider) have said that there's no hostels or bedsits or anything for me, as I need help with my mental health needs." "Different councils keep turning me down as I don't qualify for their area.… They also took the car off me when I got arrested so I didn't even have that to sleep in." "It's been murder. (Provider A) are good but the (Provider B) want me out of my three bed house after my {family member} died recently." One interviewee had many serious health problems "so I need a roof over my head". Another said: "I need 24-hour care like a care home"

- “The (Provider) let me down that many times. I was crying every day but it fell on deaf ears. They kept on making promises and I did everything they asked. They wouldn't help us because we were a couple.”
- Having additional needs created additional barriers. Being in recovery presented particular issues, with interviewees unhappy at not being offered ‘clean’ accommodation at this stage. One described leaving their hostel because there were too many alcoholics there. Another told interviewers “They put me in a hostel and everyone is on drugs there. I didn’t want to go back to drugs.”
- Ex-prisoners experienced losing accommodation during their sentence, and wanted more help after their release: “No it hasn’t got any better….no help at all”.
- Certain convictions made it even more difficult:

  > “This has been complicated due to an arson charge. I had a meeting with (Provider A), but they said they couldn't help due to the arson. (Provider B) referred {me} to (Provider A) and that was quick, but they signed me off there and then….. (Provider C) treated me really well, even though the outcome of my meeting wasn't good. (Provider A) looked down their nose at me, closed my file on the same day and didn't refer me to anyone else".

- Being in temporary accommodation created anxiety about the future. One interviewee who had a room in a hostel could stop there for six months only: “Got this hanging over me head and I don’t know Birmingham that well, but I can only try, can’t I? “
- For people who had achieved a tenancy, long-term support to maintain it was important. As this interviewee explained the ‘contract’ between themselves and the (Provider) ended in two weeks’ time: “three or four months support just isn’t long enough. Without this support I might get into debt again, become homeless again. They have helped me sort out my debts, but I still need help to keep my tenancy going. I need longer support with all sorts of things.”
- Problems with benefits and rent were frequently mentioned. Interviewees without benefits saw sleeping on the streets as their only option: “Been told I need to work six months before I can claim benefits”; “Been trying to sort benefits since May, but

still not got any”; “It is like standing on a piece of carpet and someone taking it away.”

- For those with addictions, budgeting when a month’s benefits landed into their bank account had been particularly challenging and several reported feeding their compulsions first and getting into rent arrears as a result.

Comments on Housing and Accommodation Services needs not being met

- Interviewees expressed considerable frustration about their eligibility for social housing. Housing professionals are constrained by regulations, and sometimes interviewees felt put down by this: “Someone who deals with the issue needs to understand how it is to be homeless. They need to see us as humans and not just a point system.”
- “It’s got worse. They don't look past your addiction or mental health problems. That's all they see when they look at you. I was desperate and needed help but I was just a tick box.”
- Some interviewees felt that they were offered unsuitable accommodation: “I suffer with anxiety and they put me into a house with loads of people on drugs and alcohol. The bathroom door hasn't even got a lock on it. (Provider) has set me up to fail".
- “It’s been difficult, due to family issues on top of normal housing problems.”
- Having only short-term accommodation was the source of much anxiety
- The online housing bidding system was a barrier for those without IT skills, a computer or a key worker
- Many interviewees said they needed support to maintain their tenancy, for example, to avoid rent arrears. "It seems that as long as you're in accommodation you're forgotten. I've got a roof but it’s mouldy and damp and is making my mental health worse".

3.1.2 What do people want? What would be ideal?

- Like most people, interviewees wanted somewhere permanent, affordable and suitable to call home.

- They wanted support with IT in order to apply for housing and benefits
- Once securely housed, they routinely wanted practical and emotional support from key workers over a sustained period of time.
- Interviewees wanted ‘umbrella’d’ provision: “I have all of the support I need in one place. Lots of my needs are related, but I got passed about and no-one knew what the other place had already done or said.”
- They wanted organisations to develop an empathetic culture: “Better through the (Provider) team. I've just been a number in the past, but they treat me like a person and seem to care about me.”
- ‘Clean’ accommodation was needed for people in recovery. "Just want a piece of what they're getting paid for".
- One interviewee wanted purpose-built accommodation that permitted substance abuse, whilst at the same time offering support programmes: “They should build a big building for all the homeless to live in. They should put the heroin users, Mamba’s, drinkers, crack users, all in a building for them to live.” In their view, outreach workers couldn’t help people in most hostels, because residents couldn’t admit active drug use for fear that they would be evicted.
- They wanted housing providers to understand their everyday reality: “People's addictions come into it too. Need to take the drugs to feel better to be able to engage. So {got} to get the drugs in the morning to be able to attend the day's appointments”; “Need to deal with me at the same time, not just housing and then drugs or whatever. Need to get my benefits sorted…”

Comments on what to change or improve

- Greater assistance with the online housing application system: “People like me don't have access to laptops, so it needs to be done by letter or phone. How can I bid on a house if I can't get on a computer?”
- “The assessments of your conditions should be better” and recognition of their other needs (such as mental health issues, arson and legal exclusions, or simply being a couple).

- The support of key workers on their journey from street living to stable accommodation.
- An improved attitude from professionals: “There are still big barriers up between users and providers. Us and Them.”

3.1.3 Summary of learning points on Housing and Accommodation Services

Housing services received a mixed report, with some improvements, particularly if they had experienced coordination between different types of services. Permanent housing was seen as a fundamental pathway towards a stable lifestyle. Temporary accommodation generated its own stresses, knowing that another move was inevitable, and that the new provider might operate a different regime.

As in the previous Service Users’ Perspectives Study, interviewees liked providers who could take into consideration the individual, their age, their conditions, and their support needs. They worried about being co-housed with people with the same (anti-social) behaviours that they were wanting to stop. Some interviewees spoke of difficulties in sharing facilities with those with similar compulsive behaviours as themselves. Their fragility made them vulnerable to the influence of others. This could be either positive or negative, but was frequently the latter.

Regular, reliable, all round support from key workers was highly prized and helped them to keep on track with their housing issues. Among the many positive interventions made by key workers were: navigating IT based systems, budgeting and resolving benefit issues affecting rent, and accessing appropriate health care. Knowing that there was someone empathetic to turn to helped to maintain equilibrium.

3.1.4 Change from Service Users Perspectives Study 2015/16

The 2017 interviewees had very similar perceptions as those in the 2015/16 Service Users’ Perspective Study. The lack of affordable housing was an ongoing problem. They still needed

suitable housing, they still needed help to negotiate the online application system. They still needed support once in a tenancy. Temporary accommodation still caused anxiety. Being accommodated alongside people still engaging in the antisocial behaviours was still seen as detrimental to recovery. Where individuals had received good support, and been treated sympathetically by housing professionals, they were more positive. Where interviewees had been able to access 'umbrella'd' provision, they thought the service had improved.

