

## WHOLE PERSON RECOVERY:

*A user-centred systems approach  
to problem drug use*

Rebecca Daddow and Steve Broome  
November 2010

RSA Projects







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## CONTENTS

<i>The RSA</i>	II
<i>Acknowledgements</i>	III
<i>Executive summary</i>	IV
<i>Introduction</i>	1
<b>SECTION 1. <i>The changing face of UK drugs policy</i></b>	<b>5</b>
<b>SECTION 2. <i>User-centred approaches</i></b>	<b>16</b>
<b>SECTION 3. <i>The Whole Person Recovery Project</i></b>	<b>26</b>
<b>SECTION 4. <i>Mapping the Whole Person Recovery System</i></b>	<b>36</b>
<b>SECTION 5. <i>Applying the concept of Recovery Capital</i></b>	<b>62</b>
<b>SECTION 6. <i>From recovery thinking to action</i></b>	<b>74</b>
<b>SECTION 7. <i>Conclusions and reflections</i></b>	<b>82</b>
<i>Bibliography</i>	90
<i>Appendices</i>	92

### List of figures

<b>1:</b> The user-generated systems map	<b>V</b>
<b>2:</b> The Whole Person Recovery System	<b>VI</b>
<b>3:</b> Arnstein's Ladder of Participation	<b>16</b>
<b>4:</b> From data analysis to influence maps, to system maps, to whole person recovery	<b>34</b>
<b>5:</b> The user-generated systems map	<b>39</b>
<b>6:</b> The Hold sub-system	<b>41</b>
<b>7:</b> The Struggle sub-system	<b>47</b>
<b>8:</b> The Recovery sub-system	<b>53</b>
<b>9:</b> Recovery Capital Poster	<b>66</b>
<b>10:</b> Different levels of the user-generated systems map	<b>68</b>
<b>11:</b> The Whole Person Recovery System	<b>71</b>
<b>12:</b> Operationalising the Whole Person Recovery System	<b>76</b>
<b>13:</b> The influence map	<b>111</b>

The images used in this report were taken during the project's workshops and Design Symposium.

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## THE RSA

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## ACKNOWLEDGEMENTS

This project was made possible by funding from the Wates Foundation and the Tudor Trust, and by the partnership offered by West Sussex Drug and Alcohol Action Team, for which we are very grateful.

It has benefitted from the input of former and current problem drug and alcohol users, local third sector and public sector staff, academics, central government officials and RSA Fellows. The advisory group has provided leadership and scrutiny and the local steering groups have been instrumental in developing ideas and in planning their implementation. Those people who attended the expert seminars and design symposium gave us important multiple perspectives. This report has benefited from the input of several independent critical friends. To all, our thanks.

We would like to acknowledge the role of Baseline Research in helping to train our team of user-researchers and in carrying out survey work: their expertise and energy was inspiring. Dr Karen Duke at Middlesex University helped us to build the case for a user-centred approach to recovery. Tony Hodgson provided expertise in systems thinking and helped to develop our Whole Recovery System. Emma Drew helped us to understand issues facing women with problem drug and alcohol use and continues to help in developing a women's support group in West Sussex.

We would like to pay tribute to Brian Morgan, the developer of the EXACT network in West Sussex, and to Carley O'Hara and Glen Carpenter who have been a driving force for Arun EXACT. All are exemplary Recovery Champions.

We would particularly like to thank the RSA Fellows and our RSA colleagues who have played a key role in participating and supporting the project.

Finally, we are very grateful to the people — all former or current drug and alcohol users — at the two project sites who gave and continue to give their time and energy to this project. Their contributions to the research and their subsequent development of local recovery communities were critical. We look forward to working with you over the coming year.

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## EXECUTIVE SUMMARY

Problematic drug and alcohol use has a profound impact on society. From the personal and social harms to the financial costs of drug-related crime and medical treatment, this is a burden that is increasingly hard to bear not only economically, but morally and socially. Moreover it is one that may increase as we enter a period of economic hardship. There is a constant need for new insights, and new approaches to help people address the problems associated with drug and alcohol use, and to do so sustainably and frugally given the current financial conditions.

The RSA's Whole Person Recovery Project aims to understand in a holistic way how problematic drug and alcohol users become trapped in cycles of addiction, what helps or hinders their journey to recovery, and how their recovery can be sustained. We do so not merely to contribute some fresh insight into this complex and important problem, although this is clearly important, but to make the insight a catalyst for users themselves, and members of their communities, to foster recovery through their collective social effort and innovation.

The project builds on the RSA's 2007 publication *Drugs — Facing facts*, which argued that problematic drug users have not forfeited their rights as citizens to effective public services, and for a more tailored and well-rounded approach to drug services.

Our work focussed on two areas of West Sussex as sites for inquiry and innovation. This report is the project's first, and describes research findings and pilot initiatives from the first two phases of activity, namely (i) user research and (ii) user-centred service design and social innovation.

The research that underpins this report placed drug and alcohol/service users at the centre of the approach. Through mixed methods research, their voices and experiences built our systemic understanding of the problem. Informed by this understanding, it was then their 'native' expertise which enabled us to co-design possible solutions, with help from more conventional subject and service experts.

The findings make a case for recovery-oriented initiatives and services that are more personalised, better balanced between psychosocial and medical interventions and better able to draw on a whole-community response to the problems that lead to, or are prompted by, problematic drug and alcohol use.

The core findings and recommendations of the report are as follows:

### Strategic, theoretical and political shifts

A number of factors suggest that we are entering a new 'moment' in our approach to recovery (including treatment) for problematic drug and alcohol users.

- The forthcoming (at the time of printing) national drugs strategy seems to place a greater emphasis on a holistic approach to drug treatment, and calls for a de-stigmatisation of users, especially from would-be employers.
- The localist and Big Society agendas on the contemporary political scene call for community-led responses to the challenge of recovery.
- User-centred approaches to public service design have been growing in prominence, although they are not without their problems and challenges.
- The theory of Recovery Capital is gaining prominence in the UK — the sum total of personal, social and community resources that someone can call on to aid their recovery — and provides a more holistic model with which to spark and sustain recovery.

### USER GENERATED SYSTEMS MAP EXAMPLE. SAM'S STORY OF THE HOLD

The user generated systems map opposite can be difficult to understand in the abstract without prior knowledge of systems methods. This box presents an individual's story, which illustrates one experience of the system and demonstrates how to read the diagrams opposite.

Sam described how he was always chasing the Buzz of his first experience of heroin but never managed to reach it. *"At first it wraps you up in cotton wool... but after a month, maybe 6 weeks, then that hit, all it does is bring you back to normal. You get so ill that you're using it as medication."* As Sam's need to seek an Escape from the painful 'rattle' he experienced if he did not use heroin increased, the likelihood of him seeking the Fix increased, which resulted in the Buzz and decreased his immediate desire to Escape. The temporary euphoria and relief of the Buzz also reduced his desire to seek a fundamental solution (the Desire) and get clean. This maintained his involvement in the Hold.



Fig 1. The user generated systems map

A → B Influence acts in the same direction: if A increases, B increases; if A decreases, B decreases

A ⇄ B Influence acts in the opposite direction: if A increases, B decreases; if A decreases, B increases

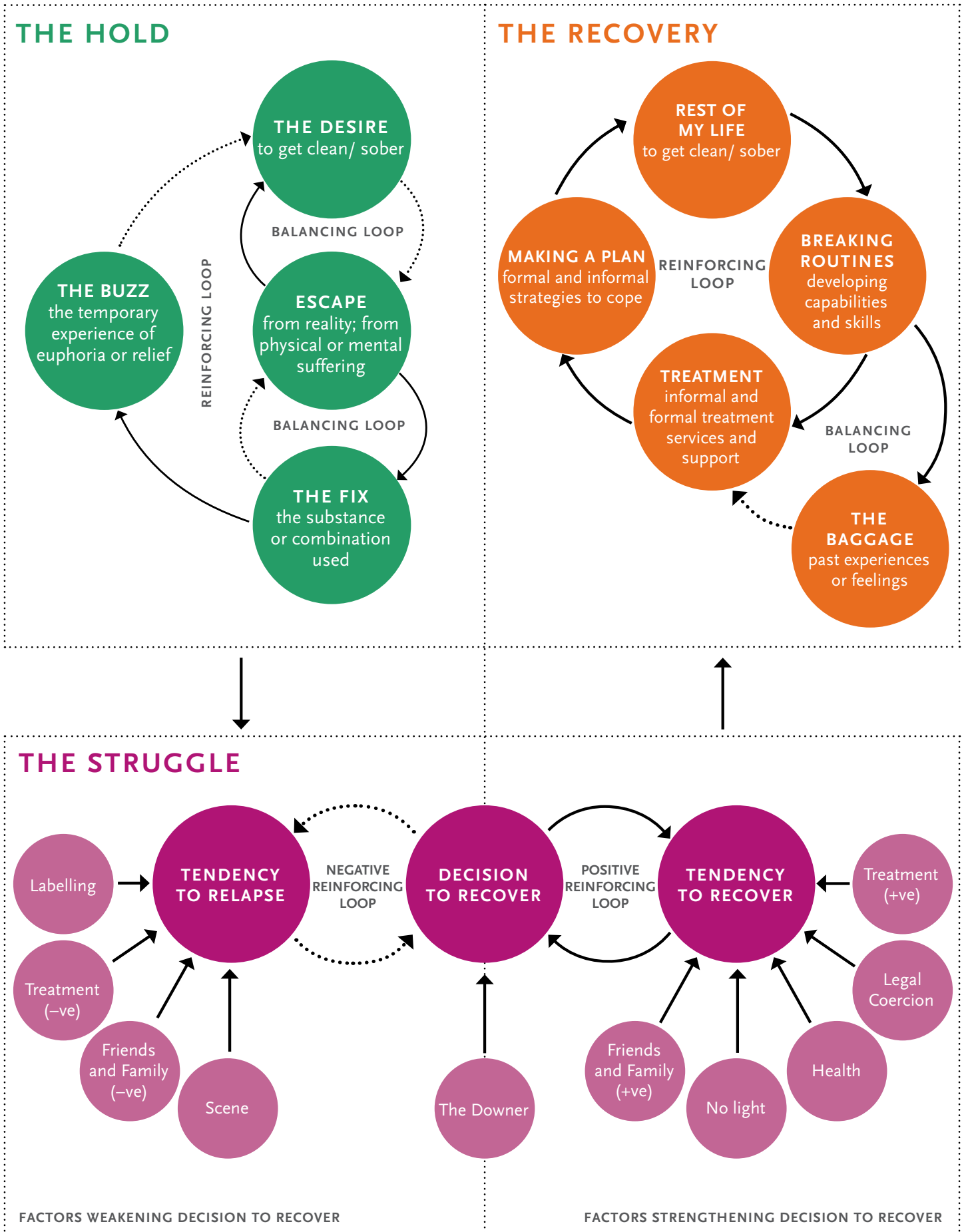


Fig 2. The Whole Person Recovery System

A → B Influence acts in the same direction: if A increases, B increases; if A decreases, B decreases

A ⇄ B Influence acts in the opposite direction: if A increases, B decreases; if A decreases, B increases





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## The value of user-centred and systems approaches to service design

- Involving drug and alcohol users more directly in the design of services is not only ethical, but substantially increases the likelihood of services targeting resources where they are most likely to have a meaningful impact on an individual's recovery.
- A systems-based approach to understanding, mapping and visualising users' experiences not only helps to render this complex issue more amenable to intervention, but also promises to create efficiencies by joining up and adding value to services in their activities.
- In the course of this project we have learnt, through a combination of design and serendipity, that user-centred approaches to research are not only vital to develop an authentic and systematic account of drug and alcohol users' experiences, but act as an intervention in that system itself. The very process of user-centred research and design is significant; training users as peer researchers and involving them at each step with other stakeholders, has been an important contributor to the creation of recovery capital.

## The Whole Person Recovery System

- Our mixed methods research enabled users to co-construct a systems map, expressed in users' own terms of reference, which visualises the dynamic forces at play in driving addiction ('The Hold'), the potential for recovery ('The Struggle'), and recovery ('The Recovery'). Each of these elements represents a distinct, but connected, sub-system which together form the whole system. (See **Figure 1**)
- The Hold sub-system mirrors the classic system archetype for Addiction which states that a problem symptom (the reason for seeking drugs or alcohol) can be resolved either by using a symptomatic solution (the drug(s) of choice) or by applying a fundamental solution (that will resolve or directly address the problem symptom).
- The Struggle describes a transitional sub-system in which an individual's decision to seek recovery is at the centre of a struggle between the Tendency to Relapse and the Tendency to Recover. Both are contingent on a range of factors, including stigma ('Labelling'), the context or environment ('The Scene'), Friends and Family, and the strength of adverse experiences with drugs ('The Downer').
- The Recovery sub-system illustrates one possible route to recovery that represents the strongest account from the research. It is heavily influenced by experience of formal treatment, but recognises the value of informal support and other forms of recovery capital.
- The Whole Person Recovery System integrates these user generated sub-systems with a greater understanding of recovery capital. It creates a mutually reinforcing system of recovery that recognises the dynamic relationships between the components and the various actors of the system and offers an improvement model to commissioners. (See **Figure 2**)

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## The System as a platform for local recovery innovation

- When used as part of a service design and innovation workshop, the Systems Maps acted as a catalyst for identifying opportunities for benign interventions in the recovery system.
- In developing these interventions we recognised the role of a wide range of stakeholders in the recovery system and so developed a Recovery Alliance at both project sites.
- Social innovations developed by the Recovery Alliances included the development of a Small Sparks scheme, giving users modest grants to assist their recovery; a peer led, dedicated radio service; a user led training package for local GPs; mapping all existing recovery capital across the sites and developing it as a resource for the local community.
- Independent user groups such as EXACT (the peer led organisation established across West Sussex), are potentially important to improving recovery oriented services. They offer a valuable way to broker personalised services and support users at any stage of their recovery no matter which pathway they choose. As such, these groups should ideally be given a statutory role, to help user-centredness and co-design to be more effectively embedded within service design and provision. However, given the lack of funding, they may need to adopt a social enterprise model, which is difficult without seed funding.
- A systems approach, of the kind we describe, should provide a framework within which a holistic attempt can be made to map and harness all the assets available to aid recovery for a given person, and a given community. This is based on the theory of recovery capital, which our research findings support and develop further by understanding the elements of such capital not merely as stocks or assets to be accrued by individuals or groups, but as flows or vectors operating within a dynamic system.

## Subjects for further investigation and intervention

- Perhaps the single greatest factor in deciding the course of problematic drug and alcohol use and recovery is the influence of people's social networks and local communities. Network effects in the context of drug and alcohol use, and their potential to aid recovery are not sufficiently understood, and our research calls for a collective response to recovery, primarily in the form of 'recovery communities'.
- Adopting this range of responses to supporting recovery, and to therefore addressing the problems and costs of problem drug and alcohol use, will require the ability to overcome a number of challenges and obstacles. These include pervasive social stigma, the difficulty of maintaining user involvement, the demographic and attitudinal diversity of users and their possible paths to recovery, power imbalances between experts by profession and 'experts by experience', cultural and institutional resistance and lack of funding and resources.
- A change in public attitude to the recovery and wellbeing of problem drug and alcohol users is of fundamental importance to any attempt to generate a collective response to the opportunity that a whole person recovery approach presents. Stories of leadership, examples of accomplishment and persistence, and more balanced accounts of the causes of problem drug and alcohol use by recovery champions are needed to extend everybody's empathy to those in our communities who may be struggling with a range of difficulties of which addiction might be one.

**If you would like to support the project ideas or find out how to join the local Recovery Alliance, please contact [rebecca.daddow@rsa.org.uk](mailto:rebecca.daddow@rsa.org.uk).**



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## INTRODUCTION

Problematic drug and alcohol use has a profound impact on society. This is seen in the violence fuelled by alcohol, in acquisitive crime driven by the need to fund a drug habit, in the damaged relationships between friends and family, and in the financial burden felt by public services. Indeed, it is the acknowledgement of these individual and social harms that has underpinned successive government responses and helped to shape public services. It has filled our papers with images of the deviant junkie and those they have sinned against.<sup>1</sup> It has fashioned our individual responses whether we are aware of this or not.

While there are some encouraging signs of genuinely collective approaches to tackling drug and alcohol problems, involving a range of services, families and community, this is not our mainstream response. Drug and alcohol problems are high profile and are increasingly a major concern for the public. However, in the main when it comes to solutions we are too ready to grasp for medical responses and warehouse problematic users within the criminal justice system.

Perhaps ashamed and afraid of what this aspect of human experience says about us, for the most part we continue to maintain a separation from the unpleasant realities of problem drug use. We do this through a combination of social stigmatisation and a compartmentalisation that places our own habits, dependencies and experiences on a different spectrum to others. Perhaps we should content ourselves with the view that all that can be done, is being done? We argue that the defences we have built up to prevent us confronting the issue of dependency directly, to deny its relevance to ourselves, are precisely the reasons we fail to make further progress.

We are entering a period of scarcity in terms of public finances, employment and opportunity. This will have significant implications for the individuals and communities already experiencing the realities of problem drug and alcohol use and often associated with disadvantage, debt and wider socio-economic exclusion. For example, this report touches on the link between unemployment, lack of opportunity, problem drug and alcohol use and crime. With the likelihood of increased job cuts and a tightening of state support, what does this mean for those who already struggle to find opportunities in their communities?

Of course the damage wreaked by problematic drug and alcohol use is all too real. However, here we argue for a fundamental change to our collective response; a shift away from focusing on the traditional harms, to one that recognises the hidden wealth and untapped strength of individuals and communities. Can we make this collective adjustment and turn the traditional deficit model on its head?

The RSA is interested in answering this and related questions through its programme of research and practical activity under its banner of 21st century enlightenment. This is a call to action that, in the words of the RSA's Chief Executive Matthew Taylor "invites us to return to core principles of autonomy, universalism and humanism".<sup>2</sup> It is about developing shared understanding of problems, shared responsibility, and shared solutions through the enhancement of human capability and the release of human potential.

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<sup>1</sup> Lloyd, C. (August 2010) *Sinning and Sinned Against: The Stigmatisation of Problem Drug Users*, London: UKDPC.

<sup>2</sup> Taylor, M. (2010) *Twenty-first century enlightenment*, London: RSA.

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In 2007, the RSA published *Drugs — Facing Facts*, the report from its Commission on Illegal Drugs, Communities and Public Policy, which argued for a more tailored and expansive approach to drug services.<sup>3</sup> It concluded that drug users should be treated like any other recipients of public services: they have not forfeited their rights to effective support and indeed may need it more than the average person if they are to achieve their full potential.

