Birmingham Changing Futures Together

Service Users' (Multiple Needs)

Perspectives Study

Final Report, August 2016

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9th August 2016

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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). Birmingham is one among twelve locations across the country taking part in *Fulfilling Lives: Supporting People with multiple needs*. All the *Fulfilling Lives: Supporting People* projects are exploring new ways of working with adults with two or more multiple and complex needs, or HARM needs. These are:

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

Alongside delivering service improvements, the programme is subject to substantial national and local research. The national research will look at results from across all twelve programmes, 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, as it demonstrates how to make services more cost effective and deliver improved outcomes. Birmingham's local research, including this Service Users' Perspectives Study will contribute to that wider learning. Birmingham Changing Futures Together commissioned this study in September 2015 as part of its local evaluation.

The Service Users' Perspective Study is an independent study by Clever Elephant. It captures individuals' perspectives on a range of services, both those services directly related to the four HARM needs listed above, and additional service needs that frequently accompany them. The study reflects BCFT's position, that it is not individuals with multiple and complex needs that create problems for service delivery, but rather that the way in which services are delivered can and often does make difficulties for individuals. Research was carried out between September 2015 and the end of May 2016. The focus of the research, the content of the interviews, and the

process of engagement were designed with the help of Experts by Experience (EBE), people with lived experience of multiple needs. It was in fact EBE who rejected the previously planned case study approach and asked researchers to listen to their voices and 'to tell it how it is', how it feels to be on the receiving end of services, to be the service user. This was a pilot study and if successful BCFT intend it to be the first in an ongoing series throughout the programme's lifetime. It is hoped that many interviewees will be interviewed again over time, so that any changes in perceptions can be captured. All interviewees to date have agreed to this, though researchers are aware that changing circumstances may often make this difficult.

Chapter 2. Methodology and approach

As a pilot this study had two aims: the first was to find out about services from the first-hand experience of people who use them. The services included health, housing, mental health, substance misuse, accident and emergency, training and employment, criminal justice like police and probation and the BCFT programme itself. The second aim was to explore the research techniques that would best suit this cohort and produce the richest data. The learning has been twofold, what was said about the services themselves and what was discovered about the process of engaging the service users in the study.

A total of twenty service users participated, with one person being interviewed twice. The interviewees' profile was not dissimilar to the statistics across the BCFT programme. Five were female, the rest male. They had an age range from 20 years to 60 years, with the highest number in their 30s. The majority were White British. All but two of those interviewed came from the caseload of BCFT lead workers, so this group of interviewees had the most entrenched needs. A major concern when reporting on a small interviewee group like this is to maintain anonymity. The report removes any specifics by which interviewees could be recognised. It is also important to note that interviewees were not asked to name specific providers, rather to comment on their experience of service areas. The aim was never to evaluate specific service provision; it was always to capture the raw experience of service use. Individual service providers are not named.

It appeared from our interviewees that, as service users, they were unused to being asked for their first-hand account of services and that they enjoyed the opportunity.

Chapter 3. The experience of using services

This chapter presents the findings relating to the experience of using services. There is a section for each of the service areas listed above, with a further topic relating to anything specific to Birmingham. Each section records interviewee's perspectives using the following structure:

1. How does it feel, using the words and reporting the views of interviewees as appropriate (given the need for anonymity for both interviewees and providers)
2. What people want, analysis provided by the researchers
3. Summary of learning points, for those interested in taking the findings forward

Here are summaries of each section:

3.1. Housing Services

The majority of respondents not unsurprisingly wanted to have somewhere "permanent to call home". Some had experienced difficulty in finding their way through various systems to apply for housing. Many expressed the need to be in long term housing, rather than short term arrangements, with worries about facing homelessness again. Those in hostels and temporary accommodation often commented on noise and tension that could increase their anxiety levels, and felt that being housed with others with addiction and alcohol issues was not helpful to their chances of recovery. Many found sharing facilities with other service users with similar problems and similar compulsive behaviours as themselves difficult to handle, and therefore appreciated it when providers take into consideration each individual's position: "People are handpicked for each house". Being in supported housing and receiving regular help from a support worker is widely appreciated. Whilst hostels could be daunting to some, sleeping on the streets also presented risks – "sleeping bags, they get robbed regularly". One person said that when he/she slept rough they hid away, so outreach workers couldn't find them.

3.2. Health Services

Many interviewees said that they found it difficult to access to regular health services: "Didn't use GPs when I was homeless as I didn't have an address". Some felt that when they did access a health service, they were often not taken seriously "[the doctor] knew I had long standing problems and advised me to show some spine - I left feeling demoralised"; fobbed off " {They thought} It's just a heroin addict, she doesn't matter" or were patronised or neglected in some way, "I've been on anti-depressants for 15 years. No-one ever noticed I needed a mental health programme". Where health services had worked well, in interviewees' opinions this was often down to securing regular access and a good relationship with a particular doctor or nurse.

3.3. Mental Health Services

Interviewees had a lot of experience of mental health services and said they needed both medication and support, including consistency of support. There were regular reports of having to wait for appointments after referrals were made, though it is unclear whether waiting lists are any longer for this group than for the general population. Some recognised that their offending behaviour directly related to mental health and anger management issues. Most felt that having the "right" support worker and the "right" medical support were essential to being able to make progress. One positive example given was of a GP who both supported the interviewee, and prescribed and monitored their drugs.

3.4. Substance Misuse Services

Interviewees commented on their experiences of a range of services and it became clear that the relationship with the support worker(s) contributes very significantly to their success or otherwise. Reliability and consistency enabled them to feel trust. Experiencing some stability they felt increased their chances of a successful detox and enabled them to start to address their long term recovery issues. Frequent contact was identified as key in any scheduled recovery programme. They mentioned the benefits of having the support of BCFT's case workers (called Lead Workers and Peer Mentors) and having accommodation where appropriate in-house support was available. Another significant factor they identified was having accommodation free of others still currently misusing substances. Several interviewees on the other hand referred to "not being ready" and mentioned their anxieties about failure and whether they would be given a second chance: "You try getting into detox - it takes months". For them navigating services when they are in still crisis is extremely challenging: "Being an alcoholic is a full time job and not a very pleasant job at that". One interviewee described deliberately offending in order to secure the help of the police in referring him/her to the support agencies that they knew they needed.

3.5. Accident and Emergency Services

This interview group expressed mixed feelings about these services. Some felt they experienced prejudice, which they thought was due to staff seeing their presenting conditions as somehow self-inflicted, or in some way related to their choices: "I hate A&E, they think I'm a waste of their time. This is what you feel from them". On the other hand others expressed gratitude for the

help they had received when in crisis, for example, when suffering the effects of alcohol withdrawal, sometimes on repeated occasions.

3.6. Services for training and employment

"Work is a bit of a way off at the moment", a sentiment expressed by one interviewee but one which most interviewees also felt. Nevertheless they saw the value of training and volunteering, not only in securing a future for themselves, but also as a way of getting out of doors "I would like a job gardening to get out of hostel"; and getting some new structure into their day: " I would like to help other people. I'm trying to build a structure to the day and get stable so can do this". Several identified being in the open air as particularly important to their well-being.

3.7. Criminal Justice Services

Many of the interviewees had convictions, many of which had resulted in prison sentences. As might be expected, feelings about the services received whilst in the system were complicated, and varied considerably. Interviewees reported being most vulnerable at the actual point of release, for example. Likewise, the capacity of the probation service to continue to provide support to an individual after they had completed the probationary period was highlighted as an issue. Feelings towards the police were equally mixed: in general there was distrust and criticism that the police simply moved them on without referring them onto other services. At an individual level however some mentioned specific police officers who had been helpful, showing once again that it is relationships that matter.

3.8. BCFT Services (mainly Lead Workers and Peer Mentors)

Interviewees strongly commended the intensive, comprehensive and consistent support provided by these roles. Without this support interviewees, juggling so many complicated and intense issues, said they would have found navigating or negotiating services extremely challenging, if not beyond them. They all felt this support was helping them to achieve some stability and to address their issues. Long term consistency of staff regularly featured as an enormous positive. Trust builds up gradually, through repeated contact, and is tested every time a fresh need arises or a new crisis emerges. Interviewees often referred to the length of support they were eligible for - as knowing that this support could be available over several years was important to them.

Chapter 4. Learning from the Study

Chapter 4 sets out the learning from both the experience of using services and from the process of engagement. The learning about services is focused on the following themes: suitability, attitude, timeliness, wrapped around the individual, accessibility and duration and continuity. An important finding is that for individuals with multiple and complex needs some service areas are more immediately important than others in addressing their often long-standing issues. Stable housing is a foundational need before being able to tackle health and wellbeing. The interviewees experienced the greatest challenges with services for substance misuse and mental ill health, due to a range of factors including accessibility, suitability, timeliness and the duration of the provision.

The learning from the process of engagement reflects on the challenge of interviewing people with multiple and complex needs, many of whom are in the midst of crisis and are experiencing chaotic lifestyles. The process whereby such a service user becomes an interviewee and is able to participate actively in research is not straightforward and requires many skills to make it happen. In this chapter, the report offers insight on what needs to be in place in order to enable and empower the participation of those with the most pressing and complex needs.

- "I'll spend a few minutes with you and then I've got to get a drink"

An important finding is that for many their engagement can in itself be described as part of the therapeutic process. Being valued as the expert and seeing oneself as a "giver" rather than a "recipient", as someone who is able to help others, has been significant. In this context having researchers who react appropriately to often distressing personal disclosures is important. They also need to understand evasions, know when to stop probing and to handle omissions sensitively and well.

"Creating the Space": Interviewing People with Multiple Needs

As a result of so much learning about the process of engagement a set of Guidelines "Creating the Space": Interviewing People with Multiple Needs, has been produced in the hope that it will be useful for others wanting to find out about services from the perspective of service users. The guidelines can be found at Appendix 1 in the report. They provide prompts for others seeking to interview people with complex needs on how to create an environment that gives service users

licence to reflect on and share their experiences with confidence. Following the prompts will help interviewers to get good quality feedback from interviewees. This in turn can help an organisation to develop more responsive services, and can help the interviewee as an individual, as the interview itself becomes a positive part of their recovery process and/or personal journey.

Findings about how a service is offered

An overview of the findings strongly suggests that the attitude of those providing services is as important as the service on offer. Chances of succeeding depend on the way in which services are presented and interviewees see a link between their resilience and the attitude of those working with them. The term a 'textbook approach' was used to describe what had not worked. Interviewees emphasised the need for frontline staff and practitioners to have some awareness of the pressures and conditions affecting the person in front of them. This could be described as 'being psychologically aware' or providing a 'psychologically informed environment'. Learning points are emotional, as interviewees' clearly showed in their perceptions of how they were treated by others, how they were on high alert in these interactions, their sensitivity perhaps heightened by their own fears of failure and fragile self- esteem. Small kindnesses were repeatedly and enthusiastically recalled by all interviewees. Many felt prevented from slotting into services by the dynamics of their needs, and wanted others to see them in the round, rather than as the crude stereotype of an alcoholic or a drug addict.

Findings about the importance of individual workers

The contribution that the support worker makes, especially in their understanding the complexity of a given individual's needs, is significant. Interviewees valued their understanding of how services must wrap round them a lot more, rather than asking them to squeeze themselves into the organisational priorities and timetables of others. Where reference is made to this happening, and the service user being placed at the centre, it is often attributed to the understanding of an individual worker.

Chapter 5. **Recommendations for further research**

This final chapter focuses on the research itself and presents ideas for discussion for BCFT regarding future service user studies. It does not repeat the learning already presented in Chapters 3 and 4.

Acknowledging the study as a pilot - it is important to remember that this was a pilot study, not only in terms of developing the research approach, but also in that almost all the interviewees were referred through one work stream within BCFT (Lead Workers and Peer Mentors) so the group must be treated as reflective rather than representative of the wider group

Embedding the learning especially in terms of PIE - the learning from this study can inform the next phase of BCFT's development, including the co-production of services, which is central to the BCFT programme. It can be used in the context of BCFT's imminent training on Psychologically Informed Environments (PIE).

Value of Ongoing Qualitative Research - further research will build on BCFT's evaluation work and complement any quantitative impact assessment. The study needs to continue over the lifetime of the programme as it will help to establish if services have improved from the service users' perspective and will help to identify what those improvements are.

Annual Service Users' Perspectives Study - an annual Service Users' Perspectives study is strongly recommended. BCFT partner organisations need to be involved from the outset to ensure that future studies capture a wider field of research participants.

Sequential Research – credibility and a more balanced picture will be achieved by undertaking second and third interviews with those service users who have already participated, wherever this is possible. This could achieve some tracking of individuals, especially for those who have moved on in their recovery or other multiple needs journey and why they think it worked for them.

Promoting and Disseminating the Learning - It is strongly recommended that a workshop is held for BCFT partners to discuss this pilot, since it expresses the service user experience, which is central to the aims of BCFT. The learning and recommendations would help to inform the next phase of BCFT development.

In conclusion, it is hoped that Birmingham's Service Users' Perspectives Study will contribute to developing a culture of understanding in relation to people with multiple and complex needs. Service providers can have a great deal of power over individual lives, both directly and indirectly, and this study has tried to capture what it is like to be at the receiving end when your particular needs are multiple and challenging. Interviewees were strongly motivated by the thought that their interview would make a difference to the lives of others. Their evidence, recorded in this report, will now inform BCFT's goal of systems change and base it firmly within real-life lived experience.

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 among twelve locations across the country taking part in *Fulfilling Lives: Supporting People with multiple needs*. All the *Fulfilling Lives: Supporting People* projects are exploring new ways of working with adults with two or more multiple and complex needs, or HARM needs. These are:

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

Alongside delivering service improvements, the programme is subject to substantial national and local research. The national research will look at results from across all twelve programmes, 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, as it demonstrates how to make services more cost effective and deliver improved outcomes. Birmingham's local research, including this Service Users' Perspectives Study will contribute to that wider learning. Birmingham Changing Futures Together commissioned this study in September 2015 as part of its local evaluation.