3.2 The Experience of using Drug and Alcohol Services

Twenty-four interviewees spoke about drug and/or alcohol services. Seven people chose to speak about it first off. Eleven interviewees felt that services were getting better, but recent changes in provision had been challenging for many: "When they set up transition, {they} mess{ed} up so many scripts {that} people went out robbing"; "I had a brilliant mentor at (Provider) but they lost funding".

3.2.1 How does it feel using Drug and Alcohol Services?

> **"**Go to sleep. Load of drink load of drugs. Just block it out."

<u>Comments on Drug and Alcohol Services that have helped</u>

- "It's a brilliant idea that people who help me have been on the same journey. (Provider) understand my behaviour." Receiving professional support from people with similar lived experience had helped many of the interviewees.
- This interviewee was taken by surprise: "First I thought oooo, this is a bit different to (Former Provider). Then I learned that my teachers were ex-alcoholics and ex- drug addicts. This encouraged me to open up. I can't speak to other people outside about my drinking problems, but here yes"
- This message came through loud, clear and often: "I can talk to my support worker at (Provider). She is a kind and nice person, she is clean eight years now, she understands, so I can always talk to her."

- The attitude as well as the background of the worker was important. One interviewee commented that their worker “is the only one who seems to understand me" and made time for them. “{I} met someone (name) who cared and got things done. He fought for me.”
- “Now I do weekly alcohol meetings and I've got an alcohol support worker and can speak with other people who have been through the same sort of things as me”.
- Interviewees reported that often provision was too short to address their underlying problems. They wanted decision-makers to be more realistic about the time it takes to resolve deep-rooted issues and the years of chaotic and unhealthy living usually associated with substance dependency. This interviewee had been attending sessions twice a week for a year with their support worker at a medical centre “although I think it was only supposed to be once a week for six months”. This was a great improvement because “I've been allowed to stay with them a year and twice a week is what I need”.
- It was a level of support that others needed too: “If it’s only once a week or a fortnight you'd drink again in between”; “I'm now on a drug referral programme at (Provider). I didn't have to wait around. I get to chat to workers about my problems and have a regular drug test. They offer support on how to stop taking drugs and they don't rush you out the door”.
- “I can give (Provider) a big recommendation to anyone who has a problem with drink. They give you the tools, help you, things you never got from (Former Provider). They even help you get into new work or training. They know the signs when you’re ready.” Providers who offered comprehensive support received the most approval
- Interviewees praised providers who tailored programmes to suit individual need: “it’s right down to the ground and suits me perfectly. Me mind’s occupied. When I was a recluse, I was just drinking, drinking. I got in with the wrong crowd and I ended up just lying down with the sheet over me head not wanting to talk to anyone”.
- Interviewees noted when professionals’ attitude towards them was good: “They’re polite and respect me. I couldn't ask for better support".

- But interviewees needed help with organising themselves especially to coordinate their appointments. One interviewee couldn't keep track: "too many keyworkers, all helping me, all concerned about me." For BCFT's clients, Lead Workers fulfil this need, but others found it almost impossible until they got a key worker: "There are too many appointments! I need help to organise them and that's where my {Lead} worker comes in. It's really hard to get support at first, but when your foot's in the door, it's a lot easier".

<u>Comments on Drug and Alcohol Services that have not been helpful</u>

- Some interviewees felt they had to wait too long for their first assessment to get medication. Some saw it as a systems fault: "It's a long hard process to get started on a script with them." "I just go and buy my own methadone as it's easier than getting it from (Provider)." "If I had the proper treatment, I would not use crack or heroin."
- Another described having to wait up to three weeks "to be assessed before seeing doctor", which was felt to be "too long".
- A much commoner complaint was having medication stopped due to missing appointments. Many interviewees found keeping these appointments very difficult, and the consequences were significant: "{I} was stable. Missed an appointment. (Provider) reduced me too quick, {I} started using more all the time." One interviewee said that as a result they had lost their flat and benefits, leaving their "whole life consumed {with} finding money for drugs". They said that they had complained but were told they "had to go back to square one".
- "It's like they want to punish you for missing an appointment." One reported they had to start the referral process again after their script got stopped. Another said they had "asked for script. Said I can't do." Another felt that the staff got "in touch when they want, but if you miss an appointment your script is stopped. I'm now waiting for them to re-contact me".
- One interviewee commented that they had been with their provider for a few years but the way they were treated was "not helpful. Go in there… no script, got two workers, not got in touch. Text them 'I need help'. Just a tick box. {They} just say 'is everything OK (interviewee's name)? Alright, see you later'." Another said that their

worker “seemed to sleep through”. Another commented “Missed getting script. Went this morning, got attitude off receptionist. Couldn't get past her”.

- One interviewee described a provider as “disgusting”, saying they didn’t trust them and that they hadn’t signposted them onto other services: “Everything's a battle with them”.
- “The streets are littered with needles and Black Mamba.” Interviewees wanted ‘clean’ environments away from active alcohol and drug abusers once they had become clean themselves. This interviewee was in hospital and drug free: “then they sent me to (Provider) and everyone was doing it”. Another said providers should be stricter, “drunk and drugged up people should not be allowed in…..but it always happens. They need to be stricter here around drugs and alcohol”.

<u>Comments on Drug and Alcohol Services needs not being met</u>

- Not surprisingly given the nature of addiction, access to medication was the interviewees’ priority issue: “It’s hard to get yourself sorted here. I counted them in fact. Out of ten, I’d give it five. It’s a bit of a struggle, but I don’t know if it’s cos they’re short staffed or because I missed an appointment. When I’m on Subutex I don’t entertain thoughts of heroin etc. This is why I’m so stressed today about getting back on my script today with these guys”.
- This was followed by the need for appropriate treatment packages: “On the streets, drinkers and drug users don't mix. I'm a drinker.” “Drugs aren't my problem, I have alcohol issues. At {NHS name] hospital {I} waited five hours with my support worker and was assessed by [department]. I am double incontinent, and the team said I have capacity, but they don't help people with dual diagnoses and they won't treat anyone under the influence of alcohol. They gave {me} nothing and sent me home. I had nowhere to go and walked back to the town centre and slept on the streets. It felt that no-one wants to help me and this led me to dabble in heroin and crack, as it’s so aggressive on the streets…..All I want is a wet room due to my incontinence, medication and detox".