If problem drug users are to be treated like any other recipients of public services, as the Commission report argued, and supported to achieve their full potential, then we need a ‘progressive universalism’; an approach available to all, but that provides most support for those who need it most. As Taylor and others have argued, our capacity to empathise — to reduce our constructed sense of separation — drives a commitment to universalism and is a core competency for twenty-first century citizens.<sup>4</sup>

The end result will not be the eradication of problem drug and alcohol use — such a thing would be both unprecedented and unrealistic — but the empowerment of vulnerable people to play their full part in society as autonomous citizens able to realise their potential. This can be realised through combined, personalised strategies that may include treatment, deterrence, self-management and habit adjustment, abstinence, community support and routes into alternative life opportunities.

## The Whole Person Recovery Project

This project marks a step forward for the RSA’s work on drugs, as we attempt to realise this goal. Like much of the RSA’s activity, the Whole Person Recovery Project combines research and thinking with practical innovation on the ground. It connects to themes that are central to our mission: empowerment, co-production, user-centred approaches, and the power of networks. These themes are key to the RSA’s account of how we make change in the world, and to how we do research. They speak to our belief that knowledge does not exist within citizens or users to be extracted by research professionals, but is something that is co-created through the interaction between researchers, users and practitioners.

Our project was conceived as a way to build and test personalised services with recipients, couched in a recovery framework. What soon became apparent was that our emphasis needed to be reversed. Personalised services generally exist within a traditional framework of service provision: we propose the re-development of the framework to ensure user-centredness, whether in formal treatment services or in the institutions that can provide end-to-end support for the entire process of recovery. As a recent RSA paper makes clear: ‘recovery is ... grounded in the community and ... is a transition that can occur without professional input, and where professional input is involved, the extent of its role is far from clear.’<sup>5</sup>

## Work programme

Our project is located in two sites within West Sussex — Bognor Regis and Crawley — and has two main aims. First, to develop a model and ideas for a user-centred approach to recovery. Second, to implement the model and ideas through broad local partnerships that support individuals to initiate and sustain recovery. With these issues in mind, our work programme was divided into three main phases.

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The first phase was research. We recruited and trained a team of current and former drug and alcohol users in research techniques. We then supported this team in creating and undertaking a survey of other current and former drug and alcohol users to understand their experience of and attitudes to drug-taking and alcohol consumption and its associated impacts. We then undertook a series of in-depth interviews and focus groups with women and black and minority ethnic (BME) users to understand their experiences and ideas in more detail.

The second phase was design, where we used the research to co-design with current and former drug and alcohol users — and a range of other stakeholders — systems and ideas for personalised recovery. The third and final phase will be to pilot these ideas within the context of Bognor Regis and Crawley. Working with local agencies and the research team, we will use a design experiment model to evaluate the changes and impacts that are produced. This report concentrates on work from the first two phases, and sets out our plans for the third stage of work.

Our research has generated complex data and as we try to analyse what our work means for personalisation and recovery we need to address some of the seemingly contradictory issues that arise. For example, the role of friends and family, who can often be both a support network and co-users that reinforce habits. We have sought a research and design framework that is capable of organising and holding such complexity.

## Building capacity for empathy and action

Around one in five people have direct or indirect experience of drug addiction.<sup>6</sup> Almost 10 per cent of those aged between 16 and 59 report using illicit drugs over the last year; this rises to one in five among those aged 16 to 24.<sup>7</sup> Experience of drug use and addiction is widespread and public opinion firmly supports investment in drug services: 77 per cent of us believe it is a sensible use of government money.<sup>8</sup>

So, there are grounds for optimism about the potential to create greater public empathy with respect to problematic drug and alcohol use. This project explores how to translate this potential into meaningful engagement that reduces stigma. In particular we are interested in how services can build ‘recovery capital’.

Our research shows that many of the assets available to problem drug and alcohol users — in the form of social networks, information communication technologies (such as mobile phones and online social networking), personal skills and attributes — are often overlooked. Social networks in particular can be a crucial resource as they spread the ‘contagious’ values and behaviours of well-being and hope that are integral to recovery.<sup>9</sup>

The visual systems and recovery mapping tools developed as part of this project enables these assets to be more easily identified and mobilised. This can be critical to helping problem drug and alcohol users become socially embedded, self-aware, citizens as it ‘generates reflexivity that we believe may in itself lead to more pro-social behaviour, better awareness of the conditions in which their actions are taken, and result in a greater ability to shape them.’<sup>10</sup>

This project has used a range of qualitative research methods with an emphasis on getting people to not just participate but to engage in dialogue, share their stories and experience of working with local and central government officials, service providers, local councillors, businesses and residents.

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3 The Royal Society for the Encouragement of Arts, Manufactures and Commerce (RSA) (2007) **Drugs — Facing Facts: The report of the RSA Commission on Illegal Drugs, Communities and Public Policy**, London: RSA.

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4 Taylor, M. (2010), op. cit.

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5 Best, D. and Laudet, A. (2010) **The Potential of Recovery Capital**, London: RSA.

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6 Roberts, M. (2009) **Drug treatment at the Crossroads — Briefing: What does the public really think about addiction and its treatment?** Report on the findings of a DrugScope/ICM poll, [Online], Available: <http://www.drugscope.org.uk/Resources/Drugscope/Documents/PDF/Policy/MarcusreportICM.pdf>

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7 Hoare, J. and Moon, D. (2010) **Drug Misuse Declared: Findings from the 2009/10 British Crime Survey England and Wales** <http://rds.homeoffice.gov.uk/rds/pdfs10/hosb1310.pdf>

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8 Roberts, M. (2009), op. cit.

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9 Best, D. and Laudet, A. (2010), op. cit.

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10 Rowson, J., Broome, S. and Jones, A. (2010) **Connected Communities: How social networks power and sustain the Big Society**, London: RSA.

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A consistent theme to emerge is problem drug and alcohol users' desire to be understood by others, for their stories to be heard, and for support from others who can empathise with them. Currently a wealth of empathic capacity is concentrated among peers in recovery: wider recovery networks that extend beyond (but keep central) peers and those already engaged in the recovery field, and that have shared understanding of whole recovery responses will be better able to mobilise the individual and social assets that are key to supporting recovery in a time of public sector cuts and raised eligibility criteria to access services. User-generated, collective solutions that do not so heavily rely on state investment and facilitation have become more and more important and underpin the notion of the Big Society.

## Report structure

Ultimately, this project is practical. Its success will not be judged on the strength of the ideas and research in this report, but on the extent to which we are able to implement them and succeed in increasing people's social assets and untapping wider empathic capacity. The evaluation of our success or otherwise will be presented in future reports.

In this first report we aim to set out the project's background and what evidence, beliefs and trends have driven our work. The report primarily focuses on problematic drug use and the responses to it. However it does consider problematic alcohol use throughout, particularly in discussing our survey findings which illustrate how problem drug and alcohol use often go hand in hand. We spend some time outlining our research methods (as these are in themselves critical to our objectives) as well as our findings. The report aims to give a true account of the 'user voice', the experiences they shared with us and their hopes for the future. Often the discussions were focussed on the challenges and barriers that individuals experienced to their recovery journey. These journeys span many years and a number of different locations across the UK — user accounts should therefore primarily be understood in terms of the experience of the individual rather than directly related to Bognor Regis or Crawley. Our experience has certainly been that the local treatment services and other health organisations are ambitious in their desire to meet people's needs, have engaged openly with the project and many are staffed with individuals who are in recovery themselves.

In **Section 1** we give an overview of current drugs policy and discuss the shift towards recovery. We outline some of the challenges and opportunities in strengthening this shift in the context of public service cuts and the government's emerging narrative of the Big Society.

In **Section 2** we provide an overview of the evidence from user-centred approaches and the challenges they present in the drugs field. **Section 3** describes the main phases of the project and the methods we have used throughout. The findings of our research are presented in **Section 4**, and we explain what they may mean in terms of operationalising personalised recovery. From here, **Section 5** introduces the Whole Person Recovery System. In the final sections we outline the ideas which we will be piloting in the next phase of the project (**Section 6**) and offer some reflections and conclusions we have arrived at through our work to date (**Section 7**).

This project has gathered a variety of personal stories, memories and anecdotes that grounded the research in real life. Some of these stories are shared throughout the report and names have been changed to protect anonymity.



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“Over the years I have lost at least ten people that have died under the age of 30 from overdoses.”

— Workshop Participant

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## SECTION 1. The changing face of UK drugs policy

This section describes some of the social harms and economic costs incurred through problematic drug and alcohol use in the UK. It then goes on to suggest how a combination of these costs, the limitations of current strategic responses, and wider trends — such as the shift of power from the centre to individuals and communities, the Big Society agenda and diminished public service spending — are prompting new thinking about the best way forward on social inclusion and problem drug use. This emerging thinking is beginning to challenge the prevailing emphasis on a combination of medical treatment programmes and ‘containment’ via the criminal justice system. In this new schema, greater emphasis is placed on personalised services, interpersonal relationships and strategies to support long-term recovery by drawing on all available community assets.

### PROBLEM DRUG USE

DrugScope define problem or problematic drug use as ‘*drug use which could either be dependent or recreational. In other words, it is not necessarily the frequency of drug use which is the primary ‘problem’ but the effects that drug-taking have on the user’s life (i.e. they may experience social, financial, psychological, physical or legal problems as a result of their drug use)*’.<sup>11</sup> For the purposes of this report we extend this definition to include problem or problematic alcohol use and refer to ‘problem’ or ‘problematic drug and alcohol use’ where this extended definition is appropriate.

### Incidence and prevalence

Estimates suggest that on average some 4 million people take illegal substances in any given year.<sup>12</sup> For most, trying drugs is limited to adolescent experimentation that is short-lived, relatively trouble free and usually restricted to the use of drugs such as cannabis, amphetamines, and ecstasy.<sup>13</sup> But for others, drug and alcohol use can become problematic, leading to a range of individual and social harms including drug-related deaths and crime, infectious diseases, unemployment, sex work, domestic and child abuse. What is less measurable but becomes patently clear when talking to problematic users, is also the sheer level of unhappiness they can experience.

Difficulties in measuring illicit activities and a variation in the definitions used for ‘problem drug use’ mean that estimates of problem drug use in the UK vary across sources (although less so for estimates of problem alcohol use). Figures suggest that there are between 330,000<sup>14</sup> and 400,469<sup>15</sup> problem drug users and an estimated 1.6 million problem alcohol users.<sup>16</sup> For drug use in England however, this number fails to capture those using powder cocaine which, as the National Treatment Agency (NTA) recently reported, is one of the emerging drugs of concern, particularly among young people aged between 18 and 24 years. While the number of people within this age group presenting for treatment for heroin and crack cocaine reduced by 30 per cent between 2005-06 and 2008-09 (from 12,320 to 8,603), the number of those presenting for treatment for powder cocaine rose from 1,591 in 2005-06 to 2,998 in 2008-09 (a rise of 88 per cent).<sup>17</sup> This trend is indicative of the changing patterns and trends in drug use among younger people. Falling levels in purity of illegal drugs such as heroin and crack cocaine have accelerated the trend of multiple drug use across all age groups but in particular amongst young people<sup>18</sup>. In addition, the internet has emerged as a new marketplace for drugs<sup>19</sup> as has been recently revealed with the exposure of drugs such as mephedrone.

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11 See <http://www.drugscope.org.uk/resources/drugsearch/drugsearchpages/problemuse>

12 Hough, M. and Mitchell, D. (2003) ‘Drug Dependent Offenders and Justice for All’, in Tonry, M. (ed.) **Confronting Crime**, Cullompton: Willan Publishing.

13 Seddon, T. (2006) ‘Drugs, Crime and Social Exclusion. Social Context and Social Theory in British Drugs-Crime Research’, **The British Journal of Criminology**, vol. 46, no. 4, pp. 680-703.

14 National Audit Office (March 2010) **Tackling problem drug use**, London: National Audit Office.

15 European Monitoring Centre for Drugs and Drug Addiction (November 2009) **New Drugs and Emerging Trends**, [Online], Available: <http://www.emcdda.europa.eu/situation/new-drugs-and-trends/4> [06.07.10].

16 McManus, S., Meltzer, H., Brugha, T., Bebbington, P. and Jenkins, R. (2009) ‘Adult psychiatric morbidity in England, 2007’ in Ward et al. (2010) **Investing in Alcohol Treatment — Reducing Costs and Improving Lives. Alcohol Concern’s learning from 10 years of consultancy and training**, London: Alcohol Concern.

17 Drugscope (October 2009) **Drugscope responds to NTA figure on drug treatment**, [Online], Available: [http://www.drugscope.org.uk/ourwork/pressoffice/pressreleases/NTA\\_o809\\_figures](http://www.drugscope.org.uk/ourwork/pressoffice/pressreleases/NTA_o809_figures) [06.07.10].

18 Drugscope (2009) ‘Street Drug Trends Survey 2009’ in **Druglink Magazine**, September/October 2009.

19 European Monitoring Centre for Drugs and Drug Addiction (November 2009) **New Drugs and Emerging Trends**, [Online], Available: <http://www.emcdda.europa.eu/situation/new-drugs-and-trends/4> [06.07.10].

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## Counting the cost

The cost of problem drug and alcohol use is borne by direct government expenditure ‘incurred by unemployment, criminal justice, health problems and social services’<sup>20</sup>, but does not include all of the harm caused to victims of crime, the emotional and financial costs to friends and family, the impact on community confidence in local agencies, or the impact on how people feel about the place in which they live.

The impact of the relatively small number of problem drug and alcohol users is significant. Drug use has an enormous economic and social cost, currently estimated at £15.3 billion per annum. This equates to £44,231 per year per problematic drug user.<sup>21</sup> Problem alcohol use is estimated to cost £2.7 billion per year in healthcare costs alone.<sup>22</sup>

It is understandable then that local and national strategies focus primarily on improving treatment services. Under the current framework, these are directed towards reducing the ‘harms’ associated with problem use, both for the individual in terms of physical health, and for society in terms of drug and alcohol-related crime and abuse.

## The dominant response

Until recently the concept of drug-related harm has been interpreted rather narrowly by those charged with reducing it, tending to focus on the effect of the substance on the user. This has sustained a dominant medical and psychological worldview to addiction that positions the substance-user as a ‘discreet individual’<sup>23</sup> or yet more abstractly, as an ‘autonomously behaving particle’<sup>24</sup> rather than ‘viewing people in terms of their relationships’.<sup>25</sup>

Crime and community safety strategies have tended to focus on community harms with crime as the main indicator. This has established the link between the use of drugs such as heroin and crack cocaine and acquisitive crime as strongest and has driven the focus of treatment provision.<sup>26</sup> Our research further suggests that it is because these drugs are highly addictive and users require increasing amounts to experience the same effect as their first hit, that individuals are driven to commit crime. As the addiction gains a hold and then accelerates, a financial imperative to commit crime is often established.<sup>27</sup>

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*“If it’s there I’d give it a try: not everything, there’s a limit. I tried crack once... I wouldn’t do crack again.”*

— Workshop Participant

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### KAMIKAZE STYLE CRIME

*“I call it kamikaze style. You’ll just run into a shop, take something and then run out and if you get caught, you get caught and if you don’t then you’re alright.”*

Heroin was one of the first drugs that David tried. Within a matter of days he was addicted, constantly chasing the buzz he experienced from his very first hit, taking more and more heroin but never managing to get it back. David regularly stole in order to pay for his habit, committing what he calls ‘kamikaze’ thefts only when he was absolutely desperate, as the risk of being caught was so great.

One day there was a display of vacuum cleaners in the front of a shop. David ran into the shop and grabbed one of the large boxes and ran out again. He went back and watched as a customer bought one of the vacuum cleaners from the display and, as they were leaving, asked them for their receipt. David promptly used this to get cash back from the item he had stolen earlier that day. While incidents like this funded David’s habit, he drew the line at threatening or attacking people to extract drug money.

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## Balancing treatment with recovery

Set up in 2001 as the specialist health authority within the NHS to improve the availability, capacity and effectiveness of treatment for drug misuse in England, the NTA has for several years been seen as a proponent of the view that we need a more balanced view of individual substance misusers and their journey to recovery. Its primary focus, until 2008, was to increase the numbers of drug users in treatment and to increase the percentage of those completing, or appropriately continuing, treatment year on year. It successfully met its targets, increasing the number in treatment by 130 per cent from 85,000 to 195,400 between 1998-99 and 2006-07.<sup>28</sup>

Notwithstanding this success, since 2009, the NTA has shifted its focus from getting people into treatment to helping service users achieve and sustain long-term recovery. In *Commissioning for Recovery*, the NTA explicitly laid out their ambition to enable ‘personalised treatment to develop and meet the needs of the diverse range of drug misusers.’<sup>29</sup> This strategy marks a significant shift away from the treatment-cure model of services in the recent past to those geared up to support recovery that is shaped by the individual themselves.

Guidance from the Home Office lays out plans for connecting the national drug strategy to the different programmes across government aimed at supporting communities and families.<sup>30</sup> This recognises the existing potential of communities and families to address the problems associated with drug and alcohol use and seeks to enable, ‘local partnerships to capture and multiply the potential that already exists.’<sup>31</sup> This will be essential if it is to make the cuts and efficiencies that every part of the public sector is charged with achieving over the coming years.

While many organisational strategies<sup>32</sup> have until recently mirrored the NTA’s early focus on the numbers going into treatment, the past couple of years have seen a strengthening of the emphasis on harm reduction, and the social dimension of recovery. The ten-year drug strategy of 2008 explicitly recognised the wider influences and scope of need that must be addressed in order to significantly reduce the harms associated with problem drug and alcohol use.<sup>33</sup>

This shift in emphasis seems to have been continued by the new coalition government as it prepares to publish a new drug strategy in December 2010. Early indications from the *2010 Drug Strategy Consultation Paper* suggest that the new strategy will take a four-pronged approach covering prevention, stronger enforcement, a focus on outcomes, and an orientation towards recovery.

These priorities emphasise the need to look at drug and alcohol problems in their broader context and considers drugs issues alongside ‘alcohol abuse, child protection, mental health, employment and housing.’<sup>34</sup> This suggests a continued expansion beyond narrow individualistic and crime-related links (and therefore the principle focus on heroin and crack cocaine) to consider the wider social and economic factors that drive problematic drug and alcohol use and that help or hinder recovery.

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20 *ibid.*

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21 Singleton et al. (eds.) (2006) **Measuring different aspects of problem drug use: methodological developments** 2<sup>nd</sup> edition, London: Home Office.