1.2 The Service Users' Perspectives Study

The study began in September 2015 and was completed in May 2016. It captures service users' perspectives on a range of services supporting them, both directly in relation to the HARM needs listed above, and the additional complex needs that frequently accompany them. The study reflects BCFT's position, that it is not individuals with multiple and complex needs that create problems for systems of service delivery, but rather that the way services are delivered can and often does make difficulties for those individuals. Research was carried out between September 2015 and the end of May 2016. The focus of the research, the content of the interviews, and the process of engagement were designed with the help of Experts by Experience (EBE), people with lived experience of multiple needs.

Its specific focus was to collect and collate service users' perspectives on services, on how they experienced/are experiencing the provision offered - or not offered - to them. Perspectives involve feelings of course, and feelings are subjective. Perceptions of interactions and interventions will reflect both the client's take on the world, as well as the service itself and the attitude of the service provider. It is therefore important that this study grows in size over time and includes a wide range of service users with complex needs. This emphasis of keeping the service user at the centre is in keeping with BCFT's longstanding commitment and ethos. The focus of the research, the process of engagement and the content of the interview, were designed with the help of Experts by Experience (EBE). It was in fact the EBE who rejected the previously planned case study approach which focused on an individual's journey towards a better life. Rather they asked researchers to listen to their voices and 'to tell it how it is', how it feels to be on the receiving end of services, to be the service user.

BCFT contracted Clever Elephant to undertake the research, with the shared understanding that this was to be a pilot with two aims: the first was to find out about services from the first-hand experience of people who used them. The services included health, housing, mental health, substance misuse, accident and emergency, training and employment, criminal justice, mainly the Police and Probation and the BCFT programme itself, in particular the Lead Workers and Peer Mentors work stream. (BCFT's Lead Workers and Peer Mentors help service users to co-ordinate and navigate services, helping individuals secure a seamless service package and capitalising on the lived experience of the Peer Mentors.) The second aim was to explore techniques that would best suit this cohort and produce the richest data. The learning is therefore twofold, what interviewees said about the services themselves, and how to engage individuals with many needs and often in personal crisis, in the research process constructively and positively.

The pilot has generated much learning on both issues. As mentioned above interview topics covered a wide range of service areas, but interviewees were also given free rein to mention any other area they wanted and to compare Birmingham to other places where they had received services. BCFT is considering making this study to the first in an ongoing series spanning the programme's lifetime. The findings of all BCFT research including this study will be made widely available through the *Fulfilling Lives* programme, and alongside other research, it is expected to inform future service design and provision including that of the No Wrong Door Network, a collaborative approach designed to achieve systems change in Birmingham. Successful

collaborative service delivery has to take into account individuals' real lives, real feelings and real experiences.

- "Drink controlled everything I did, when I ate, what socks I wore to stuff bottles in them"

CHAPTER 2. METHODOLOGY AND APPROACH

2.1 Design and focus

Actively involving people with multiple and complex needs in project design is an important value to which BCFT adheres, and in the case of this study, the consultation at the outset with the EBE informed the approach, style and content. EBE input resulted in a marked change of emphasis for the study. It moved the focus right away from case studies to that of seeking the "perspectives" of service users on services. What they wanted was to be given a voice, being able to say what it was like to be on the receiving end of services. They thought that the most valuable thing that the study could achieve would be making public their "end experience".

The emphasis of the study is therefore on the views of service users on services, often using their own words. The views of interviewees are reported in both direct and indirect speech. Which method was used was largely determined by the guarantee of anonymity given to each interviewee. It was important to remove any information which could make clients known, whether to support workers, to officials in their lives who might read the report, to programme staff or to associates and acquaintances. Often interviewees did describe personal experiences which were sufficiently extreme or sufficiently individual to make them immediately identifiable. This detail has been deliberately omitted, although it might have made for a more colourful report. The research was neither participatory nor advocacy-focused, but makes an earnest attempt to prioritise the service users' voice, whether quoted or reported.

2.2. Research approaches

The research was conducted through individual interviews using a topic list. However these were not heavily guided interviews but rather conducted in the style of a conversation, so that interviewees raised issues in the order that they wished or as they occurred to them. Researchers did not set a prescribed order questioning or insist on a full answer to each and every query. This approach let interviewees take the lead and reflected the intention for them talk about services, whilst at the same time allowing space for emotion, as well as commentary, to emerge and settle.

In each 'conversation' topics covered the following areas: housing services, health services, mental health services, addiction and substance misuse services, services relating to training and employment, accident and emergency services, criminal justice services, mainly the Police and Probation, and BCFT services, in particular that provided by Lead workers and Peer mentors. The study did not set out to triangulate any comment about any individual service provider, and none are named. The focus of the study was not to critique providers or institutions, but to prioritise the experience of being a service user. Individual testimony addressing any particular provider is subject to the same right to anonymity as accorded to the interviewees themselves.

The next chapter collates findings and reports on emerging themes, with the emphasis being on the words used by service users themselves. The study explored what helps and what hinders from a personal, first-hand experience. Questions were posed about what in particular had helped and what had been particularly difficult. Answers covered both provision and the manner of its delivery. The latter has emerged as particularly sensitive for interviewees, with lessons perhaps for those working with the wider multiple and complex needs population.

2.3 The Interviewee Engagement Process

In engaging the service users, Clever Elephant adopted a three stage process;

Stage 1 Pre-Interview

In advance of each interview researchers sought background information about the prospective interviewee from staff with whom they were currently involved. In most cases this was the BCFT Lead Worker or Peer Mentor. Being briefed about current challenges, the length of time the individual had been engaged and how he/she might best interact during the interview helped the interviewers to set the pace and level of the conversation. Some knowledge of an individual's circumstances or likes and dislikes helped establish rapport and helped with the flow of conversation. This initial stage was also where risk assessment took place, for example in determining the location for the interview. The team at Shelter in particular, provided a great deal of practical support throughout this phase, liaising with the lead workers, offering venues and generally supporting all the interview arrangement, including the risk assessment. Staff at Citizen Coaching and SIFA Fireside were also very supportive. In all cases the researchers' decision coincided with that of the staff.

Stage 2 The Interview

Interviews were held in service users' homes, in their hostel accommodation and at a provider's offices in Birmingham. Two researchers attended each interview, not just where risk assessment advised it, but every time. It was decided not to record interviews on tape, but that one of the researchers would take notes whilst the other researcher (the conversant) focussed on the interviewee. This arrangement demonstrated to interviewees the importance attached to their testimony. The note taker established a rapport with the interviewee just as the interviewer did. This made interviewees feel free to check that what they had said had been noted down which proved very important to them. Also the arrangement enabled a free-flowing conversation between the interviewee and the interviewer which they much preferred to previous 'tick box' experiences.

Interviewees were invited to bring someone along with them if they wanted, but only one took up this offer. In fact of course it is preferable that interviewees come without their caseworkers so that they can be completely open in their responses to the questions about their current service. Researchers relied heavily on support workers to encourage their clients' participation and to keep appointments, for example, ringing them up to remind them and bringing them physically to the venue. Support workers were also encouraged to reassure their clients about the anonymity of the research and that as an additional benefit, participation would be compensated by a supermarket voucher.

Although the researchers allocated one hour for each interview, the actual time varied considerably according to the individual's level of engagement, desire to communicate or fluency, and their immediate personal situation. "I'll spend a few minutes with you and then I've got to get a drink". Everyone was asked if they were willing to have a follow up contact and if they had any feedback about the researchers' style or the way the interview had gone.

Stage 3 Post Interview Follow-Through

Researchers phoned interviewees up a few days after the interview. This sometimes involved going through the support worker. The call gave the interviewee another opportunity to add to what they had said or to reflect again on their experience of the interview and to suggest any improvements.

2.4. The Interviewees

There have been three round of interviews, the first round in September 2015, the second in February and the third in April and May 2016. Twenty one interviews have taken place, involving twenty individuals, with one individual having a second interview. Others have agreed to further follow-up interviews as well, so it is hoped that that these will materialise in the future, as it may well be possible to chart changes in perceptions of services. In practice the researchers have had little control over the profile of the interviewees so far included in the study, as they have relied on Lead Workers rather than the wider BCFT programme including the No Wrong Door Network, which was in development at the time. However equalities information was sought to help future monitoring for diversity and to see if the profile of those interviewed may in any degree reflect the LWPM cohort as a whole. This information is given below:

Figure 1: Gender of Participants

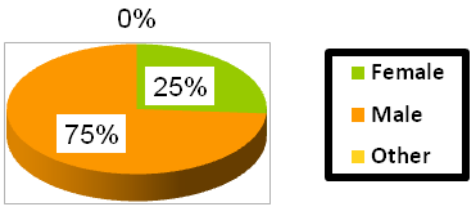


Figure 2: Ethnicity of Participants

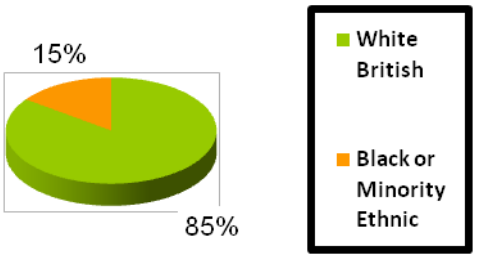


Figure 3: Participant Disabilities

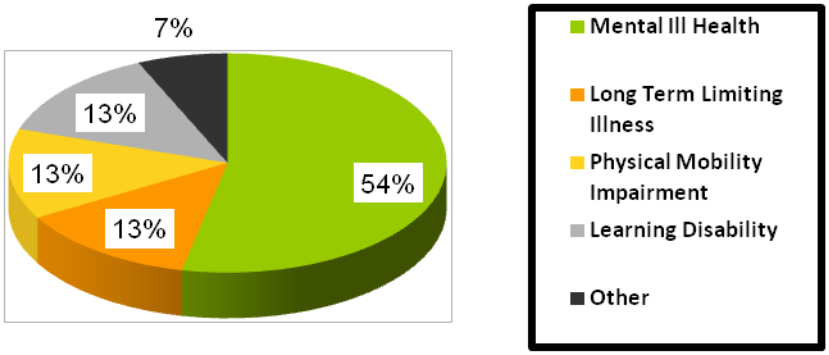
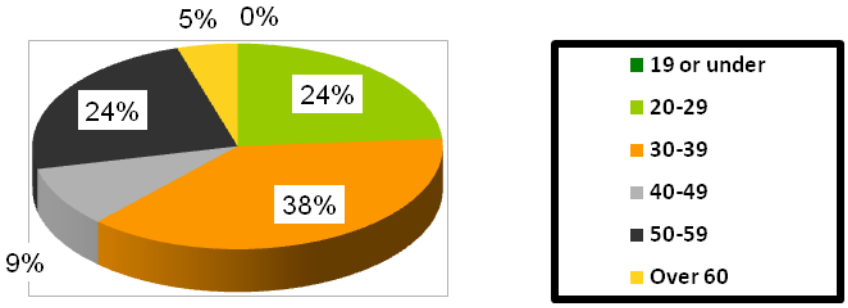


Figure 4: Age of Participant



This profile is in line with statistics produced by BCFT on service users in April 2016. For example, the number of females to males is half.

It is not unexpected that interviewees said their most significant needs related to housing, substance misuse and mental health issues, as these reflect the needs recorded in the service user data.

- 80% were currently misusing substances, with the majority using alcohol; four were in recovery for alcohol addiction
- 72% said they had a mental health problem, the majority were receiving some support and the others were waiting after a referral has been made.
- 71% were in temporary accommodation, mostly hostels, with the majority seeking a permanent solution. Accommodation included hostel, sheltered housing (mostly in shared houses), and local authority housing and private rentals.
- 28% were currently or had very recently been engaged with the Criminal Justice System, either just released from prison, on probation, or had other issues pending.
- 48% were engaged or applying to engage in some kind of activity, training and/or volunteering mainly

None of the interviewees were in employment at the time of the interview, again unsurprising given the intensity of the needs in this group. The majority received Employment Support Allowance and Housing Benefit, with a minority either in receipt or in the process of applying for Personal Independence Payments (PIP).

The majority of interviewees were born in or near Birmingham with 45% having moved into the city, many some years ago, so within the interview group only three had recent experiences of services elsewhere. The majority were not in regular contact with family members, but 30% had some contact and support from their families.

2.5. The pilot

The majority of the interviewees were referred by the BCFT Lead Workers, who as we have mentioned above, supported and made all the arrangements for the interviews. Without them the study would not have been possible. However, as these staff say that most of their clients have all four HARM issues and more, reliance on their clients has slightly skewed the study from its original intention. This was to cover a wider range of service users, including those with fewer HARM needs, and some who were further along in their personal and/or recovery journeys, even able to comment on recent services retrospectively. Towards the end of the project two individuals were referred through the No Wrong Door Network (NWDN) and this has begun rebalancing the Study, something that in future years it is hoped will be continued. However it should be noted at this stage that clients who are in the midst of service use, or as yet still disengaged with services, may have a very different perspective to those who have successfully negotiated their way through them and found light at the end of the tunnel. This study is a pilot and has involved individuals with the greatest intensity of need many of whom are in changeable, indeed often chaotic, circumstances. The outcomes of this research reflect this condition and further research in future years is strongly advised in order to secure a wider set of perspectives.

A second impact of working with interviewees with such significant complex needs has been on the resources needed for the study The majority of interviewees were facing immediate challenges at a personal level in their daily lives, so committing to a research interview was a big ask, as indeed was asking them to reflect on service experiences that were for many still quite 'raw'. To meet this challenge it was necessary to build in substantial preparation time pre-interview, to field two researchers so that the conversant could focus on the well-being of the interviewee, and to build in time for missed appointments. Given the intensity of challenges faced by many interviewees it has been quite remarkable that there were only five missed appointments.

2.6. The Structure of the Report

The aim of this study is to collect a body of information on the experiences of interviewees across a range of front line services, then analyse them thematically. Understanding how 'it feels at the receiving end' can help staff and providers understand the reactions they encounter both positive and negative, and help commissioners design future provision. The following chapter sets out the findings under the several service areas. At 3.11, anything discovered so far that distinguished Birmingham from elsewhere is reported. Each section from 3.1 to 3.10 is structured as follows:

- How does it feel, using the words and reporting the views of interviewees as appropriate (given the demands for anonymity for both interviewees and providers)
- What people want, analysis provided by the researchers
- Summary of learning points, for those interested in taking the findings forward

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 topics during the interview, remembering things belatedly, distracted by other needs or not ready to disclose some key experience until later on when enough trust had been established. The note taker organised this apparently free flowing conversation as the interview progressed. Comments are given below under each service area using the following structure: services that have helped; services that have not been helpful; service needs not being met, and other comments.