3.2.2 What do people want? What would be ideal?

- More co-ordination and communication between providers: **“**Services still aren't talking to each other either.”
- Packages of support tailored to the individual: “You don't get any actual help from (Provider), it’s just the meds. They should also be there to support me and help”.
- Easy access to support when needed: “Can't pick up phone and talk”; “Also the drugs workers keep changing so you have to keep telling a story over and again”
- Support workers with lived experience: “I want people who are a bit passionate. Textbook people haven't a clue.” “I can relate to him as he's been on a journey. Given me hope, before I started seeing them {I} didn't give a shit.”
- A more flexible appointment system with drop-in options to help with timekeeping etc. “give people certain times rather than send out appointments”.
- Positive alternatives to fill time otherwise spent intoxicated: “I can also come into (Provider) when I'm bored and stressed so that helps me stop drinking.” “Because my drinking was isolated, I did it on my own, I needed to come out and join other people. These people here have helped me”. Another interviewee commented “group members get in touch, {there’s} lots of interactivity”

<u>Comments on change or improvement</u>

- One interviewee described former alcohol services as “a bit ad hoc, though I was drinking a lot, so perhaps I wasn’t well engaged really”.
- Views vary as to how much the service had improved: “There’s been a 60% improvement in service quality over the last year”; “It’s a bit better than before as it’s a bit quicker than [previous location]. Still slow, but a bit better.” “Out of ten, I’d give it five”.
- For some getting their ‘foot in the door’ was still a problem. They hadn’t yet accessed the high level of support they wanted
- For others: “I can get all the support I want. (Provider) can refer you anywhere. Now its umbrella’d under (Provider) you can get to lots of services. It’s much better than

when it was just (Former Provider), who couldn't do this. It's the umbrella that's improved it".

- "My key worker came looking for me when I had my hospital detox, which I thought was excellent".
- Setting up a drop-in system in addition to scheduled appointments for medication was suggested
- Interviewees preferred support workers who understood their world incurred lived experience similar to their own.
- "Peer mentors for young people" were recommended: "They need to try and sink sense into the young ones".

3.2.3 Summary of learning points on Drug and Alcohol Services

Interviewees saw the following elements as vital in any programme for substance misuse: early assessment, accurate assessment, timely access to medication, drop-in appointments; coordinated cross service packages, treatment and support packages that lasted a realistic length of time; workers who understood their reality, shared their background; clean accommodation during recovery and being treated with respect by staff. These they said would enhance their chances of a sustained recovery.

Interviewees talked about their experience over what was in fact a transition period in the city's drug and alcohol services. This led to mixed reviews. Some reported frustration. Some on reflection thought the time was just not right for them: "I was drinking a lot, so perhaps I wasn't well engaged really". Others were very enthusiastic about the new programmes on offer. Levels of satisfaction may well increase as further development takes place.

3.2.4 Change from SUP 2015/16

Many of the issues raised this year by interviewees also featured in the 2015/16 Service Users' Perspectives Study: support, attitude, trust, readiness, and a safe environment.

Levels of satisfaction still vary, but post-transition, more interviewees could now identify a pathway into services than before. Interviewees offered strong approval to providers offering an umbrella service. The Lead Workers and Peer Mentors were setting a new standard in support, and where other providers offered clear pathways and multifaceted packages of support they were starting to meet the expectation of interviewees.

3.3 The Experience of using Rehabilitation /Criminal Justice Services (Help to Stop Offending)

As in the 2016/17 study, several interviewees had been involved with the Criminal Justice System and seven out of the thirty chose to talk about their experiences. They talked about the importance of being treated as a whole person. They didn't just want help with their offending behaviour but with other problems too: mental health issues, being on the street, drug dependency and alcoholism, and gang membership were mentioned in the context of offending.

3.3.1 How does it feel using Rehabilitation/Criminal Justice Services?

Comments on Rehabilitation /Criminal Justice Services that have helped

- "But the main difference has been having a roof over my head, and getting my benefits, means I don't need to do crime any more. Before that I was close to suicide"
- "They referred me to anger management, but I didn't go. Now that I've got support to control the drinking, I don't get as angry. Shows it's working". This interviewee reported getting a support worker through their mental health nurse. Now they meet every week, and they had started a training course: "The service has been brilliant". Things had got better, as they hadn't committed any offences for several months.
- "The police officer that arrested me was a great help. He treated me like a human, asked how I was and why I was doing crime. He didn't even cuff me. He then stated

that if I was charged, then I couldn't pay the fines anyway, so they dropped the charges. I haven't done anything since then.”

- One interviewee felt that it was their BCFT Lead Worker who was doing the most to stop them offending. The worker helped with appointments, provided one to one support by “encouraging”, “takes time with me” keeping them ‘on their toes’. Most importantly they set a great life example for them, something this interviewee felt they hadn’t had had before this point.
- One interviewee had found it “easy to get help. Went to the [Provider] and asked for help. EOS courses. They gave me £30 ESA to complete the offending course.”

<u>Comments on Rehabilitation /Criminal Justice Services that have not been helpful</u>

- Another interviewee felt neglected: {They} call you in once a week, but they ask the same questions and don't give any support. I'm just a number and a tick box. They should be helping me get into training or education but they've not done anything and I've no idea why. My mates say the same thing so it's not just me.”
- “They also just want to sign you off as soon as possible, as opposed to actually helping.” What was lacking was “actual support, instead of weekly tick box”.

<u>Comments on Rehabilitation /Criminal Justice Services needs not being met</u>

- One interviewee wanted more diversion from crime: "If they help you get on a course or into training or whatever, you'd have something to do with the day, and you'd be less likely to offend".
- “{Its} got worse. They switch your case worker all of the time.”
- An ex-prisoner subject to exclusion zones had not found a college in an area where he could go. He wanted to “get rid of this exclusion zone, especially during the daylight hours, so I could go to college in the day.” He felt ready to move on: “I am a big man you know, but I cried, being stopped from going to college”. “All this is stopping me progressing I’m 46 years old. All I want to do now is progress”
- Offenders with the most serious crimes needed more help to move on, especially into the workplace

3.3.2 What do people want? What would be ideal?

- Most respondents wanted more help, not just with their offending behaviour itself, but also with their other issues and circumstances. They wanted to be treated as a whole person.
- Intensive support from workers who had themselves successfully rehabilitated was described as "brilliant". It inspired them.
- Coming out of prison, ex-prisoners faced multiple problems: lost accommodation, stopped benefits, broken personal relationships and substance dependency. Individuals without resources found it difficult to deal with all these problems at the same time. In an ideal world they wanted support workers to help them: "I'm on my own in Birmingham, I'm not from round here. I'm in a state of mad depression: can't do college, can't get to my (family relative's) grave. Heroin is there just yards away, just have one taste and I'm off again, all my hard work is undone."