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22 Ward et al. (2010) **Investing in Alcohol Treatment — Reducing Costs and Improving Lives. Alcohol Concern’s learning from 10 years of consultancy and training**, London: Alcohol Concern.

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23 Adams, P. (2008) **Fragmented Intimacy. Addiction in a Social World**, New York: Springer.

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24 *ibid.*

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25 *ibid.*

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26 Kaye, S., Darke, S., Finlay-Jones, R. (1998) ‘The onset of heroin use and criminal behaviour: does order make a difference?’, **Drug and Alcohol Dependence**, vol. 53, no. 1, pp. 79-86.

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27 Bean, P. (2004) ‘Chapter 2, Drugs and Crime: Theoretical Assumptions’, **Drugs and Crime**, Cullompton: Willan Publishing.

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28 NTA (May 2008) **Improving services for substance misuse. Commissioning drug treatment and harm reduction services**, London: NTA.

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29 NTA (January 2010) **Commissioning for Recovery. Drug treatment, reintegration and recovery in the community and prisons: a guide for drug partnerships**, London: NTA.

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30 Home Office (March 2010) **Reducing Drug and Alcohol Harms to Communities and Families: Updated Guidance on Developing Local Practice**, London: Home Office.

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31 *ibid.*

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32 Updated Drug Strategy 2002. See [http://image.guardian.co.uk/sys-files/Guardian/documents/2002/12/03/Updated\\_Drug\\_Strategy02\\_Executive\\_Summary.pdf](http://image.guardian.co.uk/sys-files/Guardian/documents/2002/12/03/Updated_Drug_Strategy02_Executive_Summary.pdf)

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33 HM Government (2008) **Drugs: protecting families and communities. The 2008 drug strategy**, London: HM Government.

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34 Home Office (August 2010) **2010 Drug Strategy Consultation Paper**, London: Home Office.

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## The Process of Recovery

Three of the commonly referred to definitions of recovery:

*‘The process of recovery from problematic substance use is characterised by voluntarily-sustained control over substance use which maximises health and wellbeing and participation in the rights, roles and responsibilities of society.’*

— UKDPC Consensus Group, 2008

*‘Recovery from substance dependence is a voluntarily maintained lifestyle characterized by sobriety, personal health, and citizenship.’*

— Betty Ford Institute Consensus Panel, 2007

*‘Recovery is the experience (a process and a sustained status) through which individuals, families, and communities impacted by severe alcohol and other drug (AOD) problems utilize internal and external resources to voluntarily resolve these problems, heal the wounds inflicted by AOD-related problems, actively manage their continued vulnerability to such problems, and develop a healthy, productive, and meaningful life.’*

— William White, 2007

This report does not seek to offer a definitive definition of recovery. For the purposes of the report we have used the findings of our research to shape our understanding of it and as a result we recognise that there are a variety of routes into problematic drug and alcohol use and a variety of routes out of it. This further emphasises the need for personalised pathways that support an individual’s recovery journey and supports the key messages of DrugScope’s 2009 report *Drug treatment at the crossroads. What it’s for, where it’s at and how to make it even better.*

## Recovery oriented mental health services

*The objectives of ‘recovery-oriented mental health services’ are different from the objectives of traditional, ‘treatment-and-cure’ health services. The latter emphasises symptom relief and relapse prevention. In recovery, symptomatic improvement is still important, and may well play a key role in a person’s recovery, but quality of life, as judged by the individual, is central.*

— Sainsbury Centre for Mental Health

The focus on recovery reflects the influence of a growing body of research evidence that highlights the importance of wider personal relationships to problem drug and alcohol users in shaping their outlook and behaviour. Increasingly, voices within the drugs service mainstream are calling for treatment to ‘deal with all relevant issues in a holistic way.’<sup>35</sup> This means that treatment outcomes are emphasised over process and are being defined in terms of recovery, employment and reintegration rather than the historical focus on offending and health. This follows a broadly social approach<sup>36</sup> to understanding addiction that views individuals in terms of their complex relationships.



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## Recovery

These moves have been supported by efforts to provide greater conceptual clarity around the ultimate goals of drugs strategies. The emerging consensus focuses on the concept of ‘recovery’ from problematic drug and alcohol use, and the reduction of personal and social harms which flow from it. This concept has its origins rooted in the ‘early mental health self-help and mutual aid groups; e.g. “We Are Not Alone” (1940s), and Alcoholics Anonymous mutual aid groups’<sup>37</sup> but more recently it has been more strongly associated with the mental health discourse, with which the drugs field has much in common (see **box opposite**).

Although ‘recovery’ is not really new to the drug and alcohol field, there remains a level of divergence about what exactly it entails and how it is measured. The ongoing debate around the definition of recovery ‘touches on some of the most controversial issues within the addictions field.’<sup>38</sup> However, there is an apparent agreement on the core components across the definitions; ‘wellbeing and quality of life, some measure of community engagement or citizenship, and some measure of sobriety.’<sup>39</sup> Whether this measure of sobriety relates directly to abstinence, reduced use or medically supported recovery is not for this report to define; for us, recovery has been defined individually by the people involved in the project.

## Drivers of change

A number of factors and trends, some external to the drugs field, have added impetus and legitimacy to the shift towards a more holistic understanding of problem drug use, and a recovery-based model for drugs services. This includes changes in the political landscape, and in particular moves — begun by the previous administration and accelerated by the coalition — towards greater localism and citizen empowerment. In addition, spending cuts brings with it pressure to yield greater efficiencies. Meanwhile, there is a growing acknowledgement among policymakers of the need for drugs services to be integrated into the mainstream of public policy, and for government departments to share responsibility for their success.

## Devolution, localism and empowerment

Over the last decade, the Labour administration developed and implemented changes to the democratic system including the creation of devolved administrations in Scotland, Wales and Northern Ireland. It also implemented community-led regeneration initiatives like the New Deal for Communities programme, which gradually shifted ‘power, influence and responsibility away from existing centres of power into the hands of communities and individual citizens.’<sup>40</sup> The 2006 White Paper, *Strong and Prosperous Communities* acknowledged the central importance of capturing local peoples’ views, experiences and perceptions to ensure that local services are developed and delivered as solutions with greater flexibility in order to reflect local views and preferences.<sup>41</sup>

The coalition government has pledged to further decentralise power, handing it down to local authorities and the communities they serve.<sup>42</sup> This ambition is one of the building blocks of the emerging Big Society initiative. The government has already made substantial moves to progress decentralisation with the removal of ring-fenced funding to local authorities and the development of place based budgeting, although it remains unclear what the reality of such moves will mean for drug services and problem drug and alcohol users. It is anticipated that the Decentralisation and Localism Bill announced during the Queen’s speech in May will set out an implementation plan to meet its aim of devolving power to local authorities and communities.

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35 Home Office (March 2010) op. cit.

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36 Adams, P. (2008), op. cit.

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37 Bamber, S. (2009) **Revolution in the head**, [Online], Available: <http://www.theartoflifeitself.org/2009/11/23/revolution-in-the-head>

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38 White, W.L. (2007) ‘Addiction Recovery: Its definition and conceptual boundaries’, **Journal of Substance Abuse Treatment**, vol. 33, no. 3, pp. 229-241.

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39 Best, D. and Laudet, A. (2010), op.cit.

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40 Communities and Local Government (July 2008) **Communities in Control. Real People, Real Power**, London: The Stationery Office.

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41 Department for Communities and Local Government (October 2006) **Strong and prosperous communities. The Local Government White Paper**, [Online], Available: [www.communities.gov.uk/documents/localgovernment/pdf/152456.pdf](http://www.communities.gov.uk/documents/localgovernment/pdf/152456.pdf) [06.08.10].

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42 HM Government (May 2010) **The Coalition: our programme for government**, [Online], Available: [www.cabinetoffice.gov.uk/media/409088/pfg\\_coalition.pdf](http://www.cabinetoffice.gov.uk/media/409088/pfg_coalition.pdf) [06.08.10].

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Whether the rationale for devolving power is managerial decentralisation, community empowerment, or a mechanism to make efficiency savings and shrink the state, localism has been a significant driver of change in people's perceptions of public services.<sup>43</sup> The ambition is to develop more locally tailored services that meet the needs of 'particular places and within particular communities, with their own demography and geography, physical and social infrastructure and needs and preferences.'<sup>44</sup>

For this ambition to be realised, systems and methods to aid recovery must be established in such a way that they can be applied at a hyper-local and even individual level. In this model it is often the service user, rather than provider, who knows best. In the words of the Home Office 'it is those who experience need and receive services who are best placed to decide what services they need, inform new developments and interventions and evaluate their effectiveness.'<sup>45</sup>

However, despite greater decentralisation there is a risk that problem drug and alcohol use remains on the margins of local agendas. Localism works best when central government, the local authority, and the local electorate are in harmony.<sup>46</sup> There is a tension between the desire for a powerful national drugs strategy, and the desire to hand power to local authorities and communities. Experience has shown, for example, that few local authorities selected specific drug-related targets, such as National Indicator 42 (the percentage of people perceiving drug use or drug dealing as a problem) in their basket of indicators within their local area agreement.

Problem drug and alcohol use is often viewed as a peripheral issue, low in the public consciousness and subject to polarised debates around crime and lifestyle choices on the one hand, and advocates of greater investment and empathy on the other. Inevitably, this creates the danger of creating 'postcode lotteries' in terms of service provision. There is a need to bring the drugs agenda in from the margins, embedding recovery at its heart, and to better understand and act on the impacts problematic drug and alcohol use has on individuals, families and communities more broadly.

## Recovery in austerity

In doing this we need to find ways to extract greater value from existing resources; this is especially important in times of relative austerity. National and local governments face major social, economic and environmental challenges related to an 'ageing population, massive health inequalities and an education system which fails to overcome social and economic background.'<sup>47</sup> In tandem with the drastic public sector cuts that will inevitably diminish the capacity of public services, conditions are not favourable for aiding problem drug and alcohol users, who are among some of the most vulnerable (but 'least popular') groups at the margins of society.

Growing unemployment is just one aspect of the economic downturn that could significantly increase the incidence of problematic drug and alcohol misuse, whilst also diminishing our capacity to support recovery. It is worth considering this aspect in isolation, as an illustration of the challenges that the recovery agenda faces, but also of its potential to tap into hidden resources.

At the beginning of 2010, unemployment reached a level unseen since 1996, increasing by 0.3 per cent between December 2009 and February 2010 to 8.0 per cent equating to 2.5 million people.<sup>48</sup>

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43 2020 Public Services Trust. (March 2010) **Delivering a Localist Future: a route map for change**, London: 2020 PST.

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44 Local Government Delivery Council (2009) **Delivering public service transformation 2009**, [Online], Available: [www.idea.gov.uk/idk/aio/9627311](http://www.idea.gov.uk/idk/aio/9627311) [06.08.10].

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45 Home Office (Oct 2009) **Making it Local. A report on the London Drug Policy Forum strategic drug partnership delivery project for the Home Office**, London: Home Office.

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46 RSA — Home Office Drugs Policy Seminar — Will localism drive the national drugs strategy?, January 2009.

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47 2020 PST (March 2010), op. cit.

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48 Office for National Statistics (April 2010) **Statistical Bulletin. Labour Market Statistics**, [Online], Available: [www.statistics.gov.uk/pdfdir/lmsuko410.pdf](http://www.statistics.gov.uk/pdfdir/lmsuko410.pdf) [06.08.10].

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49 Office for National Statistics (August 2010) **Statistical Bulletin. Labour Market Statistics**, [Online], Available: [www.statistics.gov.uk/pdfdir/lmsuko810.pdf](http://www.statistics.gov.uk/pdfdir/lmsuko810.pdf) [01.09.10].

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50 The Prince's Trust (Dec 2009) **YouGov Youth Index 2010**, [Online], Available: [www.princes-trust.org.uk/pdf/Youth\\_Index\\_2010.pdf](http://www.princes-trust.org.uk/pdf/Youth_Index_2010.pdf) [06.08.10].

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51 South et al. (2001) 'Idle hands. One feature of Britain's drug treatment clients is so unfamiliar that it goes unremarked: the vast majority are unemployed. Could work promote recovery?', **Drug and Alcohol Findings**, Issue 6.

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52 Seddon, T. (2006), op. cit.

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53 Crimestoppers (January 2010) **One theft a minute**, [Online], Available: [www.crimestoppers-uk.org/media-centre/crime-in-the-news/january-2010--crime-in-the-news/one-theft-a-minute](http://www.crimestoppers-uk.org/media-centre/crime-in-the-news/january-2010--crime-in-the-news/one-theft-a-minute) [30.07.10].

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54 The Prince's Trust (Dec 2009), op. cit.

These numbers have shown a small improvement in the three months to June 2010 with a 0.2 percentage point decrease in the number of unemployed. However, the number of people unemployed for over twelve months increased by more than 4 per cent in the same period.<sup>49</sup> Growing numbers of young people are not in education, employment or training leading to concerns over a 'lost generation' as collateral damage of the recession.<sup>50</sup>

Problem drug and alcohol use and unemployment are correlated.<sup>51</sup> Endemic unemployment would seem to fuel a feedback loop in which unemployed people are more likely to use drugs and alcohol *problematically*, which then negatively influences their desire or likelihood to gain employment.

### SAM

*"I wanted to join the army but they wouldn't let me cos of my asthma. That ain't fair. So what am I gonna do then? I'll just take drugs."*

The last thing that Sam wants is to stack shelves in the local supermarket or clean offices. He wants a job that he can feel proud about and feel a sense of achievement. For him, that means joining the Army. But he has asthma and has been told that as a result, he can't join up.

A combination of drug and crime problems with pre-existing multiple conditions of social deprivation in particular areas, such as high levels of unemployment, limits the opportunities of users to engage in legitimate economic activity. Engagement in criminal activity or drug use and dealing offers 'an active solution to unemployment.'<sup>52</sup> A survey by the British Retail Consortium found that thefts by customers increased by a third between 2008 and 2009, as the first effects of the downturn were felt. With almost half a million thefts during that period, this equates to one per minute and a cost to industry of £1.1bn.<sup>53</sup>

In 2009 the Prince's Trust's reported that one in ten young people felt that unemployment drove them to drugs and alcohol.<sup>54</sup> As common sense dictates, and our research findings confirm, economic pressures can lead some people to seek an 'Escape' from reality and their lives through drug and alcohol use. At a time when unemployment is high and large numbers of people have been made redundant, alcohol and other substances offer one response to stress and a release from boredom and misery.

Our research shows that for those already gripped by long-term drug dependency, the routine offered by the need to fund and seek out a substance of choice is seen as an alternative to the routine that might otherwise have been provided by the workplace. This activity also incidentally provides opportunities for socialising with friends and acquaintances.

### MIKE

*"When I got clean it wasn't the drugs I missed, it was the environment. I missed skulking about, the seediness of it. You're always on the go."*

When Mike got clean the first time, the thing that he missed most was the whole routine of grafting for money, scoring and using and then repeating that throughout the day and he missed seeing all his mates who were out doing the same thing. Instead he was sat at home watching TV waiting for the time to pick up his methadone script. His recovery didn't last long.

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In the context of drastic reductions in public service spending, it has become even more important to identify and tap into hidden community capability and assets to cover the expected shortfall, and thereby maintain a basic level of mutual support to those in recovery.

For example, over many decades, unpaid carers have provided thousands of hours of support to family members and others within their communities to an estimated value of £87 billion a year.<sup>55</sup> Those specifically supporting problem drug users are estimated to save the NHS £750 million per year.<sup>56</sup> Such (potential) carers make up a large part of the existing resource within families and communities identified in the drugs strategy and present an opportunity to make the efficiency savings needed. As the Home Office says, this ‘does not assume that changes can be brought about without funding; rather, it is based on the principle that with the right catalyst and a systematic approach, small triggers can deliver substantial change.’<sup>57</sup>

## Mainstreaming recovery

In July 2010, the Department of Health announced that the NTA is to be abolished, with its responsibilities transferred to the new Public Health Service, to be set up by April 2012. This is part of the government’s strategy to ‘increase accountability and transparency, and to reduce the number and cost of quangos’ across government. The move is expected to deliver savings of over £180m by 2014-15 in the health sector alone.<sup>58</sup>

Perhaps surprisingly, these changes may act as a catalyst for drug and alcohol issues to be brought into the mainstream of public health and community policy. As Martin Barnes, DrugScope’s Chief Executive wrote: ‘recovery from addiction requires the support and engagement of a range of local agencies, including providers of housing, training and employment, and it is crucial that this partnership approach is reflected across departments within government.’<sup>59</sup>

This emphasis on partnership working is welcome, and overdue. In 2007 the RSA argued that drugs issues needed to be incorporated into mainstream social policy and viewed as matters of social exclusion and public health, rather than of crime and criminal justice.<sup>60</sup> An effective drugs strategy, it argues, would require ‘systematic consideration of the particular needs of a community in relation to drug use in all areas of policy and social provision rather than simply looking at drugs in isolation and delivering services in a silo.’<sup>61</sup> But while ‘integrated, locally focused and efficient public services are increasingly becoming the norm,’<sup>62</sup> drug and alcohol services still have a long way to go.

Working across government departments and ensuring that problem drug and alcohol is embedded in the policy mainstream is difficult, although the direction of travel is encouraging. The 2008 drugs strategy called for an end to silo-working and an expansion of the frameworks in which services are delivered.<sup>63</sup> On the back of this, system change pilots were launched to test new approaches to drug treatment and social reintegration. These aimed to provide better end-to-end management of individuals through the system, ‘including a more effective use of pooled funding and individual budgets, with a sharper focus on achieving positive outcomes for drug users, their families and their communities.’<sup>64</sup>

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*“If it wasn’t for my mother,  
I wouldn’t be here.”*

— Workshop Participant

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*“For years, there was the basic assumption at the heart of government that the way to improve things in society was to micromanage from the centre, from Westminster. But this just doesn’t work... The success of the Big Society will depend on the daily decisions of millions of people: on them giving their time, effort, even money, to causes around them.”*

— Prime Minister, David Cameron 2010<sup>66</sup>

The ambition for cross-departmental working extends into the forthcoming drug strategy which will seek to delegate responsibility for each of the four key areas to a different department:

- prevent drug use (Department for Education);
- strengthen enforcement, the criminal justice and legal framework (joint Home Office and Ministry of Justice);
- rebalance treatment to support drug free outcomes (Department of Health); and
- support recovery to break the cycle of drug addiction (Department for Work and Pensions).<sup>65</sup>

The reality of this structure remains unclear and suggests a potential danger of reinforcing siloed working, especially if the drug strategy fails to create holistic targets that recognise the impact and dynamic relationships between each area. The Whole Person Recovery System (see **Section 4**) that this report maps out provides a model to overcome these dangers.