CHAPTER 3. THE EXPERIENCE OF USING SERVICES

3.1 HOW DOES IT FEEL USING HOUSING SERVICES?

3.1.1 Comments on services that have helped

- "[Provider] saw that my flat was poorly maintained and unfit for me due to my disability. I asked them to help me get {a} better property."
- "I have been in and out of hostels, [Provider] helped me with food, showers, phone calls etc."
- "[Provider] is great. I was sofa surfing with friends, but drink and drugs caused arguments, but now I can stay here for a minimum of twelve months and longer if needed. I have my own room with {a} shared kitchen and bathroom." This interviewee also valued learning programmes on new behavioural skills.
- "I just keep myself to myself, but they will cook you a meal six days a week."
- "I have got support and am learning the practical skills of how to run a home and manage a tenancy"
- "They are great. I am getting the support and learning programmes that teach new behavioural skills"
- "[Provider] got me into a bed and breakfast, then I got a tenancy, but I got thrown out and was on streets for ten days, then I got this place" (supported housing for people with mental health issues). "I can stay permanently, no push to move on." This interviewee valued the support offered by his/her housing support worker, for example with medical appointments, ESA, and budgeting and particularly that should he/she decide to go into rehab they would not lose their accommodation.
- "I like the other chaps, we help each other, one is abstinent from alcohol, a big help for me being there." This interviewee lived in a shared house with shared kitchen and own bedroom. The accommodation had cleaners and support workers, and the interviewee valued seeing the support worker every week and that they could stay there indefinitely.
- "[Provider] helped me get new accommodation, it's a blessing."

- "This is rehab place, 16 weeks detox here, after two weeks short stay at [Provider] ….This is how come I can look outside now, at homes and courses." This interviewee was viewing permanent accommodation the following week.
- "The house is about to get wifi which will mean I won't need to go to the library all the time."
- "Our biggest problem here is that we are broke, I had to pawn my television." This interviewee was living on the streets before securing this hostel accommodation. He/she valued that "you are left to your own devices, the house is very quiet, you've got all the facilities you need, washing machine etc."
- "I've had flats before and struggled with budgeting and so forth. Here I get food, electric, water etc. as much as I need. If I get my PIP I will pay more rent. It'll top up my ESA. I have a fridge in my room and a TV, so I'm set up. If I grow a few potatoes, [Provider] has an allotment and [Provider] will have apples on the trees soon."
- "[Provider] allows one relapse before they chuck you out. They will help you recover from relapse. This should be in all housing places. [A Different Provider] didn't allow any relapse. I was so angry."
- "Life is not a bed of roses, but I am awaiting my future, now I can look for my destiny. I know that finally after all the hassle, I will be able to go and lie down on my own bed." This interviewee had no recourse to public funds but a charity had provided assistance

3.1.2 Comments on services that have not been helpful

- One interviewee had been at the hostel for six months, and said that he would have to move on after two years, which wasn't helpful. The hostel accommodated people with similar problems, and the interviewee had lots of "friends waiting outside to go for a drink".
- One interviewee reported having moved four times in four months, and that their support worker had to find him accommodation to avoid a re-call to prison. He/she has now entered a shared house, and though dissatisfied with the location, is happy there, after so much turbulence.
- "Problem with [Provider] Hostel is that they keep you in if you play up and have problems and cut up. If you did what I did and kept all the rules, curfews etc. they let you go after seven weeks. They just kicked me out, no counselling arranged, no alcohol treatment, nothing."

- "Housing could be quicker, too many fights, noise and drinkers at the hostel."
- "That day I just packed my stuff up at the hostel and came down here and sat till 5.30p.m. till they found me accommodation. It wasn't suitable because they were all 18 year olds partying and running riot all night. No staff on site, was awful, my head was going."
- "Not many people like going into hostels. If you're detoxifying, you don't want to be around those people who are still drinking. It's ready made for having a relapse."
- One interviewee talked about a provider with a stay limit of three months which he/she felt wasn't long enough to recover from addiction. They felt that step-down housing did not provide enough support. He/she described it as a "revolving door" situation and felt that be there should be a twelve month minimum stay not three months. "Three months is a rush, with really bad tension as a result. "
- "I'm off the streets, but can only be here for three months. I was housed before but along with other addicts, so was unsuitable."
- One interviewee had been housed for a year by [Provider] but described their approach as very condescending. Now in a new hostel, concerned that they will have to leave after two years, they want home of their own: "This would be the biggest achievement for me .... Nothing can stand up on a crap foundation."

- Internet bidding system is a problem for people who are unhoused and without IT skills. "How the **** hell are you going to bid. It has become a big issue. This is my number one issue, cos if you don't bid you won't get a place." This interviewee received help from support workers to bid.
- "I need a ground floor flat, the first viewing was unsuitable, now have enough points, my {family member} did the bidding for me".
- "They make things so difficult especially having to bid on the internet. They'll only offer you the crappiest places. It's all about statistics, they just want you off the street, even if place doesn't suit you. You don't last there, because of other people there."
- "I have been in tears in there and they didn't help me. I had flat at fifteen years old but I didn't know how to manage it and got into arrears."
- "[Provider] charges so much that I can't afford to work, as I won't get paid enough. The high rent charged means no incentive for people to get into work, people can't afford to go into work on minimum wage."

- "It is a vicious circle, there is a lack of understanding of needs of homelessness in the services provided". He/she cited putting "tinned food in a sleeping rough pack" as an example of what was unsuitable.
- One interviewee reported that [Provider] had stimulated his/her private landlord to do some repairs, but as he is the one who sold them their legal highs, they still want to stop the connection. However this individual reported that the nature of their past offending makes securing bona fide accommodation exceptionally difficult.
- One individual had an offending background and had been evicted from supported housing. She/he was now living with an elderly relative, in one bedroom flat, sleeping on a mattress in the living room. Concerning housing providers, he/she felt: "I don't think they want anything to do with me because of what I did." They said they were not ready to live on their own and that they could not cook. "When I lived at supported housing, my hygiene was really bad. Now I shave myself and I'm much better."

3.1.3 Comments on service needs not being met

- This individual deliberately hid away from outreach workers when he/she was homeless so that they could not be found. "[Provider] could provide sleeping bags, as they get robbed regularly."
- "I don't even know how I got into arrears. There was a break in my claim when I had my accident. It's then that I seem to have built up arrears. Plus I've got bedroom tax because I've got two bedrooms. I'm happy to move to one bedroom flat, but they won't as I'm in arrears. What am I supposed to do?"

3.1.4 Comments on attitudes

- "You've done a sentence, you come out clean, set all your goals, then you go to reception on the way out of prison and immediately {there's a} bad vibe, so you go to the nearest off licence, so then get steaming. No landlord will take you on then, if you're steaming."
- "Some of the lads who live in the hostels, they get their breakfast then go to [Provider]and [Provider] to get sleeping bags that they only use for begging. "If I change into ***** clothes and sit in a sleeping bag crouching down like a muppet begging..... people use the trains to go to other towns to beg. It has become ridiculous."

3.1.5 What do people want? What would be ideal?

During the course of the interviews the following ideal scenario emerged: having somewhere appropriate and permanent to call home, somewhere with access to both practical and emotional support to help them maintain their tenancy, as well as their personal stability.

- To be appropriately housed meant to be in housing suited to the individual's circumstances. Interviewees commonly expressed great concern about short-term tenancies. They added to their anxiety levels.
- Some felt they had been inappropriately housed and had suffered from the behaviour of other residents, especially if those others were much younger and/or still misusing substances or alcohol. This situation caused them both tension and temptation and they described it as not conducive to their own personal progress and/or their recovery.
- Supported housing specifically designed to help them in their specific circumstance was appreciated e.g. with alcoholism and/or gender specific housing. Generally interviewees valued both practical and emotional support, including being offered a structure to replace their previous lifestyles; help with budgeting, accessing benefits, paperwork in general; and one to one and group support.
- Interviewees talked about the anxiety they experienced in housing provision when the consequence of a relapse was having to leave. Being given a second chance was very important to them.
- Generally interviewees wanted access to permanent accommodation, as they did not feel they could stabilise whilst the threat of becoming homeless again hanging over them.
- Help to navigate through housing application processes, especially where it involved IT, was needed

3.1.6 Summary of learning points

Whilst most interviewees appreciated the help they received in short-term accommodation, its temporary nature generated its own stresses. Permanent housing was seen as a fundamental pathway in stabilising any personal progress or recovery. The pressure came from knowing that another move was inevitable soon, and that it could also involve meeting the conditions of a new provider especially regarding complete abstinence from substance misuse.

Conversely people worried about being co-housed with people with the very same (anti-social) behaviours that they were wanting to stop. Some interviewees spoke of difficulties in sharing facilities with others (especially in hostel settings) with similar compulsive behaviours as themselves. It was appreciated when providers considered each individual's position and support needs: "People are handpicked for each house."

The fragility of their situation combined with the desire to change their behaviours meant that service users were usually very vulnerable. The vulnerability manifested itself in many ways, and the behaviour of other people with whom they were living had a disproportionate influence. Service users could be influenced positively or negatively by those around them.

Regular, reliable support that was of a practical and emotional nature helped service users keep on track. Supported housing that provided a constructive environment and daily structure was also highly valued. The source of the support was less important and it could come from a combination of sources, for example, the housing provider, a visiting agency's support worker, and/or from other residents who had "recovered".

Knowing that they had someone to turn to at times of need and feeling that they were being listened to and respected helped to maintain some equilibrium and hope. Among the positive contributory factors mentioned were: successfully navigating the benefits system, dealing with forms and getting paperwork done, budgeting, accessing appropriate health care, and making contact with families.

3.2. HOW DOES IT FEEL USING HEALTH SERVICES?

Interviewees presented a wide range of health needs. These included those associated with mental health, epilepsy, head injury, diabetes, strokes, injuries and accidents. Many related their general health needs to their lifestyles.

3.2.1. Comments on services that have helped

- "They all treat us all right, like a normal person."

- One interviewee said they had a good GP, "if you can get to see him". Another described the GP he/she had now as “the best one at helping” them, but said that the doctor now worked part time.
- Several interviewees used a facility especially for people with HARM health needs: "Obviously you are going to come across the druggies and alch-ies when they start queuing at {lunchtime}. They're having a can etc. but it’s not bad.” Many received necessary sick notes, scripts and medication from this provider.
- "I do have a GP but I tend to miss appointments because I'm sleepy or I forget." This interviewee reported having a memory problem
- "I go to see my GP, they help with prescriptions for depression and anxiety."
- Several interviewees had found surgeries they described as “good”, usually because their needs had been recognised and addressed by that GP or by a practice nurse. In one case the nurse regularly visited the interviewee
- “[Provider] has links with [Health Provider], so I get to see a nurse when she comes.” This interviewee has seen the nurse once or twice a week, and she had helped him access medical help. "We are all human beings, black, pink, white."

3.2.2. Comments on services that have not been helpful

- "I'm like a cannon waiting to fire off without my meds". This interviewee now went to a surgery they described as good, however previously they had walked out of a different surgery, angry because they felt the receptionist would not process their medication
- “I use [Provider] where I can get a sick note” reported one interviewee, who felt that the service was not properly supervised, that there were not enough staff to control the people attending. He/she said there was no guarantee of getting an appointment, as opening hours were too limited, and the premises were not big enough. "It is only a matter of time before there is a stabbing, one doctor and one nurse is not enough."
- "My GP was terrible. I went to him for help and he said there was no magic pill. He was such an *****, I walked out crying. I didn't understand I was an alcoholic. My GP was arrogant, ignorant and looked down his nose at me. I felt so demoralised, walking out of the surgery. He demeaned me. He was treating me for the effects of alcohol, bad stomach, anxiety, but not alcoholism." ″My GP knew I had long standing problems and advised me to show some spine - I left feeling demoralised"
- "It's just a heroin addict, she doesn't matter"

3.2.3 Comments on service needs not being met

- "{I} didn't use GPs when I was homeless as didn't have an address"
- "[Provider] only opens at {lunchtime}. If they opened at 9.00 a.m. the people with addictions wouldn't be off their faces like they are {by then}."
- A couple of interviewees felt that their medication needs were not being reviewed frequently enough: "I don't sleep at all. Need someone to review my case, review my medication"

3.2.4. What do people want? What would be ideal?

Most interviewees not surprisingly wanted to have regular, accessible, reliable and trusted health services, and to have their health needs regularly reviewed so they could confidently pursue their personal goals and/or recovery process

- The majority of interviewees were accessing health services whether through general practice or tailored facilities. The most positive experiences arose when they felt they were being treated with respect and empathy, when they built up trust with a particular medical practitioner and when they felt sure that the healthcare professional understood their needs in the round when prescribing medications or other interventions.
- Whilst a sustained relationship with a trusted medical practitioner provided the best basis for ongoing healthcare, the changeable and challenging circumstances often characterising their daily lives often made this virtually impossible. Interviewees spoke of times when their medication was not being monitored or reviewed. Any perception of being neglected left them feeling devalued, especially if experiencing negative side effects from medication.
- Problems experienced with opening hours, getting appointments, although of course also experienced by the general population, are more of a challenge for chaotic individuals especially those in need of crisis help. Many spoke of the need for a bespoke 24-hour health service.
- Several interviewees were following an active recovery programme; most of these spoke of having a good relationship with their GP or another medical practitioner.

3.2.5. Summary of learning points

Many interviewees said that they had found it difficult to access to regular health services, especially when homeless. Some felt that when they did access a health service, they were not taken seriously "[the doctor] knew I had long standing problems and advised me to show some spine"; fobbed off "It's just a heroin addict, she doesn't matter"; or patronised or neglected in some way. Being offered inappropriate interventions was a frustration, as this appeared to reinforce any feelings of not being taken seriously, of not being listened to and hence of not being in control of one's own health.

Where health services had worked well, interviewees spoke of securing regular access and the importance of a good relationship with a particular doctor or nurse. However given the challenges of homelessness and/or temporary accommodation as well as their very challenging health needs, this is not always possible.