Comments on what to change or improve in Rehabilitation /Criminal Justice Services

- Offenders particularly ex-prisoners faced multiple difficulties. They needed help to negotiate all the agencies involved. They wanted packages of support. Interviewees felt lucky if they had managed to secure appropriate accommodation, a training place, a mental health nurse or a Lead Worker.
- They wanted activities to develop them from offending activities that would occupy their time constructively.

3.3.3. Summary of learning points on Rehabilitation/Criminal Justice Services

Trying to resettle after a prison sentence required the support of many agencies, and interviewees found this difficult to arrange without key workers. Ex-offenders wanted access to support workers who could take a personal interest in them, give them support and act as alternative role models. The attitude of professionals had at times made a profound impact. A specific police officer was singled out for praise, as happened last year.

Interviewees wanted personalised support programmes. These needed to address other negative aspects in their lives, in addition to their offending behaviour itself.

3.3.4 Change from SUP 2015/16

There was far less comment on rehabilitation services this year, but where they did comment, interviewees reinforced the perceptions of last year's interviewees, particularly about the need for support, treatment and diversion. Perceptions were generally negative and this is to be expected, given the role of Criminal Justice agencies to punish as well as rehabilitate, but kindness received at the individual level once again commented upon.

This year interviewees talked more about how having a criminal record was preventing them getting into work. They saw having to disclose their record to a potential employer as deeply hostile to their chances of getting a job. Interviewees did not seem familiar with the Rehabilitation of Offenders Act, even those with fairly minor sentences.

3.4 The Experience of using Mental Health Services

Ten people chose to speak specifically on this topic, but many others commented at other points in their interviews particularly when talking about substance abuse and other health services. Mental health was a pervasive issue. That said, about half of the interviewees thought the service they had received was 'okay'. Being ready to be helped was important: "I wanted the help. Other people have problems but they don't want the help. You have to be prepared to get help. Stop saying you need help but don't do anything about it." Interviewees mentioned a wide range of mental health conditions: anger management, anxiety and depression, psychosis and schizophrenia, bereavement and Post-Traumatic Stress Disorder. Clearly the services they had received reflected the wide range of conditions they presented.

3.4.1 How does it feel using Mental Health Services?

Comments on Mental Health Services that have helped

- Some interviewees had found securing a referral relatively easy: "It was quite easy as I am with the Health Exchange. The Health Exchange wrote a letter to the GP to say I need to see a counsellor. Within a couple of weeks, I got to see a counsellor, finished sessions now. …I wouldn't change anything." Several have found their GPs to be helpful.
- Fast access to health is extremely important: "I know help is just a phone call away".
- Several interviewees said their providers had referred them to a mental health service, which was unusual enough to merit their comment: "(Provider) - have helped me with everything. They put me together again"
- Mental health is a pervasive issue and many spoke of mental health issues within the context of their substance dependency and other health problems: "(Provider A) got me off the drink and over to (Provider B). We need more of services working together like this"; "{My} alcohol support worker referred me to (Provider) due to my mental health problems."
- "My mental health issues are linked to my drugs and alcohol. It's easier to talk to the voices in my head if I've had drink. I also think I'm worthless so the drugs help numb that."
- "I can get all my needs met here or through here now it's an umbrella": cooperation between services was rated highly
- Many liked group work with "like-minded people" and social activities: "I needed to leave the house as I was surrounded by death after my [family members] both died. I was in a bad place. Going to the meetings in the community has got me talking to other people, listening to motivational people and others that have been through the same sort of things as me".
- Interviewees valued receiving support appropriate to their condition. For one, receiving support at home was important and they had both a CPN and support from BCFT's Lead Worker Peer Mentor service. Another interviewee with a different condition preferred one-to-one sessions away from home: "it's really good. It's private, one-to-one, no one else can hear". The fly in the ointment was that a weekly one-hour session involved a 90 minute journey on two buses.

Comments on Mental Health Services that have not been helpful

- "It was really hard to get a GP but once you're in its easy. The GP was in [name of area] but my hostel is in [name of different area] so it was really difficult to see them."
- "I didn't really know I had mental health issues until I started with (BCFT Provider). I was told I was just an addict so it was difficult. I saw a psychiatrist in 2003 but just put me on meds when I thought my dreams were real. But there was no follow up so I stopped taking them. People should ask and mean "how are you?" This is a great question. Then I took drugs to forget the problems and the dreams. This also led to a constant cycle of engaging and dropping out. I was then put into mental health support but it was with older people, so I felt different and alone. They needed to go back to the very basics, which I don't think they appreciated. I couldn't talk to other people or walk around with people. This is the sort of level you need support with."
- There were several comments about the length of waiting lists. One interviewee reported waiting about three months to go to (Provider). They also felt they were given an inappropriate treatment programme so they never went back. When the provider asked for feedback they didn't explain, just said it wasn't for them.
- "I've been on the [Provider A] for years. But one appointment of about an hour every three months isn't enough. I've been diagnosed with loads of different conditions as they don't know me well enough to make a proper decision. [Worker's name] at (Provider A) has helped since I've been introduced to her but I've had mental health issue for the past 15 years."
- "I was initially referred into (Provider) but they only supported me over the phone."
- "Because of mental illness, people put me to one side and look down on me".

Comments on Mental Health Services needs not being met

- Interviewees with multiple needs needed multifaceted responses, typically "help with mental health problems to stop the alcohol and drugs.
  I would like to get onto a psychiatric ward so can get properly diagnosed. But to get

onto something like that you have to try to kill yourself or someone else. That's ridiculous."

- "It shouldn't need for me to get arrested and get the help of the (Provider) team. I should've been getting help before that."
- "I went to see a mental health professional but they didn't want to know. They just passed me back to the GP who didn't know what to do next..…. [Worker's name] has tried to get me out of the hostel and into better housing which would help my mental health. Just getting passed back and forth from people that have got fifteen minutes to spend with me."

3.4.2 What do people want? What would be ideal?

Comments on what to change or improve in Mental Health Services

- "They also need to listen to the patients. Maybe we know what's best."
- "It needs to be clearer where to go to get help." "Getting information is important"
- Having a safe place in which "to off-load my thoughts and feelings without judgement" was important and this required empathetic staff. Some professionals did not "see me as a human being. It's tick lists and points and gatekeepers".
- "They don't know how to judge me". Better training professionals on the interaction between substance misuse and mental health was suggested: "Education needs to be given to explain to people why individuals get into drugs"; "They could also get out of the offices and come and see service users in their areas";
- "If someone could identify when I have mental health issues coming up that would be great"
- "Mental health groups for similar people would be good, as I was the youngest by far in my group". Support tailored to the individual's mental health condition was prized. Some valued home based services to help with feelings of panic etc., whilst others wanted community-based opportunities to help with them with depression: "It's got a lot better. (Provider) used to come to my house and help me, but now they're community based, which allows me to get out of the house."