A critical question is whether the recent shifts to this kind of approach will withstand the current economic climate. The rising demands on health and social services that result from recession and fragile economic growth in combination with tightening public sector budgets casts doubt on the potential to realise the benefits of recent changes to drug and alcohol services, with their rebalancing towards recovery. There is a danger of tightening of eligibility criteria, resulting in smaller numbers of people receiving services. Those viewed to be the most ‘deserving’ will win in this process, and vulnerable groups, including problem drug and alcohol users, will lose out. Even within drug and alcohol services, the temptation to cherry-pick clients may increase as the emphasis on payment by results becomes ubiquitous to public services.

## The Big Society

The coalition government has placed the idea of the Big Society at the heart of public sector reform with the ambition to place ‘power and opportunity into people’s hands’ in order to ‘build the free, fair and responsible society that we want to see.’<sup>67</sup>

The Big Society programme, if it can be described as such, aims to recruit a 5,000 strong army of volunteers, and better mobilise existing resources. In some ways the narrative behind this marries well with our thinking here. Recovery, as we frame it, is an asset-based approach, which seeks to reframe conversations with problem drug and alcohol users by asking what they have and what they can do, rather than taking a deficit model in which only their failings or lack of resources are exposed, and to which it is proposed that local services are the only viable answer.

As we shall return to, the concept of ‘recovery capital’ — encompassing personal, social and community capital and tailored to individuals in its design — is the foundation of long-term recovery. Without a focus on improving and strengthening access to recovery capital, the Big Society may turn out to be not ‘big enough’ to properly include problem drug and alcohol users, who are after all, part of this society and not outside of it. This is a political problem for the coalition government who have stressed their aim to tackle social deprivation and poverty and ensure that cuts are fair.

55 Buckner, L. & Yeandle, S. (Dec 2009) **Valuing Carers**, University of Leeds: Carers UK.

56 UKDPC (November 2009) **Supporting the Supporters: families of drug users**, London: UKDPC.

57 Home Office (March 2010), op. cit.

58 Department of Health (July 2010) **Review of arms length bodies to cut bureaucracy**, [Online], Available: [www.dh.gov.uk/en/MediaCentre/Pressreleases/DH\\_117844](http://www.dh.gov.uk/en/MediaCentre/Pressreleases/DH_117844) [26.07.10].

59 Barnes, M (July 2010) **DrugScope responds to government’s decision to abolish National Treatment Agency**, [Online], Available: [www.drugscope.org.uk/ourwork/pressoffice/pressreleases/NTA\\_announcement.htm](http://www.drugscope.org.uk/ourwork/pressoffice/pressreleases/NTA_announcement.htm) [06.08.10].

60 The Royal Society for the Encouragement of Arts, Manufactures and Commerce (RSA) (2007), op. cit.

61 *ibid.*

62 Local Government Delivery Council (2009), op. cit.

63 HM Government (2008), op. cit.

64 See <http://www.nta.nhs.uk/who-healthcare-scp.aspx>

65 Home Office (August 2010), op. cit.

66 ‘Our Big Society Agenda’, David Cameron speech, Liverpool 19 July 2010.

67 Cabinet Office (May 2010) **Government puts Big Society at heart of public sector reform**, [Online], Available: [www.cabinetoffice.gov.uk/newsroom/news\\_releases/2010/100518-news-big-society-launch.aspx](http://www.cabinetoffice.gov.uk/newsroom/news_releases/2010/100518-news-big-society-launch.aspx) [06.08.10].

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## A new drugs strategy

The forthcoming national drug strategy, scheduled to be published in December 2010,<sup>68</sup> gives some grounds for optimism, seeming to call for a holistic approach that incorporates ‘alcohol abuse, child protection, mental health, employment and housing.’<sup>69</sup> Seemingly, it also recognises the need for a joint drugs and alcohol approach ‘particularly in the areas of prevention, treatment and recovery.’<sup>70</sup> The planned strategy recognises the need for a skilled workforce able to offer more ambitious and personalised services, and to understand psychosocial as well as medical components of recovery. It will question how employers can be encouraged to look beyond the stigma of drug use to the potential and assets of citizens in recovery.

Our findings provide practical answers to some of these questions. They indicate how we can improve the ‘patient experience’ of treatment and recovery,<sup>71</sup> harness existing recovery capital, and develop strong networks across disciplines and communities. What we call our ‘whole person recovery’ approach, offers a way of bridging the seemingly contradictory aims of both personalising services within a user-centred framework, and of creating efficient, standardised structures and services. It shifts the means of organisation from something that is rigid, top-down, and often siloed, to something that is capable of holding the user at the centre of the multi-dimensional process of recovery. It provides an interface with communities that is currently lacking and widens what we think of as treatment.<sup>72</sup> Finally, it offers a framework that fits the nature of the set of problems encountered and that is much broader than those constructed by crime and drugs partnerships.<sup>73</sup> This — as the next section makes clear — means taking a user-centred approach to research, service design and pilot stage interventions: this is fundamental to our project.

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68 Home Office (August 2010), op. cit.

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69 *ibid.*

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70 *ibid.*

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71 Home Office (August 2010), op. cit.

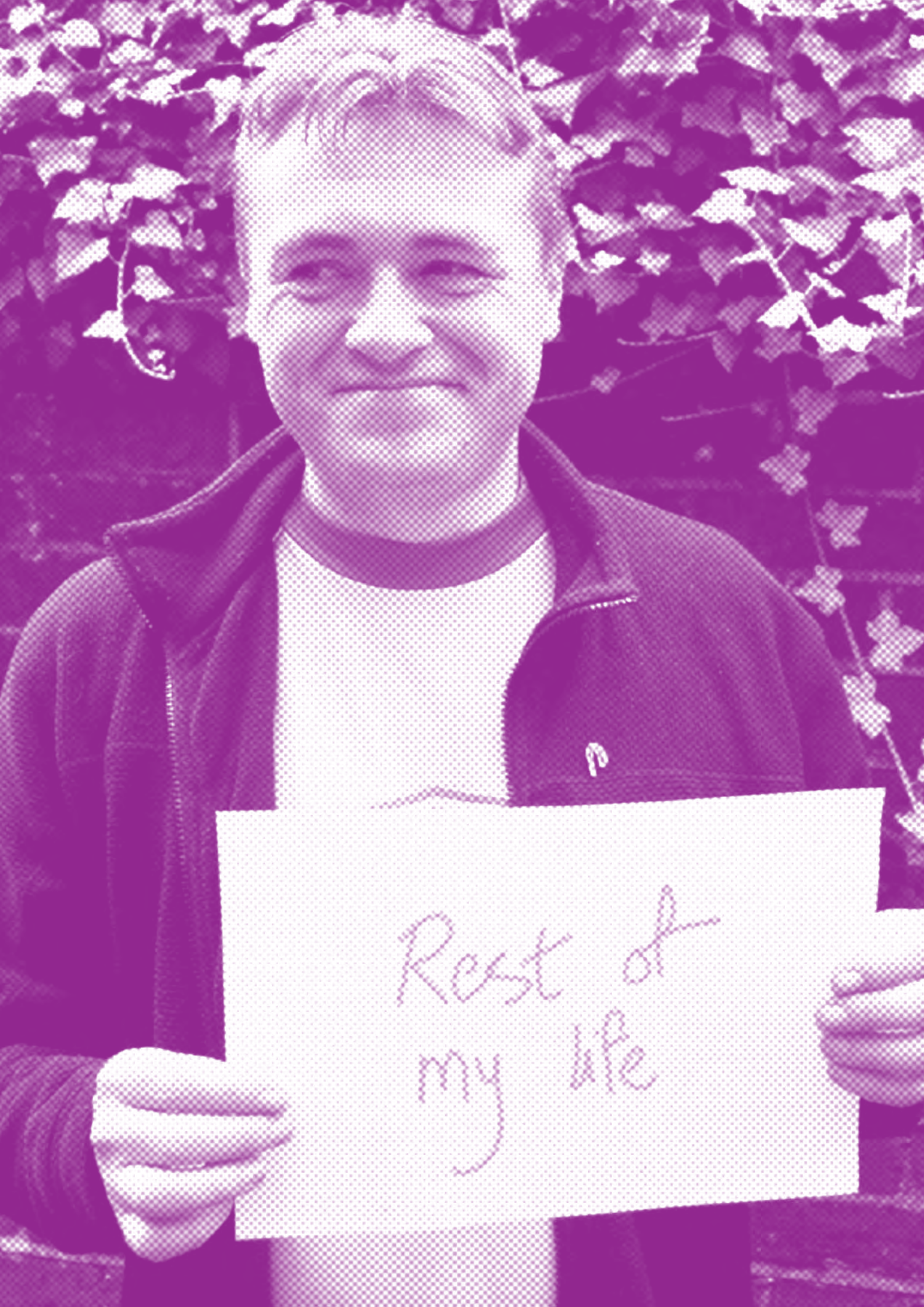
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72 RSA — Home Office Drugs Policy Seminar — User centred drug services, April 2009.

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73 RSA — Home Office Drugs Policy Seminar — Will localism drive the national drugs strategy?, January 2009.





Rest of  
my life

## SECTION 2. *User-centred approaches*

In this section, we look at the reasons for taking the user-centred agenda seriously, and the underlying drivers that make it all the more important to modern services. We discuss the barriers and challenges that exist to making such methods meaningful and accessible to all. We try here to distinguish the ‘service user’ from the ‘problem drug and alcohol user’ as a large amount of the research referred to in this section is specifically about those users in treatment services.

There has been an increasing focus on the relationships between public services and service users in the last decade. Under the previous administration, plans to give individuals, communities and service providers the information and power they need to personalise public services was set out in *Working Together — Public Services On Your Side* in 2009.<sup>74</sup> The approach advocated empowering individuals to take control and make their own choices about the services they require. For some groups, this includes the allocation of personal budgets and taking responsibility for choosing how money is spent in relation to their care needs. Under these arrangements, service users were no longer to be passive recipients of care and assistance, but active participants in the design, development and control of their support and care packages.

We argue this principal of engagement and these kinds of new approaches are particularly relevant to those with complex needs and should be available to all users of a public service, including problem drug users. DrugScope suggest that a drug system that puts people first and co-designs tailored care plans for individual service users would enable more effective and efficient treatment.<sup>75</sup>

As we have seen personalisation is coming on to the drugs agenda. A key question is how broad and deep implementation will be. Research to date has shown that there is a wide variation in the degree to which systems and structures have been established to support various user-centred approaches. There is a disparity between drug and alcohol action teams (DAATs) and the models and mechanisms they are using and the degree to which user involvement has been integrated in planning, commissioning and development of services. West Sussex DAAT, for example, recognised the importance of meaningful user involvement and created a role within their team — its Service User Co-ordinator — to establish formal networks of peer led groups that actively contribute towards shaping the service landscape (see **box opposite**).

However, this is not replicated across all DAATs. Patterson *et al.* concluded that ‘Formal engagement of users in drug treatment services is relatively new. While users have been at the heart of many voluntary sector services since their inception and there is evidence that users are engaged within NHS treatment services through various means, formalised structures and processes are not well embedded.’<sup>76</sup>



Fig 3. Arnstein's Ladder of Participation



## SERVICE USER INNOVATION: WEST SUSSEX DAAT

EXACT was initiated in September 2009 by the West Sussex DAAT, which recognised the need for more meaningful service user involvement in treatment services and the support networks that help to sustain recovery following formal treatment. The ambition was to create localised peer led groups that could take forward the aims of EXACT at a local level. These aims are to:

- give service users a voice;
- influence the planning of drug and alcohol services in West Sussex;
- offer a service user perspective to the planning, development and review of services across West Sussex;
- develop effective communication with both service users within services and with the service provider organisations;
- work in partnership with service providers to obtain access to service users and service user groups;
- collate service user views and feedback how their views have influenced decision making;
- help service users regain a place back within the local community and to help increase their self esteem and self worth; and
- create a 'safe' environment for service users to be able to come and discuss any issues they may have and receive the support of peers to help address these issues.

EXACT has six local hubs covering seven county districts: Adur and Worthing (one EXACT group covering two district council areas); Arun; Chichester; Crawley; Horsham and Mid-Sussex. The Whole Person Recovery Project has worked closely with Arun and Crawley EXACT groups. Each group is part of the West Sussex Forum, which is the central point for the network of peer led groups. This offers a huge amount of firsthand knowledge and experience and meets once a month to work together to develop the groups' capabilities and strengthen the network.



There are a range of factors that contribute towards the patchwork of user involvement across the UK, not least the ambiguity in guidance issued by the NTA. On the one hand it is defined as 'the act of professionals engaging drug users in services', suggesting a more traditional consultative involvement. On the other, NTA guidance states that users and carers should be actively involved in planning, delivering and evaluating service provision at national, regional, commissioning and service provider levels. This is welcome: involvement would help to strengthen accountability to stakeholders, create services that genuinely reflect and respond to the needs of service users and family members, and foster a sense of ownership and trust.<sup>77</sup> This report argues there are more substantial changes in approach needed to build on this.

Our project aims to shift the focus of user engagement from (often minimal) *involvement*, to one of *centredness*. Involvement is variably used to describe choice, collaboration, consultation, control, empowerment, engagement, information, participation and partnership.<sup>78</sup> In Arnstein's classic ladder of citizen participation (see **Figure 3**), there are eight levels of participation relating to citizens' power to determine outcomes. The bottom rungs include manipulation and therapy (essentially forms of non-participation). The middle rungs refer to the activities of informing, consulting and placating (forms of tokenism), while the upper rungs include partnership, delegated power and ultimately citizen control (forms of citizen power).<sup>79</sup> Our focus is the move towards personalisation and user centredness, aiming at the top rungs of the ladder.

74 Cabinet Office (2009) **Working together — Public services on your side**, London: HM Government.

75 Drugscope (2009) **Drug Treatment at the Crossroads. What it's for, where it's at and how to make it even better**, London: Drugscope.

76 Patterson, S., Crawford, M., Weaver, T., Rutter, D., Agath, K., Albert, E., Hunt, A., and Jones, V. (2007) **User involvement in efforts to improve the quality of drug misuse services: factors that promote and hinder successful working**. Research report submitted to the Drug Misuse Research Initiative, Department of Health, March 2007.

77 NTA (2006) **NTA Guidance for Local Partnerships on User and Carer Involvement**, London: National Treatment Agency.

78 Fischer, J., Jenkins, N., Bloor, M., Neale, J., and Berney, L. (2007) **Drug User Involvement in Treatment Decisions**, York: Joseph Rowntree Foundation.

79 Arnstein, S.R. (1969) 'A ladder of citizen participation', **Journal of the American Institute of Planners**, vol. 35, no. 4, pp. 216-224.

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Service user involvement can bring multiple benefits, spanning improved services as a result of increased understanding of requirements to avoiding features that are unacceptable to users. It can make services more effective as a result of greater understanding between users, staff and managers, and can increase user participation in decision-making and the development of partnerships between staff and service users.<sup>80</sup> There is little research on service user involvement in the drug and alcohol field, particularly the more meaningful forms of involvement (or centredness) described above.

Generally, service user involvement has been associated with a number of positive treatment outcomes such as higher levels of satisfaction and retention, a range of positive outcomes such as improved family relationships and employment and engagement with training opportunities. It has also been shown to increase users' confidence, motivation and independence.<sup>81</sup> Research by Patterson *et al* found that greater involvement contributed to service development including prompting changes in operation and delivery, in identifying service gaps and in deciding where new services should be located. In addition, meaningful involvement was found to have a self-nurturing and cumulative effect.<sup>82</sup> Service user involvement has been advocated as a method to increase uptake and engagement amongst traditionally hard to reach populations of drug users including ethnic minority groups and people experiencing homelessness. It has the potential to break down mechanisms of social exclusion and the stigma surrounding problematic drugs and drug users.

To date, service user involvement in the drugs field has remained largely on the lower rungs of Arnstein's ladder of participation. The type of self-directed services involved in individual budgets are much more powerful as they involve money and give people the power to shape and purchase the help they need.

New models of personalisation and co-production in public services could generate dramatic improvements as users move from being passive to active, from being powerless to powerful, and from consumers to producers. As Leadbeater *et al* argue, 'Self directed services do not mean more committees and talking shops. People get a direct voice in shaping the service they want and the money to back it up. It is not just more consultation. Traditional approaches to participation give people more of a voice; self directed services allow people to put their money where their mouth is.'<sup>83</sup>

Problem drug and alcohol users must not be excluded from these developments that have the potential to improve their experience and input into service provision, and control over their own recovery. At its most effective, co-production is not just about service users being in control of choosing and purchasing services, but about producing their own solutions and generating social capital. This is more likely to occur in recovery systems that are user-centred (see **Section 5**). To ensure that these developments are not marginal, there needs to be fundamental cultural and organisational shifts as well as changes at the professional and individual levels.

The scale of change that is required should not be underestimated: planning, training, communication, time and resources are needed for effective participation. But the prize is potentially huge: drug services which are truly user-centred have the potential to address some of the multiple disadvantages experienced by problem drug users and to build rich social networks of support.

## INDIVIDUAL BUDGETS I

Individual budgets are one particular avenue of developing personalised, user-centred approaches. Trialled mainly in adult social care, these schemes allow service users to devise their own support plans with the help of care managers, social workers, independent brokers, friends and family. They enable budget holders to purchase the support they need from a range of sources including social services, the private sector, the voluntary sector and community groups or neighbours, friends or family members. This is referred to as self-directed support. Findings from evaluations of individual budgets indicate promising results.

An evaluation by inControl found that individual budget recipients reported: more time spent with people they liked; improved quality of life; greater participation in and contribution to their local community; more choice and control over their lives, and a greater sense of personal dignity. Those who had used self-directed support for longer periods reported improvements in general health and wellbeing (including greater economic stability). The involvement of friends and family was seen to be particularly important. Individual budgets were found to promote a joint approach involving the service user, their friends and family and social workers that enabled them to combine formal and informal types of care. The majority of the budget holders (88 per cent) had accessed support available in their community that they had not previously drawn upon.<sup>84</sup>

Evaluation of the national individual budgets pilot programme (IBSEN) showed that those in receipt of individual budgets felt more in control of their daily lives than those who received conventional social care support. They were more likely to have better overall social care outcomes, and achieved in more cost effective ways, particularly for people with mental health problems and younger physically disabled people.<sup>85</sup>

A smaller scale study by Demos found that those with personalised budgets reported higher quality of life and more choice and control than those receiving traditional services. Improvements in personal dignity, feeling safe and secure at home, and enhanced economic wellbeing were also reported by participants. In terms of resources, personalised budgets led to average council savings of ten per cent on care packages. Self directed services were seen as beneficial in terms of developing new forms of collectivism, reconnecting people to their social networks and helping to foster wider social capital.<sup>86</sup>

## Challenges

As we discuss above, there is little research on meaningful forms of user centredness or involvement within drug and alcohol services. The following offers a brief overview of the research that exists.