3.3. HOW DOES IT FEEL USING MENTAL HEALTH SERVICES?

- "I have depression and anxiety, am constantly tired."

<u>3.3.1 Comments on services that have helped</u>

- "My offences are related to mental health problems and alcohol." The interviewee had Obsessive Compulsive Disorder (OCD), psychosis, anxiety, depression and paranoia and was now receiving PIP. He/she had been off medication for three months, but was now back on it. "It's like I've got a demon inside me and it's waking up. You need to give me my meds."
- One interviewee reported that [Provider] had helped him have more motivation, be more self-reliant, and not to depend on others. The three years of mental health support had been very good.
- One interviewee had been diagnosed as bipolar. He/she gets prescriptions from their GP and [Provider]. The [Provider] had a nurse who checked on their mental health.

- Another interviewee reported having anxiety and depression and used [Provider] services. They used to come out to him mainly, but now he went to their offices. Talking and medication had helped him; "I actually feel as though I have people to help me."
- One interviewee had been seeing a psychiatrist "for a while": "I suppose it's helpful. I expected someone to help me untangle my past life, but now I've just realised it's about my future life."

3.3.2 Comments on services that have not been helpful

- One interviewee had been on anti-depressants for 15 years. He/she reported that no-one ever noticed they needed a mental health programme.
- One interviewee had had a two month wait for [Provider] but was now receiving support.
- Another interviewee reported that they had used [Provider] for over five years, but that he/she had not found it helpful and found the programmes not very constructive.
- "I got out of prison earlier this year, but it's been a hard few months". He/she could not get their medicines due he/she said, to an administrative error: "workers and psychologists couldn't see that I needed them {medicines} urgently, it's confusion."
- One interviewee reported that they went to [Provider] but that they "didn't click" with the previous worker and was now waiting to be allocated a psychiatric nurse.

3.3.3 Comments on service needs not being met

- One interviewee reported that they had recently started getting support from [Provider]. He/she wants to be stabilised, but has anger issues and was hyper, wanting sleeping pills. The interviewee also said that they wanted to be pushed forward to deal with their problems.
- One interviewee reported that he/she used anti-depressants: "feels stressed out all day, every day". They said they needed something to calm them down. They didn't want to go to [Provider], as they wanted to restrict the number of agencies they were involved with.
- Another interviewee commented on using mental health services as a Trojan Horse to reach the services he/she really needed: "I have to register myself as [a] mental health patient to get the help I need, when you don't need to. You have to label yourself. You're trying to make an effort to assist yourself, as long as you're strong minded you can carry on. If you're not strong minded, you end up doing petty crime, shoplifting and so back in that circle and you can't get out."

- Another interviewee said that he/she had a history of paranoid schizophrenia and had been taking medication but then came off it. He/she started misusing substances and left their home town, arrived in Birmingham and set about getting arrested as a means to get access to the services he/she knew they needed.
- "My mind is telling me to do one thing and I do another." This interviewee was commenting on their anger issues and wanted to get back with [Provider] again for help with this. This interviewee was taking epilepsy and antidepressant tablets. He/she reported that the latter were addictive: "I leave them at my {family member's} so I don't take more than I should. I get a kick out of them".
- "My fits got worse when I was drinking 'cos I wasn't taking my tablets regularly".
- Another interviewee said that mental health crises needed to be resolved by medical help, rather than relying on interventions by police officers.

3.3.4 What do people want? What would be ideal?

Many interviewees wanted recognition that they needed psychiatric and therapeutic help with their mental health, and not just prescriptions for antidepressants. To be effective however such 'talking services' needed to be appropriate to the individual service user and be available at a time that was right for them and their personal journey to better health.

- Interviewees who had been diagnosed with a mental health problem appeared better able to access specialist services, although the experience was not always as positive as they would have liked.
- Many favoured talking therapies combined with medication, to take place over a period of time in keeping with their circumstances and needs, involving sharing and dealing with some of their deepest issues. Interviewees felt that having the "right" support worker and the "right" medical support were essential to making any progress. Positive support could come through specialist providers as well as GPs, so long as the practitioner supported them as an individual, and prescribed and monitored them as a patient.
- Not being listened to and taken seriously has been an issue, particularly when interviewees recognised that some of their behavioural challenges were due to the state of their mental health. Access to mental health support was often limited and/or inappropriate.

- The anxiety and depression experienced by many of the interviewees was often undiagnosed. Without being defined as having mental health problems access to specialist help was difficult.
- Whilst interviewees in the main accepted that mental health services were limited for everyone, several reported having to wait for appointments long after referral. As well as long waits interviewees expressed some frustration about the frequency of monitoring and review, and inconsistency of support.

3.3.5 Summary of learning points

- *"Without a cry for help, there isn't a service available to you"*

Interviewees had a very wide range of experience of mental health services. The most common mental health issues mentioned were anxiety and depression, but many also suffered complaints such as paranoid schizophrenia, personality disorders and being bipolar. Some recognised that their offending behaviour directly related to their mental health problems and anger management was frequently mentioned.

Although 40% of the interviewees had had a mental health diagnosis, other interviewees were in the process of securing recognition and specialist help. This suggests that mental health issues are pervasive, whether as a cause or an outcome of other behaviours. In a few cases individuals resisted the label of being mentally ill.

Some interviewees had not known where to turn for help, especially in time of crisis. Being unable to articulate what they were experiencing, and feeling that they would not be listened to, were mentioned as barriers. Some of the interviewees talked about deliberately displaying antisocial behaviour or committing offences as a mechanism to access help. The feeling of being fobbed off or treated in a tokenistic way exacerbated their frustrations and added to their challenges.

The combination of being respected, trusting the provider and gaining access to "right" support at the "right" time was seen by interviewees as essential to giving them the opportunity to move on.

3.4 HOW DOES IT FEEL USING SUBSTANCE MISUSE SERVICES?

- "I am still rattling today, I'll spend a few minutes with you and then I've got to get a drink."
- "Being an alcoholic is a full time job, and not a very pleasant job at that."

3.4.1 Comments on services that have helped

- "Everyone finds it hard, having been in the madness, lots of things can trigger you. Staying clean is hard." This interviewee had been helped by his/her GP to get into a detox facility but they had relapsed one day before the end. Despite the relapse they still felt ready for detox - "the time was right".
- One interviewee said the prison arranged for rehab straight after their release and [Provider] helped with it. He/she reported that in that facility patients have to "rattle it out", with no medication. He/she valued the fact that after completing the supported detox, there was a further eight weeks of support with social integration as well as help with housing.
- An interviewee said that they had not wanted to attend [Provider] because "they're all God folks, but now I'm a grateful and dedicated member", going to three meetings a week.
- Another interviewee felt that recovering alcoholics needed access to medication to help with feelings and pain, which they didn't currently get. He/she had just started with [Provider], and was finding it difficult to say "I'm an alcoholic".
- One interviewee found receiving accommodation and other support from a [Provider] whose focus is specifically women with complex needs had helped them
- "[Provider] have been amazing, they did care plans and I had to show motivation by going to groups before detox. I had weekly one-to-one sessions with the support worker and attended various group meetings. I did the detox at home supported by a nurse, but not isolated." Group sessions were still available to them.
- Another interviewee reported that [Provider] supplied them with a "sponsor", an ex-alcoholic to help them as well as three weekly meetings.

3.4.2 Comments on services that have not been helpful

- "I was with my worker from [Provider] for several years. He wasn't any good because he made appointments every other month for 4 months, but there was no follow through. I told him I was addicted to heroin and other drugs, and he asked if I wanted to start a Stop Smoking programme."
- This interviewee reported that it took ages to get a response to phone calls to [Provider]: "They finally told me to go down to see them, I went with a bowl in my lap. Then nothing."
- One interviewee felt that"[Provider] has interrupted my recovery completely, I was fighting my heart and wanted to get help and nothing happened."
- Another interviewee reported that [Provider] had offered accommodation but asked him/her to leave when they relapsed. He/she said that their possessions were simply thrown in bags on the path outside, which was humiliating. Then he/she went on a binge, had fits, and had to use the ambulance service.
- Another interviewee said that their drugs worker only saw them once a fortnight, which was insufficient.
- One interviewee reported that he/she had been on methadone for about a year, and used to see a worker every two weeks, but "I no longer have regular appointments. I need a reduction programme to detox. [Provider] is letting me down, there's not enough structure in place; there is a gap in services. My body is rejecting the dose I am on. I would like my support worker from [Provider] to chase this up."
- Another interviewee said that" [Provider] didn't work for me as too many others were there for substance abuse, not just alcohol, it was too generic".
- Another interviewee said that they had been into hospital several times since methadone withdrawal as it was making him/her sick. They said they needed more help.
- One interviewee reported that talking therapies had not worked for him/her. They felt that being a manual worker he/she would find practical help more useful in getting their alcohol consumption down slowly and at a healthy rate.
- A different interviewee felt the opposite: "[Provider] weren't much good, they told me to fill in a drinks chart and he just told me to cut down. They said that it wouldn't work for me to cut down, I need to stop completely." He/she said they attended group sessions but that most of the people were there just to get bus fare to buy more drink. "Outside they were slugging cider... so I never went back".

- Yet another interviewee commented that as [Provider] advocated controlled drinking there was no point for him/her in engaging, so he/she “dumped them”.
- One interviewee had a new worker at [Provider]. In all the years they had been using services this was the first time they had been offered detox.

3.4.3 Comments on service needs not being met

- "Addiction makes you lie to support your habit."
- "The only time I did detox was in custody. You try getting into detox, it takes months. In prison you have a seven day detox with medication and then you’re left to own devices. You can see [Provider] alcohol worker if you're there on the day for a one to one discussion."
- "My panic attacks are getting worse, because my drugs have not been reviewed for over a year. I need a new drugs programme" commented another interviewee.
- Another interviewee said that they needed “a nice, compact tight package of support, I need this, we all do". He/she wanted to not have to tell their personal story over and over again, as it felt like this precipitated their drinking.
- "I would like regular appointments and follow up appointments and a scheduled recovery programme".
- "I just don't understand why I do it {use heroin}. I want the right help at the right time for the right length of time. I need it now when I'm ready, not wait for ages when I might change my mind."
- "[Provider] kicked me out when I started drinking again."
- "I've detoxed myself at home over a couple of days, but it doesn't stick. You need residential support, then support from workers and {to} go to meetings to look at triggers etc. A peer mentor once or twice a week to say ‘I felt like using today’, thinking about triggers and resilience."

3.4.4. Other comments

- "Picking up the phone is hard when you're in the madness of addiction, you don't have the money, a phone etc., so it's hard."
- Another interviewee who is an alcoholic, said they were trying to keep down their service use as they did not want to keep going over things again and again.

- "I was drinking a litre of vodka a day and three or four bottles of cider. My {family} were distraught. I admitted that it was beating me."
- "I'm addicted, if it's there I'll have it. It feels like my best friend, I don't want to come off it. I don't spend on extravagances, and it's not much compared to what people spend on drink." This interviewee reported that psychiatrists had offered drugs treatment, but he/she wasn't ready to go for it.
- "It's not a drinking problem I have now, it's a living problem. I still have anxiety."
- Another interviewee reported that they go the gym three or four times a week to keep their endorphins up. "I always go out for an hour to make sure I physically engage with the outside world during the day, to do something normal."
- "I am vigilant with my feelings now. Alcoholics are wired differently to you. Alcoholics are really manipulative."
- ″I've been on 60ml of methadone for last year, but now {I'm} still on it, {I} need a reduction programme to detox". Interviewees spoke of being on a medication programme that was no longer relevant.

3.4.5 What do people want? What would be ideal?

- The interviewees wanted packages of tailored help to deal with their particular type of substance misuse. They wanted it available at the point that they felt ready to engage, rather than going on a waiting list. Building up courage to ask for help was always a big step, and interviewees often referred to the disappointment incurred by a long wait.
- They felt that having follow up support after a detox period helped prevent relapse. Many felt that post detox support was inadequate. Most interviewees thought that the best option was a recovery schedule coupled with supported detoxification and follow up support.
- The fear of failure was commonly expressed, which seemed to put some individuals off from embarking on a recovery schedule. The feeling was of only having one chance, so finding the right time to undertake detox had become more crucial than ever.
- They felt it was important to know that there can be a second chance, to reduce anxiety and fear of failure. A key part of post detox support was learning how to deal with triggers, so they wanted to learn coping strategies.

- Most of those that wanted to embark on a recovery programme expressed the same need, and shared a history of trying to detox on their own but of being unable to maintain it.

3.4.6 Summary of learning points

Interviewees talked about their experience of a range of different services and it became clear that trust in the service provider and a good relationship with support workers added significantly to their chance of success. Service users needed to build their trust and confidence, and needed to experience consistent support both to enable them to detox and also to address underlying and long term recovery issues. Many interviewees referred to "not being ready" and how the fear of failure can add to anxiety.

Those that had more recently undertaken a detox programme had been grateful for the follow up support afterwards. Another significant factor identified was to have accommodation free of others still currently misusing substances.

They spoke of their need for regular, frequent contact and for this to be in the context of a scheduled recovery programme specifically designed for them. It was very challenging to navigate services when in crisis. One interviewee told of deliberately offending to attract the police who he/she felt would help refer them to access the service they needed. When people with addictions ask for help and then do not get a response, they report feeling despondent, a rejection like this can trigger a downward spiral and can become a barrier to asking again.

3.5. HOW DOES IT FEEL USING ACCIDENT AND EMERGENCY SERVICES?

- "I have a fit when I rattle sometimes, so I go to A&E".

<u>3.5.1 Comments on services that have helped</u>

- "The nurses are great, and the referral team are good". The police and ambulance service had taken this interviewee to A&E several times after an overdose, and when drunk.
- "I cannot fault the ambulance at all."

- One interviewee reported having been rushed to A&E more than once, "usually when I'm down.... I start cutting myself".
- One interviewee reported frequent anxiety and panic attacks and problems with methadone dosage. He/she said they often ended up in A&E.
- Several interviewees reported that sometimes A&E staff suggested organisations which might help them, which they recognised as well-meaning.