3.4.3 Summary of learning points on Mental Health Services

Ten people chose to speak specifically on this topic, but mental ill health pervaded the responses of others to other questions. Whilst some had good access to help others had not: “to get onto something like that you have to try to kill yourself or someone else. That's ridiculous”. Suitability of treatment was also an issue and many ended up in A&E by default. They didn’t want to be slotted into inappropriate provision just because there happened to be a vacancy. Many commented on the interconnectedness between their mental health problems and their other needs. They wanted professionals to understand more about the interaction between mental health and addictions in particular, and to see this reflected in treatment packages. They thought there was little point in treating mental health in isolation. The attitude of professionals was important. To “see me as a human being”, staff needed to understand how they actually lived.

3.4.4 Change from SUP 2015/16

Despite only half of the interview group being known (as Lead Worker Peer Mentor clients) to have three or more complex issues, the 2017 interviewees identified much the same issues as those in 2015/16. Difficulty in getting a diagnosis, of getting into a treatment programme, of being listened to, emerged again, as did timeliness and appropriateness, getting the “right support at the right time”: “They just passed me back to the GP who didn't know what to do next”; “This also led to a constant cycle of engaging and dropping out”. The earlier research also noted the pervasiveness of mental health issues. Poor mental health both compounded and created other needs. The 2017 interviewees articulated the case for co-ordinated services much more strongly and about the people who spoke about mental health services did feel as though they had improved recently.

3.5 The Experience of using Health Services

Thirteen interviewees spoke about general health services. Nine people chose to speak specifically on this topic; the others commented at other points in their interviewees

3.5.1 How does it feel using Health Services?

Comments on Health Services that have helped

- One interviewee who had been recently treated in hospital after a violent attack, described the service as “brilliant”. Another reported that the hospital treated him well: “The first time I was so drunk I fell onto the railway line and ended up in hospital”. A third described being rushed by ambulance to hospital for heart condition. “The consultant at A&E was waiting for me in ‘resuss’. I have been in before with high blood pressure. The service was good”. One interviewee could not believe how A&E managed to provide such a good service under so much pressure.
- Interviewees with GPs often reported that their doctors really helped them, “almost got a flat”; “The GP has helped me stop alcohol telling me why it does me harm and where to go for recovery. They referred me to specialist recovery.” Another described their GP as good, not only supporting them through medical treatments, but also putting them on an over 50s programme and on a course about the best food to buy for their multi-various medical conditions.
- The Health Exchange specifically for homeless people received praise: “{You} just turn up there, wait in queue, and get ticket. It’s good as {you} don't have to fill in form or have ID”. Information about the service tended to spread through word of mouth: “{I} found out [from] other people on street.”
- Lead Workers were helping many to get their health needs met: “(Provider) have been a saviour”.

Comments on Health Services that have not been helpful

- A&E departments often ended up as a backstop, with one interviewee saying they turned up there at least once a month. As they saw it, A&E couldn’t deal with their mental health problems, focusing as they did on the physical: “Don’t help, take bloods and discharge in the morning”. This individual had since begun to access RAID.

- “I have been told to sit in a chair as there were no beds available. The hospital covers too big an area. I have to go to [name of] hospital as it is closest, so overall it has got worse. I have waited 20 mins for an ambulance before.”
- Securing a GP was a much mentioned challenge: “There are lots of people out there that don't know how to access a GP so need support. It shouldn't be difficult”; “How do I get to the doctor if I've got no benefits? Help me get there.” “Got a GP now, but it was really difficult to sort out. Then have to wait weeks to get me tablets. I could kill myself in the time it takes to get appointments and then get medication”.
- “Access to my GP was hard. I need to go to (name of area) surgery to get an appointment as I don't have a phone”; “Can't get to doctors. Get anxious. They don't care”. For interviewees lacking access to a phone or a computer just making a doctor’s appointment was difficult
- “I need help with the dentist. I need an X-Ray for my teeth. I am only able to go to one dentist, the one that (Provider) refers us to. I asked the dentist which teeth they could take out, and the dentist said it’s up to you. She is the professional she should know. She made me feel like they don’t care about me”.
- “My [family member] died of legal highs but (Provider) has helped with general health. Being involved with them has kept me away from the wrong people and therefore kept my health better”.

<u>Comments on Health Services needs not being met</u>

- Interviewees experiencing mental health crises felt that A&E was not set up to meet their needs, but they didn’t know how to access any other more suitable out of hours service: “They should be there for me all the time. I need more help than I'm getting and at times when I can get there”.
- Getting to see a GP was often difficult: “Now need to call or go online in the morning to make an appointment for that day. I haven't got a phone or access to the internet so this is too hard.”
- Hospital living was sometimes not suitable for interviewees in poor health. They reported weight loss and anxiety: “Once I get a flat and a doctor, I know things will be better.”

3.5.2 What do people want? What would be ideal?

Many comments from interviewees reflected those also made by the general public: “More funding for the NHS and ambulance service”; “To be able to call into the doctors on the day, to make an appointment for the next few days”. People without resources like computers and phones need an easier way to access services. For homeless people additional barriers exist to registering and seeing a family doctor.

Much better support especially out of hours and in mental health emergencies were mentioned frequently. Interviewees did not think that A&E was really able to help them, despite best efforts. Interviewees wanted to be treated as whole people, so that other serious issues affecting their health and well-being were also addressed.

<u>Comments on what to change or improve in Health Services</u>

- An emergency response service other than A&E for mental health crises.
- Better access to community-based services and GPs.
- Help with special health needs such as diet
- Treating the whole person, not just the presenting illness

3.5.3 Summary of learning points on Health Services

In discussing this topic interviewees talked more about mental health than any other health issue. They felt that mental health emergencies presented the most significant challenge to general health services. Many had found it difficult to access GPs and the Health Exchange was considered an effective temporary alternative. Interviewees also found it difficult to access through the phone or the internet, as many had neither. Those interviewees who had managed to get to their doctor, generally found their doctors to be helpful. Interviewees wanted serious issues affecting their health to be dealt with, as well as their presenting illness. Once again interviewees with Lead Workers had found their support invaluable in negotiating health and health-related services.

3.5.4 Change from SUP 2015/16

Access to GPs and the capacity of A&E to deal with mental health crises were also high on the list in the earlier study. The Health Exchange was once again rated highly by interviewees. The earlier interview group spoke much about negative attitudes from health service staff. This was still an issue in this group of interviewees: ""What's the point in going to an appointment if they don't listen to me?" However interviewees in both studies appreciated staff often gave them as much help as they could, given the limitations in resources.

3.6 The Experience of using Training, Employment and Volunteering Services

Five interviewees spoke about training, employment and volunteering, with another two making comment when talking about their housing needs. It was not a priority topic for most, perhaps reflecting the distance of their lifestyles from work. It is interesting to note that the five interviewees who did choose to comment on this topic were not from the Lead Worker Project, presumably having less entrenched complex needs.