Neale suggests there are particular challenges for drug services in involving users in service provision.<sup>87</sup> Due to the stigma surrounding drugs, problem drug users are often viewed as ‘undeserving’. The illegality of drugs and criminal activity that often coincides with problem drug use is viewed by some to undermine people’s claims to be involved in their treatment. The effects of stigma can be profound for individuals, ‘leading to feelings of low self-worth and the avoidance of contact with non-users.’<sup>88</sup> This can perpetuate their involvement in vicious cycles of behaviour and create strong conscious and sub-conscious barriers to recovery.

## Difficulties in engaging users

Problem drug users can also be difficult to engage with due to their dependency and often chaotic lifestyles. They can be hard to work with and are unlikely to seek involvement. Many will have multiple needs including health problems (such as HIV, Hepatitis C, and mental health issues), and can suffer multiple disadvantages, including poverty, homelessness, illiteracy, lack of skills and unemployment. The lack of trust between service users and providers is pervasive; problem drug users often experience prejudice and discrimination when accessing health and social services. Service users are often viewed as manipulative and not an appropriate population to involve.

80 National Treatment Agency (2002) **Models of Care for Treatment of Adult Drug Misusers**, London: Department of Health.

81 Neale, J., Bloor, M., Berney, L. and Fischer, J. (2006) ‘Feel good factor’, **Druglink**, vol. 21, no. 1, January, pp. 20-21.

82 Patterson et al. (2007), op. cit.

83 Leadbeater, C., Bartlett, J. and Gallagher, N. (2008) **Making it Personal**, London: DEMOS.

84 Hatton, C., Waters, J., Duffy, S., Senker, J., Crosby, N., Poll, C., Tyson, A., O'Brien, J., and Towell, D. (2008) **A report on inControl's Second Phase: Evaluation and learning 2005-2007**, London: inControl Publications.

85 Glendinning et al. (2008) **The national evaluation of the individual budgets pilot programme (IBSEN)**, London: Department of Health.

86 Leadbeater et al. (2008), op. cit.

87 Neale, J. (1998) ‘Drug users’ views of prescribed methadone’ in **Drugs: education, prevention and policy**, vol. 5, no. 1, pp. 33-45.

88 Lloyd, C. (August 2010) **Sinning and Sinned Against: The Stigmatisation of Problem Drug Users**, London: UKDPC.

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There is a limited number of people with problematic drug use who are willing to participate in service design, a real barrier and justification for exclusion. Many will not have the knowledge and awareness around opportunities to get involved, but may also feel inadequate, that they lack the necessary skills and that they have little right to contribute. Among those who may be willing to participate, there is the question of how to sustain this. Because service users move on and leave the treatment process, user groups can be unstable. Like others, they may also have other priorities in their lives such as family commitments, finding accommodation, accessing education and training or finding employment.

## A punitive culture

Patterson *et al* concluded that the focus on crime within drugs policy was seen by drugs workers, managers and commissioners as a challenge to service user involvement.<sup>89</sup> With all the new initiatives around drugs, crime and treatment, the emphasis has tended to be on crime reduction rather than harm reduction and health issues. Many problem drug users who have committed offences are coerced into treatment as a result of their sentence. While for some this has beneficial implications for their ability to access services, overall the research found that within this context of criminalisation of drug treatment provision, service users are often seen as offenders with few rights and little power to make contributions to their treatment and service development.

## Representation

Problem drug users are not all the same. They are a heterogeneous group which can include current and ex-service users, different ethnic groups, and users of different drugs, some using substitute prescriptions and others who are drug-free. They vary in age, and gender, and some will be parents or have other caring responsibilities. This diversity can make it difficult to develop structures to reflect different needs and ensure representation.<sup>90</sup>

Many of the hard-to-reach groups, such as women, ethnic minority groups, and those experiencing homelessness, experience difficulties in accessing mainstream drug services in the first place. For women with children, there is a real and perceived danger that some forms of user involvement would reveal their drug use and result in their children being removed by social services. Childcare and family responsibilities can make participation practically difficult and unaffordable. Engaging ethnic minority populations in both services and service development is particularly challenging.

As Patterson *et al* argue a circular issue evolves with no service user involvement developing for these populations, leading to no specific service development to cater for their needs, creating in turn barriers to accessing services.<sup>91</sup> Those drug users who are homeless have complex needs which act as a barrier to their participation; there is a clear need for outreach work and linking with other services in the community to engage them.

## Power

‘For users the fear of authority is a deterrent to involvement and for many in power the perception that drug use is a choice influenced views about the rights to participation. While acknowledging the intricacies of culture and social systems and the impossibility of disentangling the illegality of drug use, stigma and moral judgement from the practicalities of involvement, it is vital that power issues are addressed openly if user involvement is to progress purposefully.’<sup>92</sup>

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*“I just want to get my old life back but finding it difficult with a criminal record, obviously.”*

— Women’s focus group participant

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The issues of power and powerlessness are highlighted in all the research in this area. Under the medical model of drug treatment, there is an inherent power imbalance between treatment providers and service users that is pervasive and encourages deference to the professional point of view. Often, service users will expect the staff to be the ‘experts’ who will guide them through the treatment process. Fischer *et al* argue that service user involvement is both contingent and contradictory.<sup>93</sup> The degree to which service users become involved in their treatment depends on the individual and some might not want the responsibility to make all the decisions about their plans. Involvement depends on how ready they are for treatment and the length of time they are receiving it. The issue of power relationships is not easily overcome but underlines the potential role of both personalised approaches and the involvement of peers and those of who have firsthand experience of problematic drug use.

## Mismatched expectations

Service users and practitioners often have different interpretations of what involvement means, its rationale and objectives. Service users describe their involvement variably as: being able to communicate effectively with staff; having a choice about the services they receive; flexibility of staff in terms of meeting individual needs or wishes; the amount of coercion or involuntary elements within programmes; being able to shape treatment structures; and enabling service users to support one another. Many stress the importance of listening, empathy and explanations of treatment, while staff emphasise decision-making around which agencies service users should attend and being involved in early decisions about treatment.<sup>94</sup>

There are also often mismatched expectations between service users and providers regarding the treatment process. Often, service users will have unrealistic expectations and demands around the options for treatment, time frames, waiting lists and financial constraints. There may also be differences in terms of the overall goals of treatment. Fischer *et al* found that professionals tended to define successful treatment in terms of abstinence and harm reduction outcomes, while service users tended to define ‘success’ in wider terms by identifying longer-term lifestyle goals such as being employed, securing housing, gaining education and skills, and improving family relationships.<sup>95</sup> The tensions and conflicts between the two groups are clear and emerged strongly in this project, but it also demonstrated that these differences can also exist between service users themselves.

For example, a study conducted in Scotland revealed how service users tended to prioritise abstinence over harm reduction in terms of their aspirations for treatment. This finding highlights the need to ensure that harm-reduction oriented services enable people to move towards a position of abstinence over time and that drug workers explain the value of harm reduction as part of a broader strategy.<sup>96</sup> Ultimately, these studies support the need for people to have access to a range of services including those with a harm reduction focus and those with an emphasis on abstinence that can be tailored appropriately to the individual.

As the NTA makes plans for treatment to increasingly move towards a focus on recovery, we would hope to see the gap in expectations reduce, not least as the tools used to determine the individual goals offer the opportunity for a more personalised response. However, with the lack of a widely accepted definition of recovery there remains a question about how recovery can and should be measured. To some extent this may account for the ambiguity in the drug strategy consultation about how focussed the system will be in championing abstinence and its impact on the harm reduction practices that have largely defined service provision over the last decade and how this fits with service users’ goals.<sup>97</sup>

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89 Patterson et al. (2007), *op. cit.*

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90 *ibid.*

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91 *ibid.*

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92 *ibid.*

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93 Fisher et al. (2007), *op. cit.*

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94 *ibid.*

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95 *ibid.*

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96 McKeganey, N., Morris, Z., Neale, J. and Robertson, M. (2004) ‘What are drug users looking for when they contact drug services: abstinence or harm reduction?’, **Drugs: education, prevention and policy**, vol. 11, no. 5, pp. 423-435.

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97 NTA (July 2010) Board Meeting and Papers, [Online], Available: [www.nta.nhs.uk/who-board-july10.aspx](http://www.nta.nhs.uk/who-board-july10.aspx) [14.07.10].

## Policy, structures and resources

Whatever future strategies emerge, they need to try and address some of the barriers that policy, structures and resources create. Patterson *et al* found little evidence that legislation and policy directives were adequately supporting the implementation and development of service user involvement in drug treatment services.<sup>98</sup> There was a clear gap between policy and practice and difficulties were reported in terms of translating guidelines for implementation at the service level.

Service user involvement was seen to be only one factor in the equation. Performance management pressures around numbers in treatment, retention, reduced waiting times, and the emphasis on delivering standardised care and completing forms were seen to limit the capacity to undertake meaningful service user involvement activities, resulting in a tick-box mentality. Once more, the complexity of organisational structures and governance systems surrounding drug treatment provision and the absence of co-terminosity in the boundaries of DAATs, NHS trusts and other providers, served as an additional challenge. Lack of resources and dedicated funding further hinders service user involvement.

### INDIVIDUAL BUDGETS II

Research on individual budgets has raised important challenges and risks that need to be addressed.<sup>99</sup> The IBSEN evaluation identified a need for appropriate principles and processes to be devised to allocate the resources and to determine the levels of individual budgets. Although individual budgets were supposed to include resources from different funding schemes, there were legal and accountability barriers to integrating funding streams. Staff expressed frustration that NHS resources were not included in individual budget pilots and considered this contradictory to their underlying holistic ethos. Legitimate boundaries for how resources are used need to be established to guard against risky decision-making, fraudulent claims and the perception of inappropriate uses of public money. Staff expressed concern over the safeguarding of vulnerable groups. Further, these types of initiatives may empower people who are already confident, articulate and networked to get the best services while those who are vulnerable and disadvantaged will suffer further disadvantage.<sup>100</sup>

Individual budgets can be seen as the pioneering element of personalisation, especially in the drug and alcohol field. Through pilots such as this, and the UK-wide drug system change pilots, light is being shed on the practicalities involved in redesigning deeply entrenched systems that have shaped behaviour, attitudes and services for decades. It is within this light that recovery in the UK has gathered momentum, enveloping user-centred approaches, harm reduction, and abstinence, and in which we set out our project.

#### Roles, responsibilities and organisational culture

In the IBSEN evaluation, staff felt that their skills had been eroded with the introduction of individual budgets. It is clear that if individual budgets are implemented fully, then workforce reform will be necessary. Professionals will lose their power to direct and control services, while providers will have to attract demand from those holding the individual budgets. Moreover, there will be less need for the 'traditional' social worker. Their roles will transform as they begin to work less formally as advisors, navigators, brokers, service providers, risk assessors or auditors, and designers of social care as a whole.<sup>101</sup>

There is therefore a need for proper planning, training and communication. Demos researchers warned that personalised approaches must not be viewed as a 'quick fix': 'There is a danger that policy-makers and politicians at all levels underestimate the scale of change involved in moving to self-directed services. The risk is that they will see it as a quick fix to move people to personal budgets without adequate support, planning, staff training and communication.'<sup>102</sup>

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## Experts by experience

Finally, there is the more fundamental question of whether users (particularly those caught in the midst of strong cycles of dependency and who are some distance from recovery), are best placed to determine what they need and how services should be delivered. A recent report on drug use in prisons was launched with the comment that “we need Ministers, not prisoners, to be dictating government policy.”<sup>103</sup> While no-one would argue that policy should be undermined by the illegal smuggling of drugs into institutions, implicit in the message is a top-down approach that risks diminishing the user perspective in the design of recovery-oriented services and support. We argue that there is good cause for valuing the user voice.

Parallels are seen in a number of policy fields. The Expert Patient Programme, for example, places patients at the centre of healthcare and is the key decision-maker in taking responsibility for and managing their own, often chronic, conditions.<sup>104</sup> The former Chief Medical Officer, Professor Sir Liam Donaldson, has stated that: ‘We know from the findings of research that such people are often in the best position to know what they need in managing their own condition. We also know, however, that in the past too little has been done to support them.’<sup>105</sup>

The programme does not seek to replace the role of the professional with that of the service user. Rather, it aims to blend, on the one hand the experience of the service user (the lived, social reality of their condition, personal values and preferences) with clinical knowledge of disease, treatment options and outcome probabilities on the other.<sup>106</sup> By working in partnership, power and knowledge are distributed more equally between patient and professional.<sup>107</sup> Similarly, approaches to community regeneration have increasingly put local people centre stage, particularly in the area-based initiatives targeted at multiply deprived areas. The work of various policy action teams found that local people should be considered as experts in their own situations and that if communities led themselves, in partnership with local services, they would be better able to drive solutions to local problems.<sup>108</sup>

Best and Laudet argue that recovery is a lived experience, grounded in community, and a transition that can occur without professional input, and that the role of the professional is far from clear where present.<sup>109</sup> Such user-led transitions to recovery would not occur without recognition by problem drug and alcohol users on how this is best achieved. Our experience of researching and talking with users throughout this project chimes with this view. Almost uniformly, users gave considered, realistic, articulate accounts of their own situation, what would help them move to and sustain recovery, and what they were best placed to decide on or otherwise. For example, survey findings showed that 27 per cent of problem drug and alcohol users wanted individual budgets because they were comfortable with this level of responsibility and choice, and wanted to be able to purchase support for recovery that existed outside of the fixed menu of options currently available. The remainder did not want this option, recognising that they did not want that responsibility and would find it problematic.

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98 Patterson et al. (2007), op. cit.

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99 Hatton, C., Waters, J., Duffy, S., Senker, J., Crosby, N., Poll, C., Tyson, A., O'Brien, J., and Towell, D. (2008) A report on inControl's Second Phase: **Evaluation and learning 2005-2007**, London: inControl Publications; Glendinning et al. (2008) **The national evaluation of the individual budgets pilot programme (IBSEN)**, London: Department of Health; Leadbeater, C., Bartlett, J. and Gallagher, N. (2008) **Making it Personal**, London: DEMOS.

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100 Leadbeater et al. (2008), op. cit.

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101 *ibid.*

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102 *ibid.*

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103 Chambers, M. (1 June 2010) **Coming Clean Press Release**, London: Policy Exchange.

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104 Department of Health (2001) **The Expert Patient: A New Approach to Chronic Disease Management for the 21st Century**, London: Department of Health.

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105 *ibid.*

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106 Coulter, A., Entwistle, V., and Gilbert, D. (1998). **Informing Patients**, London: King's Fund.

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107 Hardy, P. (2004) **The Expert Patient Programme: a critical review**, Cambridge: Pilgrim Projects.

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108 Rowson, J., Broome, S. and Jones, A. (September 2010), op.cit.

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109 Best, D. and Laudet, A. (2010), op.cit.

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Realising the potential of the problem drug and alcohol user to be the expert in their own situation can be constrained by the framing of the conversation. When these users were asked about their ideas to improve services, responses were limited to often incremental improvements in staff skills and attitudes, opening hours and immediacy of accessibility. When asked more generally what would help them, a much more expansive, enthusiastic, recovery-oriented range of answers emerged that were tailored to individuals. In this way, a user-centred, whole person approach to recovery would help to replace what Paul Watzlawick calls 'first-order change' with 'second order change'.<sup>110</sup> This means moving from a conventional frame of meaning implemented when the overall approach to change has not been fully thought through, is adjusted incrementally, or has not been adequately updated, to a shift in the frame of meaning itself. In this way, we move from incremental improvements in and a focus on formal treatment, to a more expansive vision of recovery enabled by a broad range of personal, social and community assets.

Mindful of all of these challenges, the RSA designed a programme of work that built on our developing understanding of how to tap into existing individual and collective capabilities. The next section outlines this programme.

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<sup>110</sup> Watzlawick, P. (1974) **Change: Principles of Problem Formation and Problem Resolution**, New York: WW Norton & Co.





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## SECTION 3. *The Whole Person Recovery Project*

This section outlines the local context in which this project was developed. We summarise each phase of the project, the research methodologies used and the various activities undertaken to develop the research and ideas.

A recent report from the Joseph Rowntree Foundation on user involvement in commissioning services found that, ‘if you ask people to go beyond this to detail what it looks like, what its purpose is and how structures and models will enable it to become a reality, the picture gets far less clear.’<sup>111</sup> The ‘how’ is difficult and solving this is a key aim of this practical project.

The Whole Person Recovery Project aims to test whether a user-centred approach can be employed at every stage of service design, development and delivery. The project is ambitious and set out in 2009 to meet these aims through three distinct phases. This report focuses on the first two phases and their methodologies are outlined here. The third phase began in autumn 2010, and a report on this final phase will be available next year.

The project is located at two sites within West Sussex; Bognor Regis (which is part of the Arun district) and Crawley. We chose these areas for several reasons. Firstly, and practically, the project received support throughout the local authority (including at director level and member support) and third sector. It also coincided with the beginning of the development of personalised services by Addaction, who won the tender to provide most services across the county from May 2009. Psychosocial provision (including needle exchange, advice, information and structured treatment) continued to be provided by the service provider CRI in the Bognor Regis area.

Secondly, West Sussex is a large county with a varied geographical landscape punctuated with small pockets of deprivation: it has an extensive coastline, large and small urban centres and acres of rural land. As a result of this geographical diversity, the project is able to consider different supply and demand dynamics, both open and more closed drug markets, rural access problems, and ethnic diversity. Thirdly, according to West Sussex DAAT’s needs analysis, the county has an average number of problem drug users, and so will provide a typical sense of scale.

### West Sussex

The social and economic data contained in the **box opposite** sets out some of the main challenges facing the county. Providing comprehensive drug and alcohol treatment services in West Sussex is challenging due to its geographical and demographic profile. It is a large rural county that has its main urban areas along the coastal strip and in the north of the county around the ‘Gatwick Diamond’. As well having areas of affluence, the county has areas of extreme deprivation including Local Neighbourhood Improvement Areas that receive supplementary development support.

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111 Schehrer, S. and Sexton, S. (May 2010) **Involving users in commissioning local services**, London: Joseph Rowntree Foundation.