3.5.2 Comments on services that have not helped

- "They said I wouldn't co-operate, but I was swearing at the pain."
- "She's just a heroin addict, she doesn't matter."
- One interviewee reported that a nurse refused to give him/her something for physical pain, even though the doctor had authorised it; "She thought I just wanted more drugs."
- One interviewee reported that he/she had been taken into hospital by ambulance on having a seizure. He/she was treated well but when discharged, had no money and had to beg there and then to get the bus fare.
- "I was taken to A&E as suicidal threat, {they} didn't admit me." This interviewee reported self-harming and that he/she had wanted to be sectioned but that they gave them a cup of tea and sent them on their way, even though he/she told them "I can feel myself going. A couple of weeks later it all happened and I ended up in prison." He/she felt that they hadn't picked up the warning signs; "I think I was having a breakdown, doing mad things like smashing things, I was at breaking point, but no help in this instance. {They} have been all right on other occasions."
- An interviewee reported ending up at A&E when on legal highs but after waiting so long they re-orientated themselves, realised it was the legal high that had caused the seizure, walked out and came home. They still had a syringe in their arm.

3.5.3 Comments on attitudes

- "They need to really listen to you more …..some of them just have attitude."
- When he/she had an asthma attack, A&E staff said "Do you know that addicts cost us a grand to come and collect them?"
- "I've lost faith in {the} NHS".
- "My GP advised me to call the ambulance when infection got very bad, but the paramedics wouldn't take me to hospital"

- "I hate A&E, they think I'm a waste of their time. This is what you feel from them".

3.5.4. What do people want? What would be ideal?

The ideal for most of the interviewees was to be able to access A&E when needed, and not to be judged because of their circumstances. Many interviewees expressed gratitude for the service received when they were in crisis, and commented that the staff were really helpful. One for example, cited a good service on repeated occasions when suffering the effects of alcohol withdrawal.

Others considered the service to be poor with prejudicial behaviour towards them. It made them feel more frustrated and negative. Inter-personal relationships with A&E staff were so often commented upon that it is clearly important.

3.5.5. Summary of learning points

A&E is unlikely to be able to address the underlying behavioural and addiction issues behind the presenting health issue. Attitudes towards 'deserving' and 'undeserving' patients appear to exist though are not widespread. When they felt they were being treated with respect, the service was seen as okay, but feeling they were being viewed "as just an addict" added frustration to an already troubled situation.

In recommending other agencies that might help, A&E staff are clearly trying to be supportive, however at discharge many individuals felt left to their own devices. It was the inter-personal relationships with A&E staff that mattered emotionally to interviewees.

3. 6.HOW DOES IT FEEL USING SERVICES FOR TRAINING AND EMPLOYMENT?

- "I want to live, not just survive. I want to work, not sit on benefits."
- "I'm just getting my housing and health in place, stable. I'll go on to this in the next stage. I keep things in order."
- "I have to get up and about. I don't like sitting around, I like keeping my head occupied."

3.6.1 Comments on services that have helped

Many interviewees were engaged in or had recently completed a range of activities including:

- Vocational training (an NVQ horticultural taster course, a woodwork course; a Level 1 Diploma in Motor Vehicles. One interviewee was waiting to go on a course and hoping to get a card to go on construction site);
- Personal development training (mainly Anger Management and Offending Behaviour training);
- Volunteering (volunteer activity in the open air was attractive to many).

All interviewees were unemployed, though many had experience of employment earlier in their lives. For example one interviewee used to be a window fitter and had been self-employed. He/she had done odd jobs voluntarily helping older people and was now thinking of volunteering again, possibly at local charity shop. Others had worked in catering, food production, construction.

- One interviewee explained "I used to do a little cleaning job. I liked just to have my independence. I want to go into detox so I can work again."
- One interviewee said "I want to get a job eventually." He/she did not get any qualifications at school
- One interviewee was a qualified bricklayer and wanted to get back to work: "I'm not ready for it yet, so wouldn't last, so I'll just wait till my meds are sorted."
- One interviewee who had just finished a second Anger Management course wanted voluntary work with animals.
- One interviewee reported attending a Job Centre where they previously lived that had staff specifically to deal with people with difficulties, so it was easier to talk. He/she was worried about moving to a new Job Centre and hoped that the new one would have the same service.

3.6.2 Comments on services that have not been helpful

- One interviewee said "every time I go to a Job Centre I end up crying I'm so stressed. It's horrible, but I'll see how I get on this time".

- Another interviewee said that it was difficult to sort out benefits by phone with long waits for a reply, and then getting cut off because the office was closing.
- One interviewee commented on their experience of having an assessment for Employment Support Assistance; "It was ridiculous, they don't see alcoholism as an illness. They asked me if I washed every day, it was degrading. I suffered anxiety, had to go on buses and then when I got there they cancelled my appointment. They'd left a message on my phone but I'd already set off. They couldn't have cared less."

3.6.3 Comments on service needs not being met

- One interviewee would like some unpaid work so that he/she can build up a CV. They expressed an interest in helping older people. They are aiming to bring structure to their day recognising that they need to be stable to do this.
- Another interviewee said "I would like to be more active, I want to do lots of things, but I just {don't} know how to go about it."
- One interviewee who had been on ESA for a long time said "I would like a job gardening to get out of {the} hostel." He/she said "the best thing that is happening is I'm getting an allotment. I'll be able to grow things, flowers and things like that." They planned to be at the allotment once or twice a week, giving some structure to their time.
- One interviewee had done some voluntary gardening at {the} hostel and the [Provider] was looking for allotment-based voluntary work for him/her. This interviewee also mentioned plans to go to the library soon, as they read a lot.
- Another interviewee expressed an interest in doing some voluntary work close at hand, for example at the local care home. They had worked in a cafe but had had to leave because of their epilepsy.
- Another interviewee wanted some more IT training to be able to get into the type of work better suited to their lifestyle and health issues.

3.6.4. Other comments

- One interview said "work is a bit of a way off at the moment."
- Another interviewee stated that they wanted to be a recovery coach but needed another twelve months to consolidate: “I'm still getting to know myself."
- One interviewee said they did not need to job hunt, as they were not able to work "cos I'm an alcoholic as well as on methadone."

- One interviewee spoke of needing qualifications and the paperwork to be able get into work, and felt that apprenticeships were for younger people.

3.6.5 What do people want? What would be ideal?

- Interviewees spoke of not being ready to think about training or employment, such committed activity could only begin once their lives were more stable.
- Many interviewees were not yet ready to think about finding paid work. However some did see benefits in volunteering both as a route into work, developing new skills and interests and helping with their wellbeing and social integration. Some of the interviewees were interested in training opportunities and gaining new skills so to help them find employment.
- Some interviewees said they were strongly motivated to undertake training to help improve their skills and to manage their behaviours as these could lead to employment
- Several spoke positively about the training and volunteering opportunities with which they were involved. Being engaged in constructive activity is generally perceived as helpful. Many expressed an interest in being outdoors as they said being in the open air helped them feel better.
- For some, engagement with the benefits system had proved stressful, difficult and worrying.

3.6.6 Summary of learning points

Some interviewees articulated concern about their future financial stability, but acknowledged that they were not currently in a position to pursue employment. Many are keen to do employment-related training courses, mentioning for example, IT skills, bricklaying, and mechanics.

As well as upskilling, most expressed the need to be doing something constructive and for those in hostels, something to give structure to their day. They often focused on volunteering. Of those who expressed an interest in voluntary work, the majority were already doing some.

Many expressed a desire to help others. Being in a position to help others is a well-known strategy for people in recovery programmes. Some interviewees expressed an interest in being a mentor for others experiencing multiple and complex needs.

Some interviewees were attending Anger Management and Offending Behaviour training but no comments were given about the usefulness or otherwise of these courses. Negative feedback in relation to accessing benefits came from a few of the interviewees.

3.7. HOW DOES IT FEEL USING CRIMINAL JUSTICE SERVICES?

Several interviewees said they had been involved with the criminal justice system. A wide range of offences were mentioned including serious assaults, petty theft and shoplifting and being drunk and disorderly. Others replied vaguely to the question and were unwilling to talk about it. One interviewee referred tangentially to her experience of a prison mother and baby unit and of giving up children for adoption. Most had mixed feelings, reflecting perhaps the very direct power of the system itself to deprive them of freedom, as opposed to help and support received when within it. A few said they had not had any contact with criminal justice services.

3.7.1 Comments on services that have helped

- One interviewee described getting himself arrested for shoplifting in order to get help. They found the police were helpful.
- Some interviewees reported that the police had tried to refer them to providers.
- One interviewee who was out on licence praised the weekly appointments with his/her Probation Officer; "She keeps an eye on me, the best she can do really." It was important because "if you miss two consecutive appointments, you get recalled". "I try to keep on top of things, keeping a low profile helps"

3.7.2 Comments on services that not been helpful

- This interviewee described this pattern of behaviour for the last three years, interestingly a very similar cycle to the one described by another interviewee who had also been in prison (see 3.2.4 p.25): "Every time I was released I was positive, but once you're in

reception you begin to break up. They will only tell you to go homeless accommodation. That's a negative vibe, so it pushes you back into your addiction, mine is alcohol, so before you even get to the homeless accommodation centre, I'm steaming. I've been to nearest off licence."

- "{They} didn't do nothing for me. They said they couldn't help me. You'd have thought that {they} wouldn't have washed their hands of me given that I'm an ex-prisoner and at risk of reoffending."
- "They just chuck you a phone number and a map".
- "I don't like {them} and they don't like me, they're bullies. There's good and bad in all organisations. There was one who was good and came to check on me, but that stopped. I'm suspicious that she was just after stuff for the anti-social behaviour thing. "
- {They} just move homeless on….They could stop hassling you and instead tell you where you can go, stop threatening you with arrest. 'Take yourself away from everyone' that's what they want."

3.7.3 Comments on service needs not being met

- "Need more support after leaving prison, it is a struggle"
- One interviewee arrived with a volunteer. She said the interviewee had a head injury but that no social worker was involved. The interviewee had had volunteer support after release but that this was now coming to an end. "He sits in the background, not one to draw attention to himself. One day at reception at {service} they forgot about him, they didn't know he was there." She felt that the interviewee needed someone to structure their time.
- "No contact, I was always asleep."

3.7.4 What do people want? What would be ideal?

- Those interviewees that had been in prison valued post-release transitional support. Also community sentences were seen as an opportunity to access structure and support. There was a level of practical support needed, for example, in securing accommodation, organising health care and registering for welfare benefits.

- Being treated with respect and not being subject to assumptions about their circumstances and condition was also appreciated. Interviewees felt that some police officers assumed they were begging for money for drugs, when they are in fact they were begging for money for food. Specific police officers who had been particularly helpful were singled out for praise.

3.7.5 Summary of learning points

Many of the interviewees had convictions, many of which had resulted in prison sentences. Again, as might be expected, many of the interviewees distrusted criminal justice agencies, though there were many exceptions made for particular staff who had adopted a friendlier or more caring approach.

The lack of capacity of the probation service to provide support after the probationary period was highlighted as an issue. Also the level of support on leaving prison was perceived as inadequate and as leaving people vulnerable to returning to old behaviours. Many felt they had to find out for themselves where to go for housing, money and health and social care.

Feelings towards the police were also mixed: a general observation was that they simply moved them on without referring them to other services. At an individual level however some mentioned specific police officers whose little kindnesses had gone a long way with this group.

3.8. HOW DOES IT FEEL USING BCFT SERVICES (MAINLY THE LEAD WORKER AND PEER MENTOR PROJECT)?

- It's as if they do the work of several agencies. They bring everything together for me."
- "This is the first time I've had a proper process and can get everything in perspective"

<u>3.8.1 Comments on services that have helped</u>

- "I wouldn't have done all the stuff I do now without her, she nudges me along."
- "I had the shakes, I couldn't fill in forms, I couldn't think or write. It was just great that my Lead Worker could fill in forms for me."

- "My Lead Worker comes to appointments with me, which helps you not to get het up when you're waiting."
- "She has helped me from when I'm really, really low till now"
- ""I was in such a state that if I hadn't got this help I don't know what I would've happened. I was psychotic, in a bad state." The project had helped the interviewee to access benefits.
- "Just talking to the Lead Worker and arranging and organising things is helpful, organising appointments and stuff like that. They help with benefits appeals forms. "
- Another interviewee reported "there is a 100% consistency with my Lead Worker. He has gone above and beyond what I could have expected." They said they can tell their Lead Worker everything and that they connected well and it was a comfort that they could be with their Lead Worker for several years.
- "The Lead Worker is great, he is professional, but it's personal as well. He comes out every week and is always looking at things for me to do. Completely different to "[Provider] who just chucked me out. They will keep me on their books for three years."
- One interviewee wrote to BCFT before leaving prison, having served a long sentence. He/she explained that on release "I was outside the gates and they gave me a bus pass, toiletries etc. I was already going into a Probation Hostel." He/she explained that they now have three workers, the Lead Worker, a Peer Mentor and a housing support worker. They too said the Lead Worker could provide support for several years and that this was good.
- "She has helped me from when I'm really, really low till now. I'd recommend anyone to go there." This interviewee explained that they had had contact with a Lead Worker for a year and that the worker had visited them when they were still in prison.
- Another interviewee explained that the Lead Worker had found them homeless with no income, living on the street and brought them into the project. "If they hadn't helped me I'd still be on the streets or in hospital."
- One interviewee said that having regular personal support, and getting practical everyday help was valuable: "You need both emotional and practical help, I don't have to watch what I'm saying. I feel more comfortable when she comes on her own. She makes sure I get to appointments on time, she's on the ball."
- Another interviewee remarked that they would like the option to check in with their support worker after they had completed their programme.

- Being able to use the project's computer to access social media and keep in touch with family was appreciated by interviewees.
- One interviewee reported that the project had helped them sort themselves out physically and emotionally. The workers had also helped with a housing application and as a result, he/she got extra points and moved into sheltered housing.
- "Without this place don't know where I'd be"
- "Lead Worker has gone above and beyond what I could have expected"
- "I haven't spoken about my problems so everything festered and escalated. Now I can tell Lead Worker stuff"
- One interviewee felt that the regular case reviews and being able to check progress on score sheets was useful.
- One interview commented that the Lead Workers and Peer Mentors initiative was the main service making Birmingham better for the homeless.