3.6.1 How does it feel using Training, Employment and Volunteering Services?

Comments on Training, Employment and Volunteering Services that have helped

- Interviewees accessed a wide range of training. Personal development, boxing, creative writing, music, various vocational training courses and coaching courses were mentioned, as was CV support and work experience: "They made me a nice CV". One had "started a CSCS card here." A local catering and retail social enterprise was helping: "The man there says that he aims to get us into work in six months or he's failed in his job".
- One provider had provided bus passes for job interviews
- This was the first time many of them had received support with training and volunteering: "Before I just sat at home doing nothing. Now I have a plan for my

life"; "It's just what I needed someone to say. 'You can do this'. This hadn't happened to me before".

- Two people had previously gone to university, and one had successfully completed his degree. The other hadn't taken their "exams due to personal issues in my life. Now I'm getting back to doing what I want to do."

Comments on Training, Employment and Volunteering Services that have not been helpful

- Several spoke of benefits issues, saying they needed more help with appeals, and even legal aid for a solicitor.
- "If I don't spend 37 hours a week job hunting, they will stop my housing benefits and sanction me. They don't tell you it affects your housing benefits as well and they should".
- "Not many people in my situation know about the *Fulfilling Lives* services. Could do with putting more information out via (Provider), have a class set up down there to explain what services are available. Lack of information and communication-that's the real problem. The local authority offices don't know anything about the *Fulfilling Lives* programme. I told the worker about this programme and she's now told others."
- **"**They have taken away the money, even though nothing has changed for me since last year. It is like standing on a piece of carpet and someone taking it away"; "I lost my PIP payments, so that's been difficult, as I don't have much money. This leads to more paranoia and fear on top of my other mental health issues".
- "The person doing the assessment was rude"; "She's dealing with the vulnerable, so needs to know that".

Comments on Training, Employment and Volunteering Services needs not being met

- It was difficult to get a job once you had a criminal conviction:

  "All I need is help with drugs and jobs. There's loads of work out there but the problem to me is my criminal past. I'm not a lazy arse. I'm qualified to work on the railways. They need to loosen up the law on rehabilitation to help people like me get back into jobs. If someone will help me to get a job,

well great. I know loads of people out there, and what's stopping them is their criminal record. Lots of people stop crime after being young. Someone needs to change the law."

- One interviewee talked of working illegally and said this meant that they couldn't have Housing Benefit or social housing.

3.6.2 What do people want? What would be ideal?

- "Give me someone who's been down my route, not someone with a university degree and so on and so forth, but someone who understands what it's like"
- Supported access to a wide range of training and volunteering opportunities, work experience, CV development and help with declaring convictions.
- Better information and communication about opportunities
- Help to resolve benefits problems
- Respect from staff

Comments on what to change or improve in Training, Employment and Volunteering Services

- Address other barriers in addition to offending: "I've tried volunteering… but anger issues have stopped me doing that, due to the risk assessment. The pain of arthritis also stopped me volunteering".
- Assistance with benefit disputes and delays
- Transitional support, which used to be called "providing a gently sloping ramp into employment".
- Help in declaring convictions to potential employers; very few knew about the Rehabilitation of Offenders Act 1974.

3.6.3 Summary of learning points on Training, Employment and Volunteering Services

Interviewees faced multiple barriers in the labour and training markets. These included: unaddressed personal and behavioural issues, severe and chronic health problems,

substance abuse and dependency, lack of stability (especially in accommodation), lack of role models, low educational achievement, lack of information and low self-confidence.

They thought that providers could help them better by working together. When ready to enter the labour market, they needed help when declaring a criminal record.

3.6.4 Change from SUP 2015/16

Those interviewees known to have three or more complex needs were the least interested in this topic, possibly because their lifestyles pre-empted a commitment to routine and work. ‘Graft’ meant something different on the street. Interviewees in the Service Users’ Perspectives Study 2015/16 repeatedly said they weren’t ready for work, a sentiment that appears again in this year’s study. As in the previous research, interviewees reported positive progress in terms of training, but negative experiences around benefits and had little confidence in their chances of getting a job.

3.7 Other Services

Before closing the interview, interviewees were invited to comment on any services which they had not yet spoken about. Nineteen people did so, commenting mainly about the other services in the study. Their remarks are given in those sections. The lack of help with family issues was however raised again this year: “There's a court case coming up, and I want to get my kids back, on top of all of the other stuff. I'm scared my kids are going to go down a bad road too”; another mentioned needing support to see their family and children.

Some people made service wide comments: “Agencies should all train together, so everyone has a handle on what each other is doing.” “They don’t listen”; “It’s difficult to know where to go for support”; “Because I can't use a computer”. Several stressed the massive difference that having a key worker had made to their lives

3.8 BCFT Lead Worker Peer Mentor Service

All fifteen interviewees referred by the Lead Worker Peer Mentor service had both Lead Workers and Peer Mentors. The 2015/16 Service Users' Perspectives Study had asked interviewees to comment on this service. This was repeated this year and they were asked: "Has being part of the Lead Worker Peer Mentor Lead programme made a difference in getting your needs met? Why?" Ten interviewees responded specifically but many more made reference to their Lead Workers and Peer Mentors in their other answers. Nine people said that this support had been very beneficial: "I would have died or been in prison if it wasn't for (Provider)"; "If it wasn't for the help from (Provider), I'd end up in jail". One person said it had made little difference, as their needs were already met. Even those who weren't in this service repeatedly said how valuable a key worker could be. It seemed to be the one thing that everyone agreed on.

- "They have taken interest in my life! And they have started to sort my benefits and flat."
- "They care. They show interest. They treat me like a friend or family. They go the extra mile. They signpost me to where I need to go, and also come with me. They're amazing. They should be commended more."
- "It's only got better with help of the Lead Worker. It's good when they describe why stopping drinking will help me as a person, not just making me stop."
- "{My Lead Worker} listens to me and that, things get done. He rings up the social".
- "They manage my appointments. Tell me where to go and when."
- Interviewees found considerable value in workers having lived in their world, with first-hand knowledge of what it was like for them. One interviewee said that because their Peer Mentor had shared lived experience really they "could relate" to them.
- For one person, just being able to physically get to a service easily was worthy of comment: "{It's} easy for me to get to the (Provider's) offices".
- It was not just the support but also the access to information that they valued: "It was terrible before coming to (Provider). I didn't know what was on offer or where I should go. For about a year I didn't know how to get help. I then got into Lead Worker and it's been good".

The need for a key worker to coordinate service packages and to provide information ran like a leitmotif through interviewees' responses. Likewise they much preferred being helped by people who had shared their experiences and truly understood their reality. In their recovery or resettlement, they found hope and inspiration for themselves.