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112 Office for National Statistics (June 2010) **Mid-year population estimates 2009**, [Online], Available: [www.statistics.gov.uk/statbase/Product.asp?vlnk=15106](http://www.statistics.gov.uk/statbase/Product.asp?vlnk=15106) [02.09.10].

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113 West Sussex Drug and Alcohol Action Team (2010) **Summary Needs Assessment 2009-10**. Unpublished.

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114 See [http://www.crawley.gov.uk/stellent/idcplg?IdcService=SS\\_GET\\_PAGE&nodeId=870](http://www.crawley.gov.uk/stellent/idcplg?IdcService=SS_GET_PAGE&nodeId=870)

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115 According to professional and user participants in our project local workshops.

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116 West Sussex City Council Website, Census Bulletin **Ethnicity and Religion of West Sussex, Issue 5**, [Online], Available: [www.westsussex.gov.uk](http://www.westsussex.gov.uk) [06.08.10].

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117 Dunnell, K. (April 2008) **Diversity and Different Experiences in the UK**, National Statistician’s Annual Article on Society, London: Office for National Statistics.

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118 The Local Futures Group (November 2008). **The State of the County. An Economic, Social and Environmental Audit of West Sussex**, London: The Local Futures Group.

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119 Crank, R. (April 2008) **An Economic Profile of West Sussex**, West Sussex County Council.

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120 *ibid.*

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121 *ibid.*

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122 *ibid.*

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123 *ibid.*



## COUNTY PROFILE

**Population:** West Sussex has a total population of 792,900<sup>112</sup> most of who live in the larger towns in the east of the county or along the coast.<sup>113</sup> Our two research sites differ in spatial geography: while Bognor Regis has a recognised centre and common sense of place, Crawley is made up of thirteen neighbourhoods 'all with their own different character'<sup>114</sup> and anecdotally, are described as having few links across them.<sup>115</sup>

**Age:** the county has a higher proportion of very elderly (over 85 years) than regionally and nationally, especially in Worthing and Arun where the figures are more than double the percentage of Crawley. Bognor Regis has a large proportion of older people, whereas Crawley has a high proportion of children, young people and young adults.

**Ethnicity:** West Sussex is less ethnically diverse than the region and nation. However, Crawley has a much larger Asian or British Asian community than both regionally and nationally, and across the county, reports the lowest proportion of people born in the UK (88 per cent). Arun reports the highest rate at (95 per cent)<sup>116</sup> and nationally this figure is estimated at 90 per cent.<sup>117</sup> Recently, Bognor Regis has experienced a notable increase in immigration from Eastern Europe.

**Economy:** Relatively, West Sussex has a small sub-regional economy and is ranked 35th out of 54 across Great Britain.<sup>118</sup> Crawley has the largest economy within the county while Adur is one of the smallest. Crawley is the main driver of the local economy, creating jobs at above the average rate although its earnings growth has been on a par with national growth. Crawley has the highest average business size in Britain making it the most dependent on large firms in the country.<sup>119</sup>

**Earnings:** Residents' earning levels are generally lower than for the region but higher than the national average. Across the county these range from average gross weekly earnings of £404 in Adur up to £575 in Mid-Sussex, compared to the regional average of £437. Crawley weekly earnings average at £498.<sup>120</sup>

**Education and skills:** There is significant variation in GCSE results between districts. In 2008, Horsham had nearly 70 per cent of pupils obtaining five or more A to C GCSE passes, while Adur achieved only 38 per cent. Only Chichester, Horsham and Mid Sussex achieve higher than the regional average (59.5 per cent).<sup>121</sup> In terms of skills, West Sussex has a higher number of residents qualified to NVQ level 4+ than both regionally and nationally. Chichester district has the highest educational levels where 39 per cent have degree level qualifications. The County has a lower number of residents and a smaller proportion of workers than nationally in 'skills poverty' (qualified below NVQ 2).<sup>122</sup>

**Employment:** In 2009, 85.6 per cent of working age people were employed in the County compared to 86.4% nationally. Self-employment is high across West Sussex with every district recording a figure above the national average.

**Deprivation:** In the Department for Communities and Local Government (DCLG) Indices of Deprivation 2007, West Sussex ranked 130 out of 149 counties with 1 being the most deprived and 149 the least. This demonstrated a slight increase in relative deprivation compared to their rank in 2004, which placed West Sussex at 133.<sup>123</sup>

Friends  
+  
Community.



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## Drugs and alcohol in West Sussex

The annual Drug and Alcohol Action Team (DAAT) Needs Assessment presents the most comprehensive picture of the state of problem drug use and treatment in any given region. For West Sussex, the assessment shows that there are more injecting drug users in contact with the needle exchange services than are registered at a treatment service. Estimates suggest that 550 individuals use needle exchanges across West Sussex, while only 200 injecting drug users are registered in the Treatment Outcome Profile's (TOP) data, suggesting that there may be a large number of injecting drug users not in treatment.<sup>124</sup>

Completion rates are lower than the region would hope for, with only 28 per cent of tier 3 clients finishing treatment, while 21 per cent are transferred to other services.<sup>125</sup> There are comparatively poor treatment exits to other groups and services for black and minority ethnic clients.

Housing needs at the two sites of the project are also relatively high amongst those with problematic drug and alcohol use. Of the county's seven districts, Arun (the district which includes Bognor Regis) and Crawley have the second and third highest number of people with urgent housing needs or who have no fixed address.

Historically, there has not been a universal treatment system across the county and efforts have focused on areas of high demand (urban centres such as Crawley). Providing a full range of easily accessible drug and alcohol treatment options is a logistical challenge given the mix of large rural areas and distributed urban centres across the county.

West Sussex DAAT entered into this partnership project with the RSA on the back of their involvement in the RSA Commission on Illegal Drugs, Communities and Public Policy. At the time they had re-commissioned drug treatment services, awarding the contract to Addaction with a view to developing a personalised, innovative approach to drug treatment that is more accessible and better able to help individuals achieve better outcomes including better social integration. Given the geographical profile of the county, the DAAT is particularly interested in exploring ways to use new information and communication technologies (ICTs) to enable peer-led support and the creation of virtual recovery communities. The DAAT has the aspiration to become 'a regionally, if not nationally, recognised area of innovation and good practice' and to develop operating systems and services that will inspire others to follow.

The DAAT recognises that parts of the county have some of the highest rates of alcohol related hospital admissions in the region. There is perhaps more local public and political concern about alcohol misuse than drug misuse. The DAAT are keen to build a range of alcohol treatment services that complement and work with drug services, and that reach a broader range of people who misuse alcohol than currently access treatment. Perhaps because of this, the county did not include any drug related performance measures (such as National Indicator 42: the percentage of people perceiving drug use or drug dealing as a problem) in their Local Area Agreement basket of indicators.

Although most elected members have, according to the DAAT, been helpful in scrutinising drugs strategy implementation, it remains a contentious issue in the wider community. Last summer, the local paper reported on the tensions between local residents and traders on one side, and the council and Addaction on the other, over plans to locate a one-stop-shop drug service within the Guildbourne Centre (a retail shopping centre in Worthing).<sup>126</sup>



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The paper followed up on its story later in the year with an editorial concluding that such a location was inappropriate for such services and that ‘other premises, in a less sensitive location, should be found’.<sup>127</sup> In the following weeks, the application was unanimously rejected by members of the council development and control committee.<sup>128</sup>

This illustration serves to show that despite some support for tackling drug issues, there is some way to go to bring the drugs agenda in from the margins. DAATs can be reticent in openly engaging communities about drug use and treatment, even though reducing local concerns of drug use and dealing is best achieved through highly visible work that engages residents directly.<sup>129</sup>

In order to create the conditions that will support the social and economic reintegration and wider recovery of problem drug and alcohol users, a richer, more expansive local discourse around drugs is needed. Part of the aim of this project is to change the conversation and attitudes towards problematic drugs and users to prepare the ground for a ‘recovery community’ that utilises a much broader range of assets than have until now been involved in supporting recovery.

## Methods

Our project has three broad phases. We provide a detailed account of each phase below in order to help interested parties to replicate this model elsewhere; because the process of engagement is innovative, detailed and difficult and is a key outcome of the work in itself; and to be transparent.

### Phase 1: Relationships and research

#### (i) Build partnerships

Given the project spans user, local area, and national interests, we created three interlinked levels of discussion and collaboration. Firstly, the project brought together local key players who have the access and authority needed to deliver the project. This includes the West Sussex DAAT; housing, community, and adult social care services; the Primary Care Trust; a range of third sector groups including Addaction and CRI ClockWalk; and user, black and minority ethnic and faith groups. A local steering group was set up to help to design and oversee each component of the work, helping to facilitate the relationships and shared ownership needed for more effective inter-agency working.

Secondly, a drug strategy seminar series was established to discuss key challenges in designing and delivering drug services. The series covered five themes pertinent to the project:<sup>130</sup>

- user-centred approaches to drug services;
- the tensions between localism and a national drugs strategy;
- engaging communities in the drugs agenda;
- the role of the third sector; and
- new insights from social psychology, neuroscience and behavioural economics.

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124 Further analysis is being undertaken and scoped through the Needs Assessment (due to be published in January 2011) that will provide greater clarity as to whether needle exchange users are accessing parts of the treatment service.

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125 These figures have been taken from the Summary Needs Assessment 2009-10. A refreshed Needs Assessment is due to be finalised in January 2011.

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126 See <http://www.worthingherald.co.uk/worthing/VOTE-Anger-at-Worthing-shopping.5527465.jp>

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127 See <http://www.worthingherald.co.uk/herald-says/Guildbourne-Centre-is-the-wrong.5814613.jp>

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128 See <http://www.chichester.co.uk/worthing-news/Worthing-says-no-to-drug.5843152.jp>

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129 RSA — Home Office Drugs Policy Seminar — Community Engagement and Perception, June 2009.

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130 The RSA is very grateful to the Home Office for supporting the seminar series, and to all speakers and attendees at the five events.

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Seminars were attended by representatives from across government, including the Home Office, Ministry of Justice, Department of Health, Department for Communities and Local Government, Department for Work and Pensions, Department for Children, Families and Schools, the Cabinet Office, and the Prime Minister's Delivery Unit. They were also attended by representatives from the National Treatment Agency, academic experts, third sector organisations (including Addaction, DrugScope, UK Drug Policy Commission, Adfam, and The Alliance), representatives from the judiciary and think tanks, local authorities, as well as RSA Fellows, and members of our local steering group. Presentations and discussions were used to inform the design and delivery of the project.

Thirdly, we built relationships with service users, user groups, those who were not in treatment and other problem drug and alcohol users. This strand is central to the whole project. The aims of the project were discussed with local treatment and service users through attending drop in sessions in local treatment and community centres, and working with EXACT, the county-wide umbrella service user group.

Following these discussions, we recruited and trained a team of current and former drug and alcohol users in research techniques and ethics with a view to undertaking primary fieldwork with other substance users. Training was provided by an organisation that specialises in user-led research with hard to work with groups<sup>131</sup> alongside RSA staff. This training prepared the ground for the research phase.

This user-led research team has been instrumental throughout the project and will continue to be so in helping to deliver (in the final phase of the project) the interventions they helped to design, in developing strong peer support and extended recovery networks, and in evaluating and monitoring the pilot interventions. By the end of the project this group will be a source of valuable skills and knowledge for West Sussex and a key outcome in itself.

## **(ii) Undertake mixed methods research**

Collectively, the team designed and piloted a questionnaire to understand problem drug and alcohol users' experience of, and attitudes to, drug-taking and alcohol use and their associated impacts; their experience of and attitudes towards treatment services; their involvement in the criminal justice system; their access to different forms of recovery capital; and their attitudes towards and ideas for personalised drug services. A socio-economic profile of each respondent was recorded. The questionnaire was informed by discussion of the main aims of the project, the national drivers (as relayed through the seminar series), and the local context.

Based on local intelligence, data from the PCT and the University of Glasgow's Centre for Drug Misuse Research, we aimed to make the sample representative demographically; by type of drug used, and whether respondents were in treatment or service naive. By working with drug and alcohol users, we were able to incorporate a snowball element to the sampling, in which users recommended and provided access to other users, enabling us to include participants we would otherwise not be able to reach. The team started by interviewing those in treatment through the main service providers (Addaction, CRI Clockwalk, Crawley Open House and SANDS) and asked for introductions to others in respondents' social networks who were problem drug and alcohol users.

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In addition, researchers sat in local drop-in sessions and opportunities to participate in the research were advertised in local centres and through word of mouth. Survey data was analysed using SPSS.<sup>132</sup>

In all, 152 interviews were completed, with 76 conducted in each area (Crawley and Bognor). Based on prevalence rates estimated by the University of Glasgow for the total number of opiate users and crack users in the county, and by estimating the proportion of county-wide users who reside in the two district council areas covered by our project, we estimate that our survey covers 15 per cent of the total number of opiate users and crack users.<sup>133</sup> (No estimates are available for how well our survey represents use of other substances.) Our survey was consistent with drug using population estimates for both women (23 per cent of referrals to drug triage services in 2009-10 were women, compared to 25 per cent of our sample) and non-white British drug users in the general population (13 per cent of referrals to drug triage services in 2009-10 were of non-white British ethnicity, compared to 17 per cent of our sample). Given our approach to recruit and train a team of user-researchers, and our available resource constraints, we have had to trade off to some extent increased sample size and statistical reliability against building capacity and a user group to place at the heart of our project.

Once the survey had been analysed, findings were explored, tested and validated through workshops which brought together 29 participants. These were held in the two sites of the project and included a mix of experts by experience (former and current problem drug and alcohol users) and experts by profession (such as treatment service providers). In total there were eight experts by profession and 21 experts by experience.

The workshops provided a space for participants to give an account of their substance using experiences in their own voice. They elicited stories, anecdotes and experiences to enrich and challenge our survey data, to develop new lines of inquiry, and to understand the user perspective in greater depth. We worked with participants to identify themes and patterns from these personal accounts, and debated the relationships between the various components of user stories, which covered people, places, social values and attitudes. From here, we built user-generated 'influence maps' to visualise how components were inter-connected and impact on users and help or hinder a journey to recovery. These emerging systems of influence formed the basis for organising our research findings and thinking about personalised services and systems and how recovery is catalysed and sustained.

Throughout the workshops, user accounts were compared to professionals' interpretation of the data and experience of working with problem drug users. This presented a way of probing user accounts, eliciting further explanation and detail, and identifying points in the user experience which clashed with the experience of service providers and other non-user stakeholders.

As the previous section discussed, user voices are often under-represented in certain groups, such as women and black and minority ethnic communities. As only one quarter of survey respondents were women, and only one in six were of non-white ethnicity, further targeted fieldwork was undertaken to better understand the experiences, recovery capital and ideas from these groups.<sup>134</sup>

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131 Baseline Research assisted the RSA in training local substance users and in supporting them in recruiting participants, and administering the survey. Based in the North West of England, the organisation aims to build capacity and understand the issues facing marginalised groups such as drug users, homeless people, sex industry workers and asylum seekers. They have undertaken several studies for DAATs and have worked on the Adult Chronic Exclusion Pilots.

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132 SPSS (Statistical Package for the Social Sciences) is a computer program used for statistical analysis.

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133 Drug prevalence data was provided in the West Sussex DAAT Summary Needs Assessment 2009-10, and mid-year population estimates for 2008 were provided by Office for National Statistics. Data estimates in our survey are therefore accurate to around +/- eight percentage points.

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134 As the previous section which gave a thumbnail portrait of the county showed, our proportion of respondents from black and minority ethnic groups is representative of the West Sussex population. However, given the small numbers in our sample, we wished to undertake further fieldwork with BME substance users.

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A focus group was held with women from the two project sites. This enriched our understanding of the gender-related issues, challenges and opportunities faced by these participants. But after discussion with local black and minority ethnic groups, it was felt that given the strong stigma attached to problem drug use in certain cultures, a focus group that aired issues would not foster an open discussion. Instead, our fieldwork team tried to arrange a series of one-to-one, semi-structured interviews to explore and enrich the data gathered for these groups. However, only two interviews were completed, and the research findings do not include the same depth of understanding as for other groups involved in the project's research. This issue will be examined again in the final phase of the project.

## Phase 2: Co-design and embed

### (i) User-led design

The findings and user-generated influence maps were then used as the evidence base to brainstorm and design ideas for user-centred drug services, how they should be delivered, and how they take account of and are informed by the influences on whole person recovery described by problem drug and alcohol users. This co-design work took place in a full day user-centred Design Symposium at the RSA in January 2010. Over 80 participants attended, including the former and current drug and alcohol users engaged in the project (as well as other members of their networks). In addition this was attended by the project's local steering group, senior policymakers, academics, local community members, local councillors, mental health professionals, substance misuse practitioners, homelessness practitioners, RSA Fellows, and employment advisors.

Participants with different areas of expertise were mixed together and groups were carefully facilitated to ensure the user voice and research findings remained central. Each group developed a number of ideas which were worked up into outline proposals and challenged by other groups, and further developed based on this feedback. The Symposium ended with 'pitches' on the best ideas and proposals from each group. Full details of the Symposium methodology and proposals can be found in **Appendix C**.

### (ii) Contextualise and prioritise

The proposals developed at the Symposium cannot be understood and applied in a vacuum. Consequently, they were taken back to local workshops in Bognor Regis and Crawley in which they were re-engineered to take account of existing operating environments, structures and resources. Workshops were attended by local former and current problem drug and alcohol users, steering group members, and other local stakeholders such as ward councillors and police officers. The re-engineered ideas were prioritised by participants and we describe these later in the report.





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### **(iii) Generating systems**

Just as our primary research data formed the basis for user-generated influence maps, so in turn our influence maps provided the basis for developing formal systems that describe addiction and recovery dynamics. In moving from one to the other, we make a distinction between mental associations, and system dynamic linkages. We retained all associations where there was a strong consensus among users, and translated these into system linkages in our systems maps. In both sets of maps, we kept the names and descriptions of variables in the influence maps/systems given by users to keep the user voice central throughout.

We discuss the benefits of a systems approach in the following section, and the work draws heavily on the expertise provided by RSA Fellows and their experience in developing new systems-based approaches to drugs and alcohol in Scotland.<sup>135</sup> While our work sought to build on this experience of systems approaches to drugs and alcohol strategies, our starting point for the system is fundamentally different: it is the experience directly articulated by the problem drug and alcohol user.

### **Phase 3: Pilot**

The final phase of the project will involve attempting to make these proposals work in practice, including the use of systems thinking in the planning and delivery of recovery support. Work to implement these ideas is underway and the results of the interventions will be presented in a future RSA report. As pilots will be innovative, learning how best to implement them is likely to be rapid and ongoing through their implementation. Consequently, we will use a design experiment model to evaluate activities in which researchers are embedded in the project and capture experience, impact and learning through observation and qualitative methods in real time. Researchers will work in close collaboration with practitioners to enable learning to inform delivery of the pilot on a continuous basis.