3.8.2. No adverse comments were made by any interviewees about BCFT services

3.8.3. Comments on attitude

- "She bends over backwards to help. I've had support workers in the past who've belittled me and patronised me. She always cheers me up, she always has a smile on her face." She was now helping him with banking and voluntary work. In the past she helped with food parcels etc. "She does make a big difference, she certainly does, she certainly does."
- Another interview stated "text book crap, I thought that's what the Lead Worker would be like, but I was totally shocked, he has so much empathy for someone who hasn't had an addiction problem themselves."
- "He's like my mate, I can trust him, I'd rather have him there than some stranger. He stops me going off the rails and arguing. He came to the training course with me, comes into meetings with me, so he helps with interpersonal relationship. Really important to have someone like him around." This interviewee also said that having a long term support worker was really good.
- "You're so used to being isolated as an alcoholic that you need social contacts. We don't want people to tell us the answers as alcoholics, we just want someone to listen to us, let us vent. Body language is really important, we don't want that leaning forward in a chair

with patronising tilt of the head." This interviewee saw Lead Worker support as filling this need.

- Another interviewee said: "Peer mentors, I think they're brilliant. It's not all about text book. Needs to be someone who won't ask stupid questions. It has definitely helped, I will stick with them. I see them once a week. I've got my whole life in front of me - hopefully."

3.8.4. What do people want? What would be ideal?

- The majority of interviewees stated that having a worker that they could rely upon to provide both practical and emotional support, and to help them with personal challenges as and when they arose, was extremely beneficial. They very much valued being able to have a long term relationship with their workers, as it gave them space and time to rebuild their lives at a pace appropriate to them, and to make mistakes without the risk of losing the support.
- The importance and value that interviewees attached to the roles of Lead Workers and Peer Mentors cannot be overstated. Interviewees appreciated their intensive, comprehensive and consistent support. All interviewees felt it was helping them to achieve some stability, and to deal with their priorities. Many interviewees had been assisted to address their housing and health needs and now that they had achieved some physical stability, workers were helping them to think about other aspects of their lives.
- The consistency of the support of Lead Workers and Peer Mentors regularly featured as an enormous positive. Their capacity to respond to clients' needs as and when they arose was said to be of great value. Trust was built up gradually, through repeated contact with the same worker, and this trust was tested each time a new crisis arose when workers made themselves available. The flexibility and commitment shown by workers must be applauded. They appeared to provide essential continuity and all round holistic support. It is hard to see how service users, concurrently handling multiple complex and intense issues, could ever negotiate services or navigate service packages without their support.
- Interviewees often said they were eligible for long term support over several years and that this commitment was important to them.

3.8.5 Summary of learning points

The Lead Workers and Peer Mentors service was spoken highly of by all those who had contact with it. The most important aspects to interviewees were: having regular contact with someone empathetic with whom they could discuss their issues, someone who would help with a range of needs, and who didn't just tell them to go to a different provider, but actually helped them to navigate their way there. They appreciated the way that workers knitted services together for them, and did not leave them stranded and confused, not knowing where to go.

Lived experience was also valued. They valued having contact with someone who understood their challenges from first-hand experience and understood what kind of input or response would be most effective. The lived experience brought into the programme by Peer Mentors was mentioned in particular. Having a non-judgemental attitude built up trust and respect and reduced interviewees' fear of making mistakes, as they knew they would not be turned away by their worker as a result. Not having this pressure, combined with getting support with all aspects of their lives at a level and pace appropriate to them, was seen as a winning formula by many.

The phrase "going the extra mile" was often referred to in relation to Lead Workers. Those interviewees who already felt they were making progress often attributed their being stronger both physically and emotionally, to their relationships with their workers. This relationship seemed to encourage them to persist, and even if they had relapsed, to try again.

Interviewees greatly valued not having to repeat their personal histories over and over again, as the workers often intervened. They also felt their workers could sometimes foresee when they were likely to forget to do something or be at risk of not continuing with a course of action, and that they helped them to avoid such pitfalls. For instance, workers frequently phoned them with prompts for appointments, or accompanied them to them, both of which interviewees found very reassuring.

A comment regularly made by interviewees related to the sustained length of time Lead Worker support would be available, over several years. Whilst the potential long term nature of Lead Worker support was reassuring to them, it does raise the issue of transition planning in order to pre-empt dependency. The findings from the BCFT Beyond the Basics pilot project in encouraging independence will be important in this instance.

3.9 RESPONSES TO SUPPLEMENTARY QUESTIONS AND ANY OTHER COMMENTS

Towards the end of the interviews, interviewees were asked for a general comment on “What would be ideal in the future?". They were invited to talk on any subject that they wished. Many reiterated comments they had made earlier about services (see below on health and housing), but some points were new (see below on transport and personal relationships):

3.9.1. Personal relationships

- "To stop using alcohol and see my daughter"
- "Not losing my girlfriend, or family or my health due to drinking"
- "No more racial prejudice, promote unity"
- "Like to stop alcohol completely to see daughter in few months’ time"
- "Want to stop telling my personal story over and over again"

Relationships with family were mentioned by several interviewees at this point. Those who had contact with their families had concerns about being able to maintain those relationships, not only during chaotic periods but also during their process of recovery, being anxious about being rejected if they relapsed. Others talked about how they would like to rekindle relationships with family members from whom they had become estranged because of their substance misuse or behavioural problems. Some interviewees had experienced long separation from their children and were keen to prove that they were able to reconnect. One interviewee mentioned “family counselling …. to talk about relationship difficulties". Another interviewee wanted a home so that he/she could “have a family”.

3.9.2. Housing

- "Housing is the biggest issue"

The comments about accommodation and housing reinforced the findings set out earlier in this chapter. The housing shortage was recognised, with one interviewee suggesting that empty homes be brought back into use. Housing security was the primary issue. “To live somewhere permanently to call home” and not having to worry about having to move to another temporary situation, was the major theme. Some interviewees reinforced comments made earlier about some zero tolerance hostels: "hostels need to change their approach, we need a gently sloping

ramp" and felt that they all ought to give tenants “a second chance, which some hostels don't do". All the interviewees who commented here felt that having housing security would go a long way in helping them to rebuild their lives, as it would provide a sanctuary and a solid foundation, an opportunity to put roots down and to begin to address their many challenging issues.

3.9.3. Health

- “A 24 hour helpline"
- "Better access to medication when needed and regular reviews"
- "To get good supervision of my medication and see the danger signals to react earlier"

Comments made here about health reinforced previous comments on this subject. Access and the anxiety of not being able to get help when most needed emerged as key issues again. Interviewees felt that not being able to find appropriate support at the right time had sometimes led them into even further difficulties.

3.9.4. Transport

- "Bus passes are needed"
- "Mobility scooters made available"

Being able to get around was also important, and interviewees said they were relieved when they could afford to travel, so bus passes were very helpful. One interviewee mentioned the need for a mobility scooter, saying that they wished there was a hire scheme that provided them at low cost.

3.9.5. Volunteering and Training

- "Get out more, do some volunteering"
- "IT training so I can get work"
- "I want to help other people who really want help with drugs problems"
- "To be straight and help others with drug problems"
- "There should be a waste food collection scheme, should get unused food from supermarkets and clothes donated from shops"

Many interviewees saw volunteering as a way of not only of being usefully engaged and introducing some structure into their lives, but also as a way of rebuilding feelings of self-worth,

and offering something of value to others. This again raises the issue of rebuilding self-respect. A small number of the interviewees expressed an interest in helping others with similar problems to their own, as they had valued the lived-experience support that they had received from Peer Mentors. One advocated a voluntary clothes and food donation scheme specifically for homeless people with multiple needs.

3.10 BIRMINGHAM COMPARED TO OTHER PLACES

Interviewees were asked if they had experience of services in places other than Birmingham. The majority of interviewees had lived in Birmingham for most of their adult lives, many had been born here. Of the seven interviewees who could comment on differences, three mentioned the following:

- One interviewee felt that there are more people on the street in Birmingham, but was not sure why: "So you see you are falling off a brick wall all the time."
- Another interviewee was not sure that there were in fact more people sleeping rough in Birmingham, but did think that people came into the city just to sell the Big Issue and specifically to beg. He/she said they had a friend who went to London to beg.
- "Birmingham has more empty properties than any other city in Britain".
- Other interviewees commented that Birmingham is more multi-cultural than other places, seeing this as a positive element.
- One interviewee had grown up in a small village and had lived in market towns before coming to Birmingham. He/she said "there is nothing much available in terms of services and leisure. Everyone knows your business, and you're very visible. I did look for help in {Place Name} for drinking but when I went in, it was my friend's sister, so I shut the door and never went again". He/she valued both the anonymity in Birmingham offered and as well as its access to more services.
- One interviewee had had experiences of services in London and said "there is nothing in London comparable to this..... London is overwhelmed. Here in Birmingham they chuck people at you."

Interviewees appreciated the range of services being offered in Birmingham on the whole, and particularly when compared with other locations. There was a suggestion that Birmingham was a good place to beg, which they suggested, was due to greater tolerance or greater generosity

here. The anonymity that the large population of Birmingham offers was seen as a plus, as it meant that service users were unlikely to come across people they knew when accessing services. The multi-cultural dimension of the population appeared to support service users' desire for privacy in services, as it reduced the likelihood of individuals being recognised by members of their own communities.

3.11 SUMMARY OF PERCEPTIONS OF SERVICES

The majority of interviewees reported that they were in receipt of some services that they found helpful and supportive. In categorising the findings in each of the service areas, it became clear that many interviewees were receiving support from multiple service providers at the same time, and that many services were helpful and supportive.

This study has shown that some of the service areas are more immediately important than others to service users wishing to address complex and often long standing issues. Stable housing is fundamental, needed before tackling health and wellbeing. The interviewees reported experiencing the biggest challenges with services for substance misuse and mental ill health, due to a range of factors including accessibility, suitability, timeliness and the duration of the provision.

Other areas of service provision, such as general health care, A&E, training and employment, and criminal justice system services were also important, and interviewees highlighted the need for these interventions as and when they needed them. However the likelihood of an intervention being successful was enormously dependent on the attitude of the person interacting with them.

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.

Wrapping services around the individual rather than asking people to ‘fit’ into services, was identified as the most productive way to work. The experiences interviewees shared of when this

did not happen suggested it created a detrimental rather than a positive effect. Likewise having a trusted worker who could continue to work with the individual over a sustained period of time was seen as hugely valuable. This worker should respond in a timely and personalised way, and support individuals' access to all the services they need. As such a worker is not and will not be always available, it is incumbent on commissioners and providers to change their systems so that they revolve around the individual, to work together so that individual even with the most complex of needs can easily find their way into and their way around their services.

CHAPTER 4. LEARNING FROM THE STUDY

4.1. LEARNING ABOUT SERVICES

This pilot set out to understand the experience of service users rather than those providing or external to the system. All interviewees were in receipt of some services, including support from Lead Workers and Peer Mentors, whose aim was to support them to navigate and access services. The majority of interviewees reported being broadly satisfied overall. However further research is needed to provide a fuller picture, in particular to capture the perceptions of those who are not thus supported by case workers, or who are not currently engaged with providers. With that caveat, the following learning summary focuses on where improvements could be made now. Many issues are shared by the wider population. This is to be expected. It should be remembered, however, that problems such as access, timeliness and suitability are much compounded for homeless people. Even for those housed but with other multiple and complex needs, these barriers can be higher.

4.1.1 Suitability

Housing is a key unmet need. The experience of being inappropriately housed was common, and interviewees repeatedly mentioned housing situations where the behaviour of residents or neighbours caused them difficulties. This was particularly the case where others were still misusing substances or alcohol. To be appropriately housed meant being in accommodation suited to the individual's circumstances and geared towards meeting their support needs. Many of the interviewees found supported housing specifically designed for specific client groups, helpful, e.g. housing for alcoholism and/or women only.

The temporary nature of short term accommodation presented concerns, for whilst interviewees appreciated the help they received, they experienced stress from knowing they would have to move again. Temporary accommodation was not seen as conducive to gaining maintaining a process of recovery or progressing towards stability.

Supported housing that provides a constructive environment with regular support and structure worked well for individuals.

The suitability of health services was also a frequently raised issue , often reflecting individuals' feelings that they are offered interventions that are not suited to their situation, just because that was all that was on offer at the moment. This reinforced the perception that they were not being taken seriously. Another issue expressed by several interviewees was that their medications were not reviewed frequently enough, and that this had resulted in them using medicines that were no longer appropriate and in some cases were actually causing more difficulties.

4.1.2 Attitude

In all service areas interviewees reported that the greatest benefits were realised when a respectful relationship existed between service users and workers and practitioners. Where services were working well, trust and respect between the worker and the individual were evident. Interviewees recalled experiences when they had felt patronised, not taken seriously or neglected in some way. This had had the opposite effect, impacting negatively on their outlook and on their chances of living a more fulfilled life and/or participating in a recovery process. Asking for help is a very big first step, and feeling thwarted in doing so is detrimental.

The need for respect of course, is true for everyone, but it appears to be a particular issue for people with multiple and complex needs, whose own feelings of self-respect can be that much lower due to their circumstances. Interviewees often referred to successful interventions in the context of working with people who encouraged and supported, who went the extra mile and had some empathy for them and did not disrespect them because of their circumstances.

4.1.3 Timeliness

Being able to access the "right" support at the "right" time was considered to be essential. Interviewees often acknowledged that it was up to them to make the changes to which they aspired but that this could only happen when they felt ready. Programmes for detox and rehabilitation were referred to often as being attractive to them, but only when they thought they could manage it, and when they felt safe in the knowledge that there was good after-support available for the right length of time.

Discharge from A&E and release from prison were the two areas where crisis seemed common. Individuals often felt they had been left to fend for themselves at the very time they were at their

most vulnerable. This was largely a question of the availability of follow up services, and of the wait for services to become available.

4.1.4 Wrapped around the individual

Packages of support that were tailored to the needs of the individual were identified as giving the greatest benefit. Interviewees described programmes that they found unconstructive or inappropriate. After being valued as an individual, having support to navigate services for their personal set of needs was viewed as being of the most benefit and a good contributor to success.

As individuals progressed or relapsed, they needed different types and levels of service. Having their service plans regularly reviewed helped them to address any changes and built their confidence in the process. Receiving regular support and learning coping strategies for challenges and triggers (especially those during and after a detox programme) helped them to continue.