3.9 Summary of Experiences and Perceptions of Services

Interviewees' perspectives on services have not changed significantly in the last year. The exception was the improvement reported in drug and alcohol services through a new "umbrella'd" approach. The desire for better coordination among providers had also featured in the 2015/16 report. "We need more of services working together like this." In no area was wrapping services around the individual a common experience. Most of those interviewed were getting support from several providers concurrently, but for those without a co-ordinating worker, finding and keeping up with all the services they needed was frequently impossible. Current arrangements make demands on individuals whose problems mean that they probably won't be able to meet them so commissioners and providers need to revisit some of the systems. One respondent pleaded that agencies work together more. Co-operation would help individuals, even those with the most complex of needs and furthest from services, to find their way into and around provision.

Many of the problems highlighted were common across all the main service areas, inaccessibility, inappropriateness, and untimely waiting lists and being 'cut off at the knees' when support terminated too early. In terms of priority, stable housing was unsurprisingly number one. Interviewees saw having a home as fundamental to well-being and homelessness had to be tackled before considering health and wellbeing issues or employment. After housing, the interviewees focused on drug and alcohol dependency, and then on mental health services, an issue which cut across several service areas. They wanted more integration between these services and health care, training volunteering and employment, and offender rehabilitation. Complex needs they thought required complex interventions.

A negative attitude from staff decreased chances of success. “Went this morning, got attitude off receptionist. Couldn't get past her. Wouldn't relate.”; “They (staff) could also get out of the offices, and come and see service users in their areas”; “See me as a human being”; “I also think I'm worthless, so the drugs help numb that”. The previous report also found this:

> “The fragility of the service users with multiple and complex needs was tied up with their self-respect and self-esteem often being at rock bottom. This means that those who work with them need to be overtly respectful, and very clearly demonstrate a positive, encouraging and empathic approach. This approach would help build their confidence in the intervention” (p.53).

It will be interesting to see if this has changed when the next Service Users’ Perspectives Study takes place.

CHAPTER 4. LEARNING FROM THE STUDY

4.1 Learning about Services

Both Service Users' Perspectives Studies to date have tapped directly into the voice of service users. They have placed those voices at the very heart of systems change. This supports the aims of *Fulfilling Lives*. If intention is to wrap services around the individual, then it is essential to listen to what people say. They are telling us what they need and given their lifestyles, how they need it to be delivered. Policymakers and providers should listen to their voices.

It is true that the general public shares many of the same concerns about public services, particularly resources for the NHS or inadequate mental health services, and the growing reliance on IT. This is to be expected, but for chaotic, homeless and addicted individuals problems are doubled and compounded by lack of resources.

The two Service Users Perspectives Studies show that services must offer not just the right content but also a way in that takes into account the lifestyles characterising this community. A good example of this is the universal importance attributed by interviewees to key workers, preferably key workers with personal insight into how these lives are lived:

> "I want people who are a bit passionate. Textbook people haven't a clue."

The following summary focuses on where improvements could be made. It reinforces much in the earlier study; many issues remain outstanding.

4.1.1 Suitability

Housing is the biggest unmet need, and getting a stable home, rather than a short-term hostel place, is seen as increasingly difficult. Being accommodated alongside people engaging in detrimental lifestyles was of particular concern. To be appropriately housed meant being in accommodation suited to your individual circumstances, with support

geared towards meeting your particular configuration of needs. Supported housing designed for specific groups, such as the over 50s, was seen as helpful.

The temporary nature of much hostel accommodation caused anxiety. Whilst appreciating the help they were receiving, interviewees nevertheless became stressed as the time to move on grew nearer and they had no idea where they would live. Interviewees thought that being in temporary accommodation rarely gave enough stability for recovery and/or resettlement.

Interviewees also commented on the unsuitability of their medications. This echoed earlier research findings. It also reinforced the perception that professionals weren't listening.

4.1.2 Attitude

In all service areas, interviewees reported that they made the most progress when a respectful relationship existed between themselves and workers and practitioners. Where services were working well, trust and respect between the worker and the individual were evident. Interviewees as in the previous research recalled experiencing both good and bad attitudes from staff. The attitude of others is disproportionally important when dealing with people whose self-respect can be rock bottom.

Asking for help is a very big first step, and feeling put down is massively detrimental. The interviewees valued the people who encouraged and supported them, who went the extra mile and showed empathy, and who did not disrespect them because of their circumstances.

4.1.3 Timeliness

In the previous research, interviewees stressed that being able to access the "right" support at the "right" time was essential. This time, interviewees spoke more favourably about timely drug and alcohol programmes. They focused much more on waiting for suitable housing at critical moments in their lives, such as on discharge from prison, or after a de-tox.

Individuals often felt they had been left to fend for themselves at the very point at which they were at their most vulnerable.

4.1.4 Wrapped around the Individual

‘Umbrella’d” support and packages tailored to your needs were again identified by interviewees as the best way to organise provision. Without this organisation, interviewees needed the support of workers to navigate the many services they needed. Providers also needed to keep abreast with changing challenges: “Mamba is worse, as there is no detox from a mamba rattle……services have got worse.”

4.1.5 Accessibility

Interviewees were still experiencing major challenges in getting access to services. Juggling several needs in reduced circumstances compounded their access problems. For example, some said they had lost their GPs with their homes; others that, having lost their benefits, they couldn’t now have a GP. Some couldn’t bid for housing or make a doctor’s appointment because they didn’t have a computer or a phone. Without the help of workers, they were cut off from services.

They also wanted better information about where to go when in crisis and longer ‘opening hours’. There were high levels of frustration in particular about access to mental health services, for both acute episodes and chronic conditions. Conditions ranged from PTSD to psychosis, depression and anxiety.

4.1.6 Duration and Continuity

Interviewees wanted services to last for longer, in order to deal with their problems properly. The view was often expressed that not enough time was permitted and short termism was a constant anxiety.

Interviewees commented on staff turnover. Retelling their history, building a new relationship, rebuilding trust, all diverted their energy away from recovery. They wanted ‘someone who knew you well’ and ‘could help you to stay on course’ and ‘stop you from

falling through the gaps'. Things were getting better for some: "It's improved. People are now willing to help more than in the old days. Support workers used to change a lot too, and it's better to have the same person for longer." Having a sustained long-term relationship with a particular key worker gave individuals the space and time they needed to rebuild their lives from the bottom up.