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<sup>135</sup> Expertise on systems thinking has been provided by RSA Fellow, Tony Hodgson (Hodgson, A.M.) of Decision Integrity, for which we are very grateful. See Scotland's Future Forum (2008) **Approaches to Alcohol and Drugs in Scotland — A Question of Architecture. A systems mapping approach to how Scotland can reduce the damage to its population through alcohol and drugs by half by 2025** [<http://www.scotlandfutureforum.org/assets/files/report.pdf>].

Fig 4. From data analysis to influence maps, to system maps, to whole person recovery



Figure 11  
See page 71

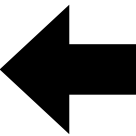


Figure 13  
See page 111

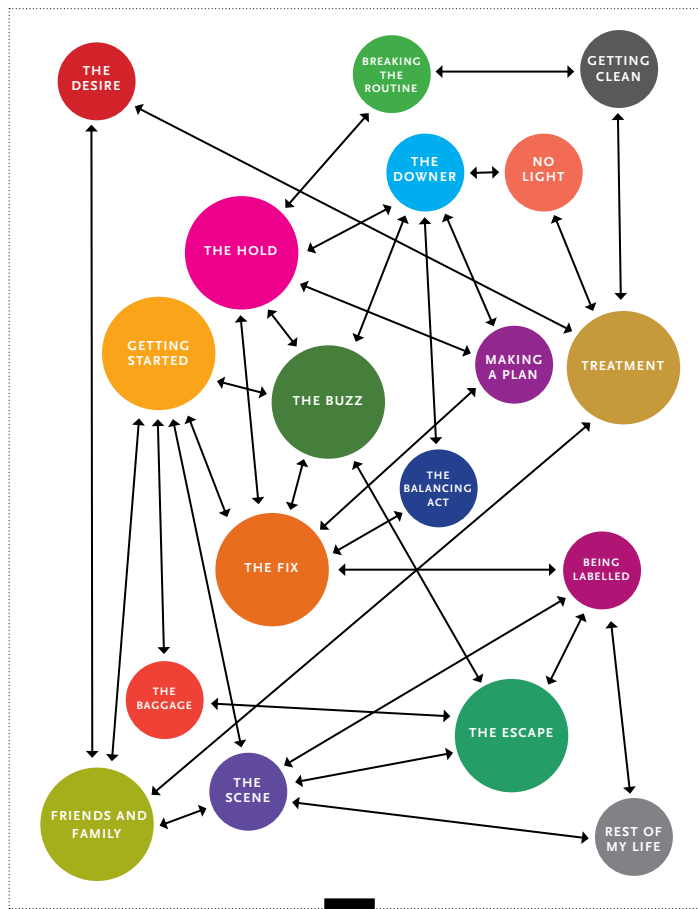
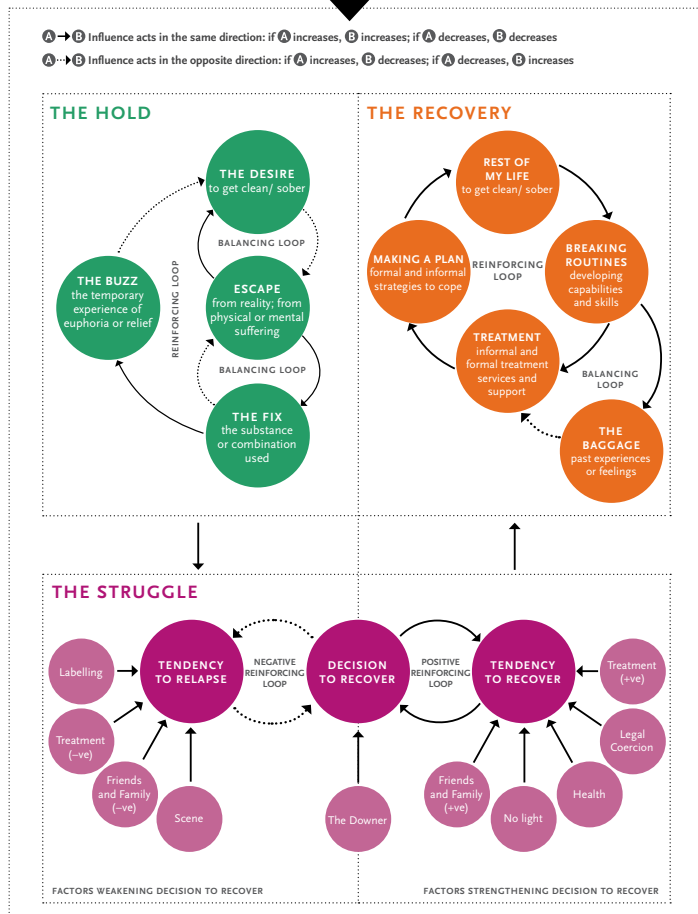


Figure 5  
See page 39



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## SECTION 4. Mapping the Whole Person Recovery System

This section introduces a systems approach to the research findings generated by the activities outlined in the previous section. A systems approach provides a structure around which to present the project's wealth of information and has resulted in a user-generated system illustrated in **Figure 5** as a map. This system is made up of three sub-systems. Each sub-system is described separately and explained by quotations from the workshops and focus groups and analysis of our survey findings.

Almost 200 problem drug and alcohol users have been involved in this project to date. Collectively, they take dozens of different drugs. They have a vast range of physical and mental health problems, pressing housing needs and face barriers (that may have existed before any problematic use began, or be a result of it) including criminal records that hinder their social and economic reintegration. Such factors make the challenge of supporting problem users to initiate and sustain recovery highly complex.

This complexity goes beyond surface measures of deficits. Problems are *dynamically* complex if cause and effect are far apart in space and time. They are *generatively* complex when the future is or appears unpredictable and unfamiliar; and they are *socially* complex in cases where stakeholders have different assumptions, values, rationales and objectives.<sup>136</sup>

This project faces problems that are complex in all these ways. Long-term users often describe pathways into drug taking that are long past and that occurred in different places. Being in recovery from problematic drug use is very hard to imagine, both in terms of how to undertake that journey and in terms of what a future life could look like. In fact, neurobiological research suggests that damage done to the frontal lobes by chronic drug use affects users' capacity for a 'memory of the future',<sup>137</sup> the ability to see or imagine future options. Among young people in particular, there is a substantial time-preference operating: the long-term, uncertain potential costs of drug use are discounted against the immediate benefits of taking drugs, which works in tandem with people's natural optimism bias about their own life course. Only when people start to enter employment, for example, do perceptions about the future become longer.<sup>138</sup>

### A systems perspective

To tackle such problems, we need emergent, system, and participatory processes.<sup>139</sup> We have sought to employ a participatory approach throughout our research and design phases to place the user experience and voice as the foundations upon which to build ideas. We have understood and organised our research through a systems approach. This approach allows us to better understand the complex relationships between the different component parts of a whole system; how they interact and influence one another and therefore how particular components impact on the entire system. A systems approach aims to better understand how human activities currently interrelate and should interrelate, so that they can be designed and improved on the principle that valid wholes perform much better than the disconnected sum of their parts. In this way, we lay out all dimensions of cause and effect and make visible the interdependencies that help or hinder an individual to spark and sustain recovery.

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136 Kahane, A. (2004) *Solving Tough Problems: An Open Way of Talking, Listening, and Creating New Realities*, San Francisco: Berrett-Koehler Publishers.

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137 Ingvar, D. H. (1985) 'Memory of the future: an essay on the temporal organization of conscious awareness', *Hum. Neurobiol.*, vol. 4, no. 3, pp. 127-136.

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138 RSA — Home Office Drugs Policy Seminar — What do advances in neurobiology, behavioural economics and social psychology mean for drug strategy?, September 2009.

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139 Kahane, A. (2004), *op. cit.*

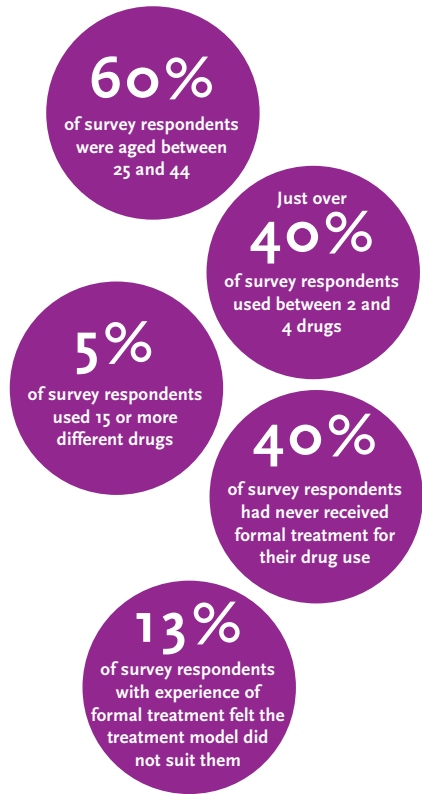
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140 *ibid.*

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141 Hodgson, A.M. (1992) 'Hexagons for systems thinking', *European Journal of Systems Dynamics*, vol. 59, no. 1.





As our systems are centred on the user and their experience, they describe and fit the individual, rather than requiring the individual to fit established systems. Consequently, we have moved forward through ‘generative dialogue’<sup>140</sup> that reflects all actors being able to understand the whole system and reflect on their role in it. We believe that these approaches, the journey that has been taken in arriving at our final ideas are as important as the ideas themselves.

Further, our systems approach offers a way for policy makers, commissioners, treatment services, problem drug users themselves, and the many other components of recovery, to better understand and plan for recovery in personalised ways. We suggest that systems for whole person recovery form the foundations for a new drug strategy that makes better use of the assets that exist in individuals, social networks and communities.

### OVERVIEW OF SURVEY RESPONDENTS

Three quarters of the survey respondents were male. Just over a quarter were under 25 years old, 60 per cent were aged between 25 and 44, and one in eight were aged 45 and over. One in six were of non-white British ethnicity.

70 per cent of respondents described their drug use as problematic. More than two in five also said their alcohol use was a problem for them. Around one in seven were no longer using drugs, and a fifth used a single drug. Just over 40 per cent used between two and four drugs, and five percent used 15 or more different drugs.

Almost half of the respondents (45 per cent) used heroin, and a quarter used prescribed methadone. Over a quarter took crack/rock, one in five used benzos, and one in five took cocaine. One in six used sleepers, and over a third used cannabis with most preferring skunk. Almost 10 per cent used ketamine, 13 per cent used amphetamines, and 7 per cent took acid.

Two in five had never received formal treatment for their drug use. More than half who had received treatment did not finish their treatment programme as originally intended. A number of reasons were given for not finishing treatment, including: started using again (22 per cent); treatment model did not suit me (13 per cent); not being ready to stop using (16 per cent); and moving out of the area (13 per cent).

In this section we present the main findings from the survey, interviews and focus groups as they have been described and situated within the systems generated by users involved throughout the research. We have used systems mapping to help visualise and discuss findings and interdependencies, which is part of the language of systems thinking.<sup>141</sup> It provides a tool to visualise the projects research and its findings, in order to simplify what would otherwise be an enormous amount of complex information. A full write up of the survey results is given in Appendix A.

 See page 93 for Appendix A

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## HOW TO READ A SYSTEMS DIAGRAM

Systems diagrams, including the maps used in this report, enable complex information to be presented visually. The following rules of thumb will help readers to navigate the maps presented in the following section.

1. Systems diagrams have two main components; the variable and the arrow.
2. The variable (the circles on the maps) is a factor of importance that will change according to various influences.
3. The arrow represents the direction of some significant influence or causality.
4. In systems thinking, causality can flow in both directions. When this happens it is represented by a loop which is formed between the two (or more) variables by single headed arrows.
5. The importance of this has several aspects to bear in mind when reading the maps:
  - The sequence of connections in the map suggests that one thing depends on another; this is represented by the arrows flowing between each circle.
  - The relationship between variables is not linear. As such, a change in a looped variable will not necessarily produce proportional change in the system as a whole. The loop can cause for example, exponential growth or decline.
  - Even two simple loops tied together may demonstrate complex behaviour such as oscillation or even wild swings to and fro.
  - Where the map shows patterns of current behaviour not all connections may be present as the system may be fragmented.
  - The map may be constructed as an idea of how the desired behaviour of the system may be increased, by taking action to join things up in a different way that we believe may be more effective.
  - The map may also be used as part of a learning or participatory design process in which practical experience and the patterns in the map are constantly matched and both progressively improved.
6. System diagrams and maps are, above all, additional aids to communication and discussion which can bring out other aspects of people's experience and insight than just through words alone.

## The user-generated system map

The first stages of constructing a user-generated system of experience are described below in three sub-systems: The Hold, The Struggle, and The Recovery. **Figure 5** demonstrates how each of these three sub-systems relates to one another. These links offer only one of a number of possible relationships between the sub-systems as well as the components within them. The links of this system attempts to visualise the most common threads found within the research rather than reflecting each and every individual journey of problem drug use and recovery.

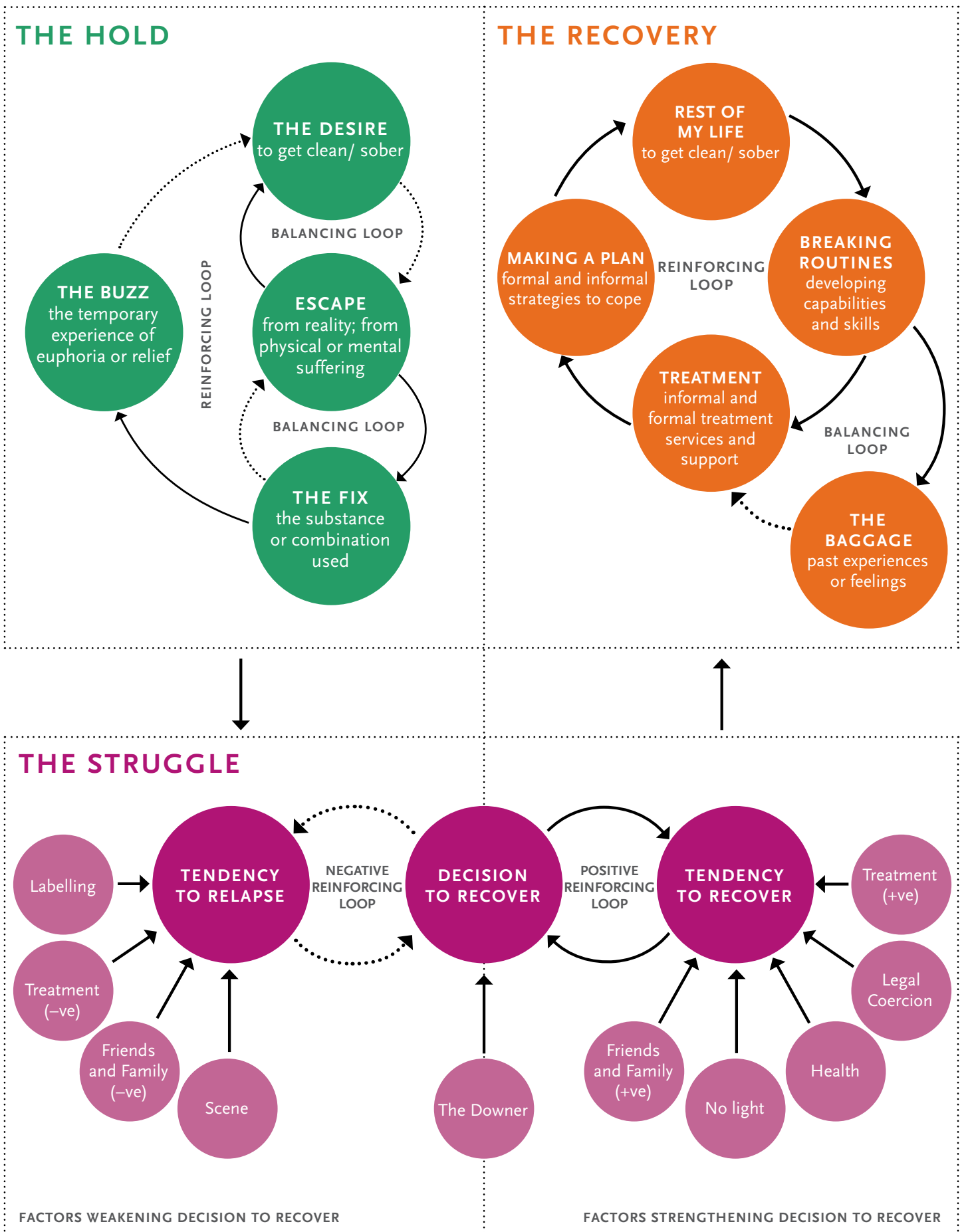
It is important to resist a natural inclination to view the system and the relationships between each sub-system as a linear process. Although users may clearly move from being in addiction, to struggling to overcome it, to long-term recovery (perhaps with several attempts at trying to overcome it), in systems thinking, users exist within the system as a whole and are therefore influenced (to a greater or lesser degree) by all system dynamics at the same time. So, for example, even those in long-term recovery may experience the pull of the Escape and a glance in the direction of the Tendency To Relapse and The Hold. Similarly, those caught in cycles of addiction can simultaneously build elements of recovery capital necessary to support a transition to recovery. Understanding this enables us to begin to take a whole person look at problem drug use and recovery and explore how to support long-term, sustainable recovery.

The following pages explore each sub-system in more detail illustrating them further with the voices of those involved in the research and using data from the survey.

Fig 5. The user generated systems map



A → B Influence acts in the same direction: if A increases, B increases; if A decreases, B decreases

A ⇄ B Influence acts in the opposite direction: if A increases, B decreases; if A decreases, B increases



## The Hold

Figure 6 demonstrates the Hold sub-system. The components of this sub-system are:

- *The Escape* — ‘why’ individuals use substances; to escape. 
- *The Desire* — to get clean, to stop using their drug(s) of choice. 
- *The Fix* — the drug(s) used by an individual.
- *The Buzz* — the feeling individuals experience (and sought) by taking ‘the Fix’.

As a sub-system, the Hold mirrors the classic system archetype within systems thinking known as either ‘Shifting the Burden to the Intervener’ or, in the context of substance misuse, as ‘Addiction’. This archetype states that a problem symptom (the Escape) can be resolved either by using a symptomatic solution (the Fix) or by applying a fundamental solution (the Desire).