4.1.5 Accessibility

Access to the services had presented challenges for interviewees. People with multiple and complex needs often lived in changeable circumstances. For example, access to health services had become problematic for some when they became homeless; access to online housing systems was difficult; identifying housing that provided relevant support and interventions was virtually impossible unless a worker was there to help.

Some interviewees felt that health services were not sufficiently available. They felt that longer opening hours for existing services and/or a dedicated 24 hour drop in centre might provide them with services at the times they needed it. Several interviewees spoke of wanting to go into detox programmes, but that it was not available to them. The fear of failure added to their issues of "readiness" as some services were said or perceived to provide one chance only. This generated anxiety for many interviewees. Waiting lists for services, for example for mental health support was also raised as an issue.

Many individuals reported difficulties accessing mental health services. A difficult situation appeared to exist, whereby before being defined as having a mental health problem, they could not get access to mental health services so that in times of a mental health crisis, individuals

reported not knowing where to turn for help. The role of GPs and their practice nurses was seen as central by interviewees.

4.1.6 Duration and continuity

Having access to both practical and emotional support through a long term relationship with workers gave individuals the space and time to rebuild their lives at a pace most appropriate to them. It also provided some necessary latitude to make mistakes without the risk of losing support.

Navigating lots of services when all were supplied by different providers was difficult, if not impossible without the support of a professional. Gaps in provision, of course, existed. It was the trusted worker that many identified as key to helping them to avoid "falling through the gaps". Conversely, lack of consistency from workers had resulted in interviewees feeling let down, quite quickly losing their momentum and confidence again.

4.1.7 Overarching lessons from service provision

An overview of the findings strongly suggests that the attitude of those providing services is as important as the service on offer. Chances of success depend on the way in which services are presented, and the interviewees seemed to see a link between their resilience and the attitude of those working with them. One interviewee said “don’t pressurise”. They wanted “Respect, value, choice, {to be} seen as a person, not as a bottle of vodka walking in." The following points underline why this is the case.

- Priorities for interviewees primarily focused on housing, and then addressing problems of substance misuse and mental health. This was in the context of having a stable base from which to embark on a personal progress plan or a recovery programme, with support available to address issues that were often longstanding and deep seated.
- Interviewees had not experienced themselves as being at the centre of services. They felt that they had to fit in with the services’ priorities, not the other way round. With such complexities of need themselves, they were simply unable to fit into the schedules and timetables of different organisations.

- Where there were exceptions to this, it was often the result of support from individual workers. Interviewees were quick to point out who these exceptional individuals were.
- Irrespective of the discipline or service provider, interviewees reported that they secured the greatest benefit and satisfaction when they had been able to establish a positive and reliable relationship with practitioners and workers.
- They also felt that getting help with their most immediate and overwhelming problem, as it occurred and whatever it was, was essential both in maintaining this trust and in making the most progress. Continuity for this support was seen as essential.
- Being supported to find the most appropriate intervention at the right time and overcoming new issues was considered vital. They felt moving at the right pace for them was important, which meant not being referred into something that happened to be on offer, while having to wait for the service they really needed.
- Although the interviewees were, of course, looking to service providers for some basic services, they felt that it was very important that those they met did not take a 'textbook' approach. They wanted frontline staff and practitioners to have some awareness of the pressures and conditions affecting the person in front of them. This can be described as 'being psychologically aware' or providing a 'psychologically informed environment' (PIE), an aspiration of the organisations in BCFT's No Wrong Door Network. For further information on Psychologically Informed Environments see Appendix 11.

4.2. LEARNING ABOUT THE PROCESS OF ENGAGEMENT

4.2.1. Lessons

The Service Users' Perspectives study has been a pilot, both in terms of the content and the research process itself. Its focus, the topics covered in the interviews, and the process of engagement were designed with the help of Experts by Experience. Experts by Experience asked researchers to listen to service users' voices, and 'to tell it how it is', how it feels to be a service user. The process proved more time consuming and resource intensive than originally foreseen and there is no doubt that collecting conventional case studies would have been easier. The innovation introduced by Experts by Experience, in switching to the articulation of the service user experience, however offers a different and potentially richer kind of learning. For example we have seen above how critical attitude is, and the potential value of service cultures becoming

psychologically informed. In order to reach its full potential, this research needs to continue over several years and track a wide range of service users, at different stages in their journeys.

Chapter 2 sets out the methodology adopted in detail, and it is true to say that the process has been one of learning, with new ideas emerging about the research that will enhance future studies. Another consideration is that this research has focussed more than originally planned on people with multiple, intense and pressing concentrations of needs, most of whom had Lead Workers. The research has made explicit the consequences that arose from this, in terms of interviewees' capacity to engage in interview, the high level of support for the research required from support workers, and that interviewees perceptions of services usually reflected that they were at the start, rather than further along their recovery and/or personal journeys.

Learning from the research pilot has identified some clear pointers about how to engage with interviewees with complex needs, and also with those working with them. Psychological and emotional intelligence on behalf the interviewers has been essential in securing positive interaction throughout. The kind of conversational interview conducted required interviewers to have appropriate 'cultural competences', as well as well-honed research skills. They needed empathy to be able to work effectively with individuals, individuals who can be very disaffected, very sensitive and psychologically very vulnerable. They needed to be able to extricate meaningful information from an interaction that was often periphrastic, discursive and sometimes evasive.

The process of engaging and interviewing service users has generated some in-depth learning. Here are some of the lessons:

- Support workers are gateways to the clients with intense needs. Workers therefore need to both understand and value the study, so they can encourage and support the participation of their clients. It is best if staff are persuaded both by their own team managers and by the researchers themselves. For example our researchers attended team meetings and Shelter's management team worked hard to communicate the value of the work.
- It is also important that researchers gain the confidence of support workers. They need to demonstrate not just their competence as researchers, but also their ability to

empathise and understand the client group. Frontline workers often fear that researchers will make matters worse by reacting inappropriately to disclosures made by their clients.

- It is vital to get some background information about the interviewee from a support worker in advance of the interview. This will inform the risk assessment and determine how the interview is conducted, at the very least how to help to put the interviewee at ease. For example, the interviewee may be suffering from anxiety or phobias, withdrawal symptoms, or have particular sensitivities in certain areas, such as family. Knowing this in advance helps the interviewer structure the interaction.
- Establishing contact with a support worker pre-interview also means that they are more likely to facilitate the interviewee's attendance at the interview, indeed some actually brought individuals to the interview, though only one (a volunteer) stayed. Most support workers encouraged their clients to do the interview on their own, giving them the opportunity to comment on their service as well. In some instances their support has also helped the post-interview, follow-up contact as interviewees may tend to change their phones and their accommodation often.
- It is very important that the interviewee is confident enough to speak frankly about their experiences. It is essential to emphasise that the interview is totally anonymous and nothing will be attributed to the individual.
- This kind of conversational interview benefits from having two researchers present, one to focus exclusively on the conversation (the conversant) and the other to act as a note taker. This is not only useful in dealing with occasional risk, but it also allows for active listening. Both researchers must introduce themselves to the interviewee and find a point of contact, as a completely silent and unknown note taker will certainly not put an interviewee at ease. Sometimes the note taker can ask supplementary questions. The study was originally budgeted on the premise that one interviewer would be the best option, being less intimidating. However it took only one interview to show that this was not advisable.
- The interview took the form of a conversation. The use of microphones was considered but rejected as both inappropriate and too time-consuming post interview. It is the scribing interviewer's task to accurately capture what the interviewee is saying and to record it in appropriate sections within the enquiry framework specifically designed for the interview. The conversational approach ensures that the interviewee is contributing

information on their own terms, helping them to feel safe and confident in sharing their experiences and views.

- Close observation of the interviewee throughout the interview helped the conversant guide the conversation and questioning, thereby working at a level and pace that was comfortable for the interviewee. Individuals were not encouraged to reveal things in their personal histories which would cause them any significant distress, this being inappropriate in an interview setting. However, although individuals were not asked for their personal back story, they often volunteered information to help researchers understand their points. As researchers it was important to be aware that what was articulated was therefore often selective. For some interviewees, some experiences were simply too sensitive to be reiterated or referred to. This awareness was accepted as part of this kind of study.
- Since the interviewee is the "expert", it is his/her views that are being sought. Sometimes some memories can be very painful to talk about. It is therefore important for researchers to express appreciation of the efforts they are making. This demonstrates respect and places a value on their contribution to the study.
- Interviewees welcomed this approach, with many saying that they had got involved with the interview because they had something to say, and they wanted to make a difference for others in a similar situation. It appeared to the researchers from their interviewees that service users were unused to being asked for their first-hand account of services and that they enjoyed the opportunity.
- Most interviewees preferred to be interviewed in their own accommodation, rather than at other facilities, even though privacy was guaranteed at these. Attendance rates were not markedly different, so convenience and cost were perhaps the determining factors. Where interviewees came to a venue, bus fares were usually paid through their support workers.
- Having contact with interviewees following their interview has been a positive step, with most interviewees seeming pleased to be asked for their feedback on the interview process in particular. This re-emphasizes the value given to their personal input and addresses the need to feel overt respect from those with whom they are interacting.

4.2.2. Summary on learning from the research process

The interview process and the process of pre- and post-interview involvement have been positive. Once individuals had committed to being interviewed, as interviewees they were all forthcoming in telling their experiences of different services. For several their engagement could in itself be described as part of the therapeutic process; being valued as *the* expert and seeing oneself as a "giver" rather than a "recipient", as someone who is able to help others, has been both significant and important. Some have been able to reflect, in the neutral setting of the interview, on their own progress and have felt comfortable enough to comment on things within services that may have contributed towards relapse or resilience.

Feedback on the interview process has been received from sixteen of the twenty participants after completion. It has been very positive. This is a typical comment: "Absolutely fantastic, great that people like me can give feedback and that you are listening to us. Not a bad thing to say at all."

4.2.3 Creating the Space

Appendix 1 contains "Creating the Space"; a Good Practice Guide, produced by Clever Elephant as a specific response to this process. It includes some of the key points about how to approach engagement and deliver successful interviews. Some good practice pointers are given below.

<u>The pilot has highlighted the following in terms of preparing for the interview:</u>

- Ensure interviewers have appropriate skills, attitudes and experience. This could include a background in working with people with multiple and complex needs, lived experience, an understanding of addictions, counselling and understanding mental ill health, as well as being experienced researchers comfortable with qualitative and discursive approaches.
- Secure case worker support for the interview to increase chances of interviewees attending.
- Ask for a profile of the interviewee in advance, both for your own risk assessment and to enable you to establish rapport with the interviewee quickly.
- Arrange a venue where client feels comfortable, and feels safe talking to you. Don’t expect them to come to you.

The pilot has highlighted the following in terms of conducting the actual interview:

- Establish from the outset the context - this is research (as opposed to counselling or other support or psychological interaction); and should enable an emotionally mature exchange, with the interviewee being regarded as the expert.
- Make sure the process is clear, explain the purpose of the study and emphasise the anonymity and confidentiality of the interview.
- When disclosure takes place do react, but react appropriately. When an interviewee reveals their personal history to you, remember that telling you may be part of their recovery process or personal journey, they may be 'testing' things out. Their purpose in telling you should be respected; it is usually to explain to you better why they experienced something in the way that they did.
- Record what people say carefully, personal testimony is vital; let individuals speak in their own voices, using their own vocabulary. Check with them if you don't understand something.
- Remain professional, independent and unengaged in any case work.
- Hold a conversation not an interview. The note taker can allocate answers to your questions as and when the interviewee comments and the discussion flows. You can prompt but don't fire questions, remember they may be struggling with all sorts of emotional and physical difficulties at this moment.
- Expect gaps, memory lapses, evasions and avoidances; see these as coping mechanisms rather than a rejection of the interview itself.

The pilot has highlighted the following in terms of the role of the interview in supporting the resilience of interviewees:

- Being valued, listened to and being taken seriously, being treated as a person with views that are valid, as opposed to being patronised or 'fobbed off', is always noted by interviewees and appreciated when it happens. Remember that for many self-respect is an issue, so overt respect from you and others is essential.
- Having empathetic and practical support through consistent and reliable contact with a key worker where trust has been established is consistently identified as a critical factor. The same values apply to the research situation, where the interviewers too must demonstrate their trustworthiness and empathy and in a sequential study, their reliability over time.

- Being allowed to make mistakes and given a second chance, being supported by people who understand this, and not adding to their anxiety levels is important.
- When asking about services, you or your interviewee can start the conversation with any service area, but those that meet basic physical and well-being needs such as housing and health usually crop up first. This is because interviewees see them as fundamental to their personal stability. However, comments can and do come in any order, just as in a normal conversation.
- Contributing towards designing one's own recovery schedule or personal programme, and being able to access services as and when in urgent need is seen as vital. Becoming an interviewee and making a contribution towards bettering the lives as others can also be seen as a positive step in self-empowerment.
- Researchers should encourage second and third interviews with existing interviewees, wherever and whenever this is possible. However we do recognise that people both move on and relapse and are therefore prepared to work at the pace that individuals go. This is one way of tracking changes experienced by interviewees.

CHAPTER 5. RECOMMENDATIONS FOR FURTHER RESEARCH

5.1 Introduction to Recommendations

These recommendations focus on the research study itself. Detailed learning from the findings can be found in chapter 3, with a summary in chapter4.

5.1.1 Acknowledging the study as a Pilot

It is important to remember at this stage that this was a pilot study, not only in terms of developing the research approach, but also in that almost all the participants were referred through the one work stream within BCFT (Lead Workers and Peer Mentors). The research therefore focused on people with particularly intense needs and people in pressing current need. Their perceptions and feelings about services may be very different to others, people for example as yet unreached by Lead Workers and Peer Mentors and completely disassociated from services; or on the other hand those nearing the end of their recovery and/or reaching a new stage in their life journey. Re-interviewing participants over the lifetime of their engagement with BCFT will help to track changes in perceptions. Interviewing a broader range of service users engaged in different types of BCFT work streams will add to the robustness of the findings so far. The study was a pilot and will accrue credibility as the evidence base expands both numerically, and especially if participants can be re-interviewed over time.