4.2 Overarching Lessons about Service Provision

User Centred Services

- The first Service Users' Perspectives study showed that people in the most chaotic lives mostly had to chase up what they needed for themselves. Interviewees had not experienced themselves at the centre of services. Rather they felt that it was up to them to fit in with others' schedules and agendas. For anyone negotiating several different organisations at any one time, this would present a considerable diary challenge. With such complex needs of their own, they were rarely able to do this.
- The recent study has shown some progress, with a few interviewees enthusiastic that their provider was bringing together as many services as they could. However it was "maybe just after getting {your} foot in the door" that things got better. More work clearly remains to be done: "It's really hard to get support at first, but when your foot's in the door, it's a lot easier".
- Interviewees also said they were often let down when they had crises and agencies were not open or had no spare places. Experiences of having to wait, or of not knowing where to go and ending up in A&E by default, were commonplace. Often people found themselves at the end of a waiting list or in a service that could not help them. For many untimeliness and poor information remained significant issues.

A Stable Starting Point

- For most interviewees housing and accommodation services were issue number one, followed by substance misuse services, and then services for their mental health issues. It is not surprising that permanent, affordable and suitable housing was so

important. People said they needed security before addressing their deep seated and troubling issues.

Personal Support

- As in the previous research, interviewees reported that they benefited most from services when they had a positive and ongoing relationship with practitioners, and with support workers in particular. Both studies reveal how important continuity and trust is, no matter what the service area. Those with Lead Workers were particularly satisfied with their help. Those without key workers usually said they were struggling. Lack of information and lack of online access was acute for those on their own.

Added Value of Lived Experience

- Both studies showed how much interviewees valued workers who had shared similar life experiences. They thought such workers understood them better, and knowing their challenges first-hand, knew instinctively what to do to help them. They also acted as role models, giving people hope for their own eventual recovery and/or resettlement.
- The Lead Worker Peer Mentor service was mentioned on many occasions. It offered a non-judgemental space where interviewees could discuss their mistakes, and to be bolstered against peer pressure and self-doubt. Having a place where they could be honest without fear of judgement removed a lot of pressure off interviewees. This when combined with receiving help at a level and pace appropriate to them, was once again seen as a winning formula.

Appropriateness

- As in the previous study, interviewees said how much they needed good onward referral, but they also emphasised that it had to be to an appropriate service, not into something that just that happened to be on offer.

Attitude

- When dealing with people with very low self-esteem, it is doubly important to show respect. Interviewees once again emphasised how important it was that service staff understood something of the pressures affecting the person in front of them. They recommended training. The previous study mentioned BCFT's Psychologically Informed Environments training for the No Wrong Door Network. There was an additional suggestion this time, that reception and other office-based staff should go out and see how their customers lived.

  (For further information on Psychologically Informed Environments see Service Users' Perspectives Study Year 1 Appendix 11.)

CHAPTER 5. RECOMMENDATIONS FOR FUTURE RESEARCH

5.1 Introduction to Recommendations

As in the first Service Users' Perspectives Study, these recommendations focus on future research, not on the findings detailed and discussed in chapters 3 and 4 above. Nor does this report include details of the Peer Research Project, for this is available separately. In these recommendations, we look over the last two studies and explore what should be done to enhance future research.

5.1.1 Changes in the research process

The first Service Users' Perspectives Study was a pilot study. It adopted an innovative approach which centralised and amplified the voices of service users. All the participants came through the Lead Worker Peer Mentor service, as other projects were still in development.

The current study has continued to amplify service users' voices, but it has accessed a wider pool of interviewees. Half the interviewees came from other BCFT partners as part of the No Wrong Door Network, often service users with fewer or less entrenched needs. Some were further along their personal journey. As a result, these interviewees tended to regard the services they had received more positively. This diversity has added to the robustness of the earlier study's findings and should be expanded further.

It was not possible to re-interview any interviewees from the previous year, all of whom had very chaotic lives. However now that some interviewees have more stability, it is realistic to aim for re-interviews. Re-interviewing will help track levels of satisfaction with services.

5.1.2 Embedding the learning

Chapter 4 sets out many lessons based on the evidence in chapter 3. Service users are still reporting similar barriers as a year previously. This is not unexpected given only twelve months has passed.

Putting service users at the centre of the research was initially suggested by Experts by Experience and its delivery is now in the hands of Peer Researchers, supported by BCFT. Interviewees wanted to know what steps were being taken to embed the learning in practice. When lessons are coming so directly from service users it is vital that providers and policy makers listen to them, and take action. Lessons from the Service Users' Perspectives Studies should be adopted by BCFT and its partners, as well as influencing *Fulfilling Lives* evaluations.

5.2 Recommendations

5.2.1. Value of On-going Qualitative Research

BCFT has a strong track record in statistical and quantitative research. However, to 'get the whole story' for systems change, a qualitative study like the Service Users' Perspectives Study needs to run alongside. Qualitative research should be repeated over the lifetime of the programme, for listening to service users describing how they are being treated, will 'speak volumes'.

5.2.2. Sequential Service Users' Perspectives Studies

Carrying out sequential research will help track improvement or deterioration in services. A sequential study (in future with interviewees being re-interviewed if possible) will show whether services are really improving from the service user's perspective. Moreover, involving people who are themselves making progress will add significant insights about the rungs on the ladder upwards.

5.2.3 More Interviewees from more BCFT Partners

Only a few BCFT partner organisations engaged in this research. Reaching the target figure of thirty interviews was much more difficult than predicted. In future core partners need to be more involved and to understand the innovatory approaches. They need to encourage their clients to participate, since they are the ones with access to them. They should help their service users to get involved either as interviewees or peer researchers. If they do this, they will maximise the opportunity for their clients to get involved but also lend the

research a highly differentiated pool of interviewees, which can only make it more interesting.

What motivates the interviewees to participate? They were rewarded with a £5 token in appreciation for their input. However almost every interviewee said they wanted to 'make a difference', and that this interview was their one chance to do this. With partners' support Study Number 3 could offer this to more people with multiple needs.

5.2.4 Co-production and Disseminating the Learning

Promoting the evidence in these two studies to partners and providers is strongly recommended, so that they can plan evidence-based service. The key value here is coproduction. Partners and stakeholders with a commitment to co-producing services with the people who use them value such an opportunity. Co-production is a particular challenge when the people you are supposed to be coproducing with are chaotic and marginalised.

Nevertheless the aspiration to coproduce remains and this research makes it possible. A dedicated workshop, covering the findings, the learning, the links and the recommendations is recommended.

5.3 Conclusion

In conclusion, it is hoped that these two Birmingham's Service Users' Perspectives Studies will contribute to a culture of understanding towards those people most marginalised in our society. Service providers have a great deal of power over individual lives, both upfront and indirectly. These studies show that it is often uncomfortable and sometimes impossible to get what you need at the receiving end. Interviewees were strongly motivated by the thought that their testimony would make a difference to the lives of others. If their voices are listened to, change for the better can happen, change based upon their real-life and hard, lived experience.