5.1.2 Embedding the learning especially in terms of PIE

The following points are made for the BCFT team at BVSC and the partner organisations in the Core Group. The learning from this study can, if understood, endorsed and agreed upon, be used in the next phase of development and to support co-production with service users, which is a central plank in the BCFT programme. The process information on the other hand can be used within BCFT's imminent Psychologically Informed Environment (PIE) training initiative. (See Appendix 11 for more information on Psychologically Informed Environments). Partners could use the learning from this study in their planning, development, delivery and review of PIE.

5.2 Recommendations

5.2.1. Value of On-going Qualitative Research

BCFT has a strong track record in evaluation and plans for the future will include some form of quantitative cost benefit analysis and/or Social Return on Investment, to assist with potential replication. However a qualitative evaluation needs to run alongside and complement any quantitative impact assessment. For this reason the study of service users' perspectives should continue over the lifetime of the programme. Conducting a sequential study (where interviewees are interviewed two or more times whilst on their personal journeys in the programme) will establish whether service users are in fact experiencing improved services, and define what those actual improvements are, through recording how they feel they are being treated.

5.2.2. Annual Service Users' Perspectives Study

Whilst an annual Service Users' Perspectives study is strongly recommended, the design should take into account the learning from this pilot and any learning gained through PIE training. BCFT partner organisations should also be involved from the start to ensure that they are signed up to putting forward different types of service users, so that reliance on the Lead Workers and Peer Mentors work stream is reduced. For example, now that the No Wrong Door Network is up and running, network members are with the right encouragement likely to field research participants, likewise the Inreach/Outreach work stream and Every Step of the Way. Year 3 should provide the next study with a much wider range of interviewees and a more diverse cohort of participants.

5.2.3 Sequential Research

Carrying out second and third interviews with existing participants (wherever it is possible) will help to achieve some tracking. Involving people who have advanced further on their personal plan and/or recovery journey will add significant breadth to the study and secure a more balanced picture.

5.2.4 Promoting and Disseminating the Learning

Discussing this pilot with BCFT partners is strongly recommended, not least for what the study shows about the service user experience which is designed to be at the heart of BCFT. A dedicated workshop is recommended, covering the process, the findings, the learning, the links and the recommendations that have emerged. It should involve partners and stakeholders with an interest in the co-production of services with those who use them, however challenging those service users and their circumstances might be. It should also include frontline staff, especially those engaged in PIE training.

In conclusion, it is hoped that Birmingham's Service Users' Perspectives Study will contribute to developing a culture of understanding in relation to people with multiple and complex needs. Service providers can have a great deal of power over individual lives, both directly and indirectly, and this study has tried to capture what it is like to be at the receiving end when your particular needs are multiple and challenging. Interviewees were strongly motivated by the thought that their interview would make a difference to the lives of others. Their evidence, recorded in this report, will now inform BCFT's goal of systems change and base it firmly within real-life lived experience.

APPENDIX 1

Service Users' (Multiple Needs) Perspectives Study

CREATING THE SPACE: GOOD PRACTICE GUIDELINES

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August 2016

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"Creating the Space": Good Practice Guidelines

Interviewing People with Multiple and Complex Needs

These guidelines are based on Clever Elephant's substantial experience of working with people with multiple and complex needs, and in this instance, in accessing their voices through a positive interview process. The guidelines focus on how researchers can secure and interact positively with services users within a research process, both before, during and after interview. They are written with special reference to those individuals with HARM needs:

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

They are usually very difficult to engage, as many are grappling with chaotic lifestyles and with multiple, very challenging issues. The guidelines set out how to "create the space" for their involvement. They are a series of top line prompts, a guide to what to consider in designing an approach and each needs to be worked through in depth before moving into implementation.

The aim is to help others who want to develop productive, research-orientated relationships with people with multiple and complex needs, with a particular focus on garnering valuable information through interview through the personal insights of service users. The guidelines are formatted as a series of questions. The underlying principle is one of respect and value for each and every individual. In "Creating the Space" the principal element is the overt display of respect for the views and experiences of interviewees. It is essential to establish a relationship that expresses the value of the information that the interviewee is sharing, for rebuilding self-respect and feelings of self-worth are often crucial for people in such troubled circumstances.

By “Creating the Space” we mean having a self-reflective culture of practice and insisting on an environment that is sufficiently safe and so gives licence to service users to share their often painful, and usually convoluted, experiences. This in itself can be valuable for an organisation. It can enable feedback that might improve services in the future, possibly even explain why some things have gone wrong in the past. Participation often has a positive effect on the interviewee, as participating itself can become a part of their personal journey and/or recovery process.

Creating the space for service users to openly express their feelings means:

- they are being asked to contribute to something that could really help others
- emphasising the fact that it is their experience that really matters
- helping them recognise their own expertise and needs and reflect on their process of change
- giving them permission to trust their own feelings and wisdom
- assuring them that they have the autonomy to make their own choices
- helping them understand that making mistakes is okay when trying to change
- that they are not being judged or looked down upon

Clever Elephant bought considerable experience to the task of interviewing people with multiple and complex needs, since both researchers had also worked with this group over many years. Nevertheless additional lessons were learnt in the process. The guidelines are not theoretical in any sense, and we leave it to others to consider how they fit into qualitative research approaches, and the comparative validity of different approaches.

Section 1 - Getting ready: pre-interview

What planning and preparation is needed? The following points are a guide to the pre-interview stage

- How will you secure independence for the research? How will you convey this to gain the confidence of the service users?

- How will the research be managed and monitored? What criteria will you apply to help with monitoring? What latitude will you allow to be able to flex and change how the research is carried out depending on the outcomes of the monitoring?

- Support workers are the gateway to interviewees, so how will you achieve the active involvement of staff working with the service user?

- Do the people who will be conducting the interviews have the appropriate skills, attitudes and experience? For example, a background in working with a relevant client group, and/or counselling, as well as being experienced researchers?

- Do your interviewers have the skills and abilities to develop successful relationships with service provider staff as well? If not, how will this relationship be built?

- How will you encourage service users to get involved? What advance information are you going to give them?

- What reimbursement will you offer to service users to contribute to your study, to those who agree to be interviewed e.g. vouchers?

- What reassurances will you give about the confidentiality of the information they give you? Are you going to promise anonymity? If so how will you assure anonymity?

- What do you need to know about your interviewee prior to meeting with them? Consider how you will access any necessary information about individual's backgrounds? What do you need to know for the purposes of risk assessment? To establish a rapport with them?

- Where will you meet interviewees? How will you identify suitable venues for the interviews, where the service user is comfortable and there are minimal risks involved for all?

- How will you minimise the number of interviewees who don't turn up? What flexibility will you have to make alternative arrangements? How much responsibility, if any, do you have for support workers if their clients don't turn up?

- How will you convert your research framework into questions to be answered during the one to one interface with your interviewee? Will it be question-and-answer or will your researchers be able to secure the information they want conversationally?

Section 2 - Conducting the conversation: the interview

It is essential to get the structure and the approach of the interview right, if you want to reflect the central role of service users in your research. Most importantly you need to equalise the relationship between the interviewee and the interviewer.

- What considerations will you give about the use of the physical environment at the venue of choice, for example making sure no-one's exit is blocked and everyone is comfortable? Who will take responsibility for this?

- The interview will work best if it is carried out as a conversation. How will you structure this? How will you establish rapport from the outset and gain the interviewee's confidence? How will you make sure you get all the answers you need from a conversation that may be structured and diffused?

- How are your interviewers going to explain the purpose of the research and the role of service users as interviewees? What encouragement and reassurances are you going to give that will gain their confidence and help them speak out?

- How are the interviews going to be conducted, who is going to attend and what roles will they have? Our experience clearly demonstrates the need for two interviewers, one to maintain the conversation and one to record the voice of the service user.

- How will the interview be recorded, scribed or taped etc. Will the interviewee have a choice in advance?

- What methods will you use to maintain the conversation and help the service user contribute information on their own terms? What will work best in making the service user feel safe and confident in sharing their experiences and views?

- How will you make sure you have sufficient time for the interview, for example, making sure you can give people with multiple and complex plenty of time to reflect, articulate and deal with any emotions arising? Interviews may therefore last much longer than you

are used to and there may be a need for several breaks, especially if interviewees need to look after their addictions or are under emotional or mental stress.

- Think about the approach to the interview to allow any breaks in the process as needed, or indeed if the interview needs to be discontinued. How you will encourage service users to return?

- How will you make sure that the interview is at the level and pace that is most comfortable for the interviewee? How will you know that your interviewers have sufficient emotional intelligence to spot if the interviewee starts to show distress? How will you advise them to recalibrate the conversation and level of questioning?

- Consider how a conversational flow with the service user can be maintained. How will the interview be managed in such a way that the interviewee can safely recall or retell their experiences, when sometimes this will be a challenge for them, and sometimes where the experiences are acute, for the interviewer too?

- Prepare for how you will react appropriately in response to the information being shared with you by the interviewee. They may be disclosing sensitive matters, so how will you deal with this? How will you deal with evasions? Will you respect them?

- How will you make sure you take everyone on face value and treat all with the utmost respect, and avoid stereotyping people? What measures will you take to achieve this? How will you know you are doing this?

- What risk assessment and safeguarding measures will you have in place to ensure the safety of both the researchers and the interviewees? Will you work with providers for example in deciding on the location of the interview? Do you have a policy relating to sensitive information disclosed during the interview?

- How will you make sure that the conversation supports the interviewees to give their personal testimony on their own terms and in their own words? How will you make sure you have heard their voices and accurately recorded it?

- Consider how you remain professional, independent and unengaged in any case work as interviewers. What will support this clarity?

- What next steps will you offer to the interviewee? For example, what feedback do you want from them on you, the interviewers and the interview process? Is the research going to continue, will there be a follow up interview?

Section 3 - The information: using the data

You will need to consider how, once you have it, you will use and disseminate the qualitative data that you gather. How will the learning from the interviews be used?

- When you write up the report, how will you maintain confidentiality and make sure the data is totally anonymous? How will you do this, recognising that when the interview group is numerically small and social links exist between the interviewees and potential readers, you may have to leave out a lot of specifics?

- When writing up the research, how far will you claim to be merely the conduit of the service user's voice? How will you position yourself as a researcher and interpreter of the data? Will you try to balance these two positions?

- Who do you want to learn from the study? Who can change things on the basis of the study? Who has the authority and power?

- How will you monitor and measure the impact of the data you have collected?

- What feedback are you going to give to interviewees and service users about the outcomes from the study?

Clever Elephant hopes you find the Guidelines useful. Please remember that they are just guidelines, a starting point in considering how to access the voice of service users with multiple

and complex needs through an interview process. If you require further support or information, please contact BVSC on changingfutures@BVSC.org.

Appendix 11 A Note on Psychologically Informed Environment (PIE) Training

The findings of this study support developing Psychologically Informed Environments (PIE), in this case in relation to the research process. This is in line with the aspirations within the BCFT programme, which is set to implement PIE training in year 3 of the project. The information below has been extracted from *Psychologically informed services for homeless people, a Good Practice Guide***,** Communities and Local Government, Southampton University *et al* (2012) accessed via web (p.3 - 26).

A Psychologically Informed Environment is a place or a service in which the overall approach and the day-to-day running of a service has been consciously designed to take into account the psychological and emotional needs of the service users. The authors list these five components essential to a PIE, reinforcing the importance of both practice and evaluation:

- A Psychological Framework
  - Cognitive
  - Psychodynamic
  - Eclectic
- Social Spaces
  - Welcoming and non-institutional
  - Designed to encourage interaction
  - Safe movement, and safe meeting spaces
- Staff Training and Support
  - Reflective practice
  - Good supervision
  - Client involvement
  - Ongoing evaluation

  Corporate theoretical framework and approach (including corporate commitment)
- Managing Relationships
  - Consistent boundaries, sanctions and rewards
  - Pro-social modelling
  - Awareness of power
  - Positive regard

    - Psychological and emotional awareness
- Evaluation of Outcomes
    - Policy level measures, whether defined by government or local commissioners. These may be fairly broad, and more sophisticated than mere 'targets'. Examples may be reduction in overall antisocial behaviours, reduction in rough sleeping; or shared outcomes across multiple departments e.g. reduction in police time, reduction in emergency care use.
    - Service level measures, defined by the services themselves. These should map on to what the service believes that their interventions may deliver, e.g. quality of personal relationships, reduction in antisocial behaviours, reduction in distress, increase in cognitive flexibility etc.
    - Individual measures, defined by the staff member in collaboration with the service user. These should be meaningful for the service user, realistic and – usually– behaviourally defined (although relationships and emotions as well as other factors may of course feature). These measures may result from the question 'what do you want to change in your life?'

The guide recommends that a commitment is made at all levels in an organisation including its mission statement, strategy and business plan, where a commitment to create a PIE is clearly stated and showing process by which this will be achieved. The PIE implementation plan should be regularly monitored and reviewed.

It is fundamental that PIE needs to be co-produced by service users and staff. The authors present five key PIE elements to help staff work more effectively with people with complex and multiple needs, with a strong focus on relationship-building to promote progress and recovery. This approach can be used in all settings where service users with complex and long term needs. It can also assist service users to gain an understanding of their own behaviour, take responsibility for themselves and develop negotiated and positive relationships.

The five elements are:

1. Relationships: these are recognised as the principle tool for change. Organisations need to evidence their emphasis on the role and value of relationships in everything they do, behaviour, ethos and culture.

2. Staff support and training: The purpose of a PIE is to help staff understand where behaviours are coming from, enabling them to work more creatively and constructively with challenging behaviours. The psychological needs of staff are considered and supported through developing skills and knowledge, increasing motivation, job satisfaction and resilience.

3. The physical environment and social spaces: Providing a non-institutional, safe and welcoming service facilitates interaction between staff and service users. There is a sense of physical and emotional safety for both; clients have choice and control over how and when they engage. A culture of health and wellbeing is developed.

4. A psychological framework: Insights and principles from psychological approaches to working with complex needs are introduced. Staff understand, and keep in mind, the connection between thoughts, emotions and behaviour.

5. Evidence generating practice: Understanding and verifying what works to support continuous learning and improvement. Having evidence that will demonstrate the impact of PIE, evidence such as progress for service users, staff, and commissioners.