The term Addiction suggests that a drug dependency has developed to such an extent that it has serious detrimental effects on the user<sup>142</sup> which was certainly true for a large number of the research participants. For these people the Hold related to the feelings and experiences that were linked to the physical and emotional dependence they had on drugs and alcohol. However, for some, their involvement in the Hold was not necessarily related to ‘drug dependency’ or the physical or psychological effects that this can imply<sup>143</sup> but was more an explanation for using drugs problematically as a way to forget about their surroundings or situation.

In this section we explore the various reasons for participant’s involvement in the Hold, the internal and external pressures that intensified their involvement and ultimately for some, that led them from drug use to drug dependency.

### The Escape

The ‘problem symptom’ described by the system archetype above is referred to as the Escape in the user generated account. There was no single explanation for why participants sought the Escape; however commonalities began to emerge across the accounts which fell broadly into two main themes: ‘internal factors’ and ‘external factors’.

*Internal Factors:* Participants described a range of internal reasons for seeking an Escape that included escaping emotions related to past memories, escaping feelings of low self-esteem and escaping feelings of depression.

*“I’m a better person on drugs. Without them I wouldn’t be sitting here right now; I’d get angry, I don’t talk at all. I’m just no fun to be around unless I’ve either taken something or drunk something.”*

— Workshop Participant

*“Drink’s a symptom of what’s going on — you can have such powerful emotions. It’s so easy to take chemicals to take it all away again.”*

— Workshop Participant

*“With heroin, it’s not for boredom... It’s that you get so low that you think it’s the only way out.”*

— Workshop Participant

For those who had been using for a long time, we were told how they were using to self-medicate to escape the mental and physical effects of prolonged use.

### USER GENERATED SYSTEMS MAP EXAMPLE. SAM’S STORY OF THE HOLD

The user generated systems map opposite can be difficult to understand in the abstract without prior knowledge of systems methods. This box presents an individual’s story, which illustrates one experience of the system and demonstrates how to read the diagrams opposite.

Sam described how he was always chasing the Buzz of his first experience of heroin but never managed to reach it. *“At first it wraps you up in cotton wool... but after a month, maybe 6 weeks, then that hit, all it does is bring you back to normal. You get so ill that you’re using it as medication.”* As Sam’s need to seek an Escape from the painful ‘rattle’ he experienced if he did not use heroin increased, the likelihood of him seeking the Fix increased, which resulted in the Buzz and decreased his immediate desire to Escape. The temporary euphoria and relief of the Buzz also reduced his desire to seek a fundamental solution (the Desire) and get clean. This maintained his involvement in the Hold.

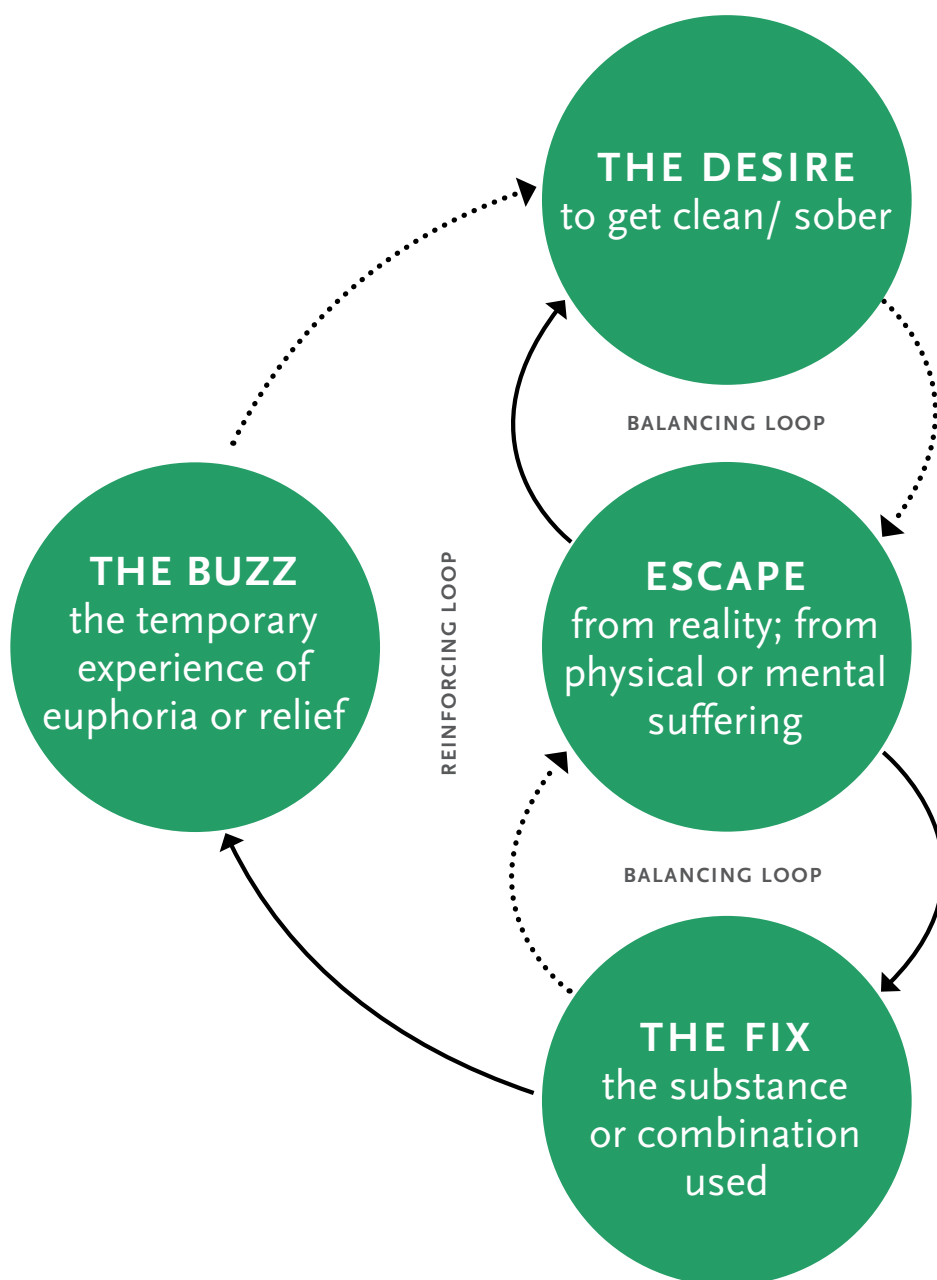
<sup>142</sup> See <http://www.drugscope.org.uk/resources/mediaguide/glossary>

<sup>143</sup> See [http://www.cks.nhs.uk/patient\\_information\\_leaflet/drug\\_misuse](http://www.cks.nhs.uk/patient_information_leaflet/drug_misuse)



Fig 6. The Hold sub-system

- Ⓐ → Ⓑ Influence acts in the same direction: if Ⓐ increases, Ⓑ increases; if Ⓐ decreases, Ⓑ decreases
- Ⓐ ⇢ Ⓑ Influence acts in the opposite direction: if Ⓐ increases, Ⓑ decreases; if Ⓐ decreases, Ⓑ increases



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*“Unless you get that fix, then you feel like you’re going to die.”*

— Workshop Participant

*“It became medication to keep my head and body straight.”*

— Workshop Participant

*External Factors:* Participants predominantly discussed the external factors which influenced their using behaviour. Homelessness and other pressing housing issues (including safety) were considered big drivers of their involvement in the Hold.

Participants with experience of homelessness often became exposed to networks of individuals using drugs and alcohol problematically which encouraged them to use at an increased rate so that they felt like they fitted in and could feel safe among other people on the street; while for many, increasing their use enabled them to cope with the realities of being homeless.

*“It makes heat to keep me warm on the streets”*

— Workshop Participant

Women were more likely to seek an ‘Escape’ as a result of domestic abusive.

*“I was with an abusive partner at the time... and you just take it, there’s nowhere else to go. And I was too scared to go anywhere”*

— Women’s Focus Group Participant

For many of these women, problematic use developed and for the majority of women in the focus group, their dependency on heroin led to sex work to raise the funds needed to support their habit and in many cases to subsidise their partners’ habits.

*“I was a call-girl, an escort, for quite a few years and of course, certain drugs are involved in that and I just got dragged into it.”*

— Women’s Focus Group Participant

These women were then using for multiple reasons: to Escape the immediate situation associated with sex work, but also to Escape the physical and mental effects of their dependency that perpetuated the situation.

*“You have to, you have to block out what you’re doing.”*

— Women’s Focus Group Participant

*Internal and External factors:* Often the internal and external factors described by participants were linked. In Bognor Regis for example, a special police task force has been set up to deal with the increasing number of Eastern European street drinkers. Many of the problems associated with these groups result from a cultural norm of heavy drinking which has been amplified by their inability to secure employment, housing or for some, legal residence status once in the UK.

While the cultural nuances and additional pressures around language and seeking asylum are significant for many new arrivals, the external factors described (lack of housing and employment opportunities for example) were shared across a majority of all participants. This was true even for those participants who told us initially that they took drugs because they enjoyed the feelings.

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*“When I ended up on the streets I started using a lot more heavily than when I had somewhere to live. The only way to get some sleep, any rest at all, is to get absolutely out of your face.”*

— Workshop Participant

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*“I do actually want to find a job. I just can’t be bothered to be honest and there’s just crap work out there. I’m not going to give up to have a job... But if I had a job it would be different. I wouldn’t go out every day, I’d probably only get fucked at the weekend. But like, because I haven’t got a job at the moment, there’s nothing better to do, there’s nowhere for us to go or to do.”*

— Workshop Participant

*“Drugs are amazing, they take you into another dimension that you’ve never been to.”*

— Workshop Participant

Ultimately, through discussion and challenge by other users, it emerged that these participants were trying to Escape: they felt that their communities had little to offer them; that they could not get a job they wanted and/or could feel proud about; and were having difficulties with claiming benefits.

*“I try to get the best out of life and it gets chucked straight back in my face.”*

— Workshop Participant

For them, drugs in particular offered an Escape from boredom and an alternative to the lack of opportunity in the community. Participants with these views were typically among the youngest in the research and reported using a variety of drugs including ketamine, cannabis and ecstasy, but reported little to no use of heroin or crack cocaine.

### **The Escape and Recovery**

An individual’s ability to cope with and address many of the difficulties described above is often determined by a range of factors that are related to their Recovery Capital (an idea we will discuss further in **Section 5**). In the context of the Hold, if an individual is suffering from some difficulty that does not have a perceived simple solution or perceived alternatives, then this may lead them to temporarily relieve this difficulty through drug use. Drugs can be the symptomatic response which can subdue any urge to seek a fundamental solution, which might be difficult to attain quickly, for example, finding somewhere to live or finding help to address a past traumatic experience (see **Table 1**).

**Table 1: How symptomatic solutions hinder difficult fundamental solutions**

Problem Symptom (The Escape)	Fundamental Solution (The Desire)	Difficulty in accessing / finding Fundamental Solution (example)	Symptomatic Solution (The Fix)
Homelessness	Having somewhere safe to live	Lack of available housing	Drugs and alcohol to cope or forget
Domestic violence	Admit to the violence and ask for help. Move out of the home, leave violent spouse	Fear. No family or friends. Don't know where to ask for help	Drink to forget and cope with the pain and humiliation
Mental and physical effects from long term substance misuse	Getting clean	Lack of suitable treatment. Painful rattle. No hope for recovery. Anxiety about the future	Drugs and alcohol to deal with the physical and mental pain
Boredom	Meaningful activity such as a job or community activities	Lack of opportunity in local community and reducing jobs market	Drugs and alcohol for pleasure or experimentation, cope with boredom

As this cycle is reinforced, the need for a real (fundamental) solution gets more and more obscured, trapping the person in The Hold. Certainly this is true for a majority of our survey respondents, of whom 70 per cent recognised their drug use as problematic yet continued using or felt unable to stop.

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## The Desire

In the user account of the Hold, the Desire refers to an individual's wish to find the 'fundamental solution' to the reasons for seeking an Escape (the 'problem symptom'). As we suggest above, many of the 'fundamental solutions' available or accessible to address problem symptoms can seem unobtainable, too difficult or painful, and in some cases too dangerous. Participants often found that their attempts to find a fundamental solution were hampered by the poor resources (or recovery capital) available to them.

*"I was living in a bail hostel and there were 49 men in there and me and I was really harassed in there. They ran a book, the first night I stayed there, they ran a book on who was going to sleep with me first. And they knew I was a Valium addict. One of them knocked on my door, gave me £20 in Valium and I woke up the next day with him in the bed next to me. I can't call it rape 'cos I would've probably been more than happy at the time but obviously I can't remember. So he won £30 cos they'd all put a quid in. I had to stay there, it was a homeless shelter."*

—Women's Focus Group Participant

This known or perceived lack of suitable resources has a significant impact on participant's likelihood to seek a fundamental solution, especially if a previous experience of trying to attain a fundamental solution has been difficult, and ultimately continues their involvement in the Hold. Without a fundamental solution, the need to Escape remains and may even become more acute, which leads the user to seek the Fix.

## The Fix and the Buzz

The Fix refers to the substance used by an individual. For a significant proportion of participants, this involved a range of drugs and alcohol. Many of those with experience of the Hold were multiply-addicted and regularly moved from one drug to another. Just over 40 per cent used between two and four drugs and 5 per cent used 15 or more different drugs. Almost half the respondents (45 per cent) used heroin, and a quarter used prescribed methadone. Over a quarter took crack/rock, one in five used benzos, and one in five took cocaine. One in six used sleepers, and over a third used cannabis with most preferring skunk. Almost 10 per cent used ketamine, 13 per cent used amphetamines, and 7 per cent took acid.

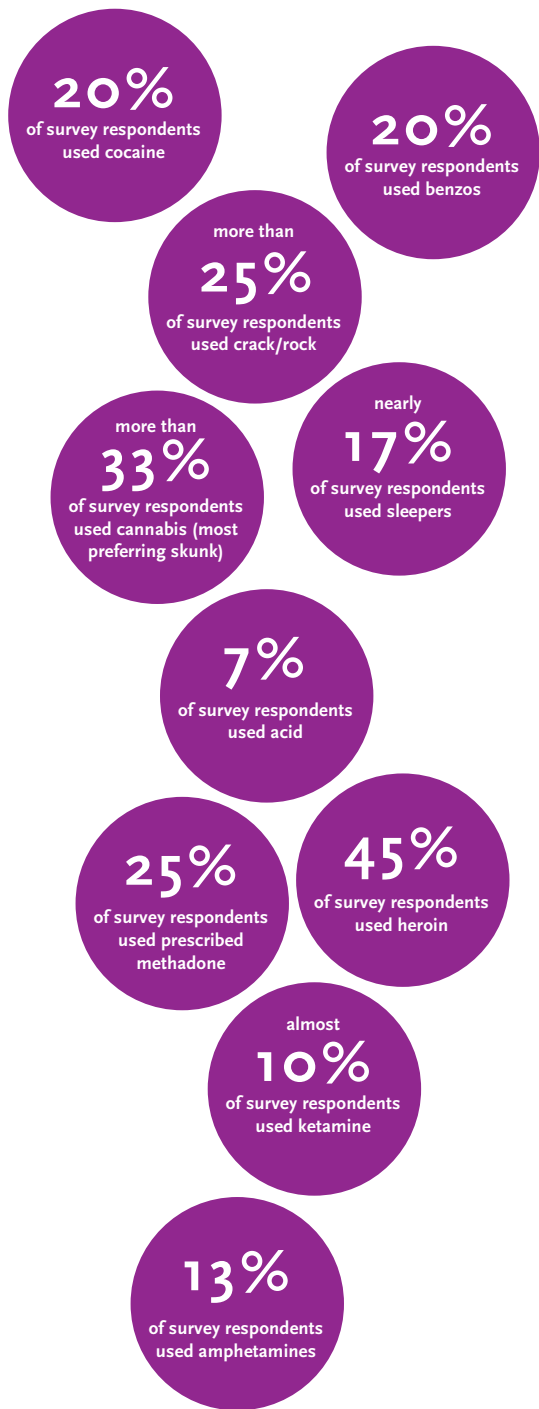
For those workshop participants who reported drug rather than alcohol use, this was simply a way of life, moving from one drug to another according to the relative strength (the Buzz) of the street drug on a given day, or as a means to manage the effects of one drug over another.

*"When I did cocaine, I'd try all kinds of drugs. It'd be ecstasy, then it was Valium, and then I tried Subutex. And there was a few years of that."*

—Women's Focus Group Participant

Research has suggested that while alcohol is considered a necessity by its users, who have seemingly constant, inelastic demand, drugs are a luxury and have elastic demand to some degree. Research showed that drug price changes meant that users would shop around for alternatives (or even stop using in extreme cases), while price changes in alcohol had little effect as its users regarded it as indispensable, economising on basic provisions if necessary to enable its purchase.<sup>144</sup>





Provision for problem drug use is predominantly focussed on those drugs considered to be the most problematic — heroin and crack cocaine — but as our research demonstrates, the range of drugs being used in any given week stretches far beyond these ‘problematic drugs’ and associated provision. While focusing to a large degree on ‘problem drugs’ is arguably justified as a resource allocation strategy for services, it means it is very difficult to recognise or deal with the array of drugs that are used concomitantly or as a replacement to the drug being addressed through treatment. This can mean that while individuals may be seeking a fundamental solution through formal treatment, it may only address one of the factors influencing a person’s involvement in the Hold.

The range and permutations of individual drug use points to the need for personalised recovery treatment and a whole person approach that addresses more than a single element of an individual’s need. Failure to expand and personalise treatment options will mean individuals will continue to be part of a drug-using world, making it difficult for them to free themselves from the Hold; increasing the likelihood of developing dependency; and increasing the likelihood of relapse for those individuals already dependent on drugs.

As the next sections demonstrate, the strength of the Hold and the availability/strength of positive factors that make the Desire possible, are part of a larger system in which the sub-systems operate simultaneously.

144 RSA — Home Office Seminar — Neuroscience, Social Psychology and Behavioural Economics Seminar, September 2009.

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## The Struggle

The components within this sub-system are predominantly taken directly from the workshops. However, those variables in the larger circles (see **Figure 7**) were developed by systems specialists (drawing on further research within this project, and from systems architecture) to provide the framework for this sub-system.

Many participants described a ‘Struggle’ that oscillated around their Decision to Recover. They described experiencing a series of internal and external influencing factors (the smaller circles) that either weakened their resolve (and drove the Tendency to Relapse), or strengthened it (towards the Tendency to Recover). It is these influencing factors that are the main focus of this sub-system. Below we offer summary descriptions of the factors discussed by participants. The full range of influencing factors are discussed in detail in **Appendix B**.

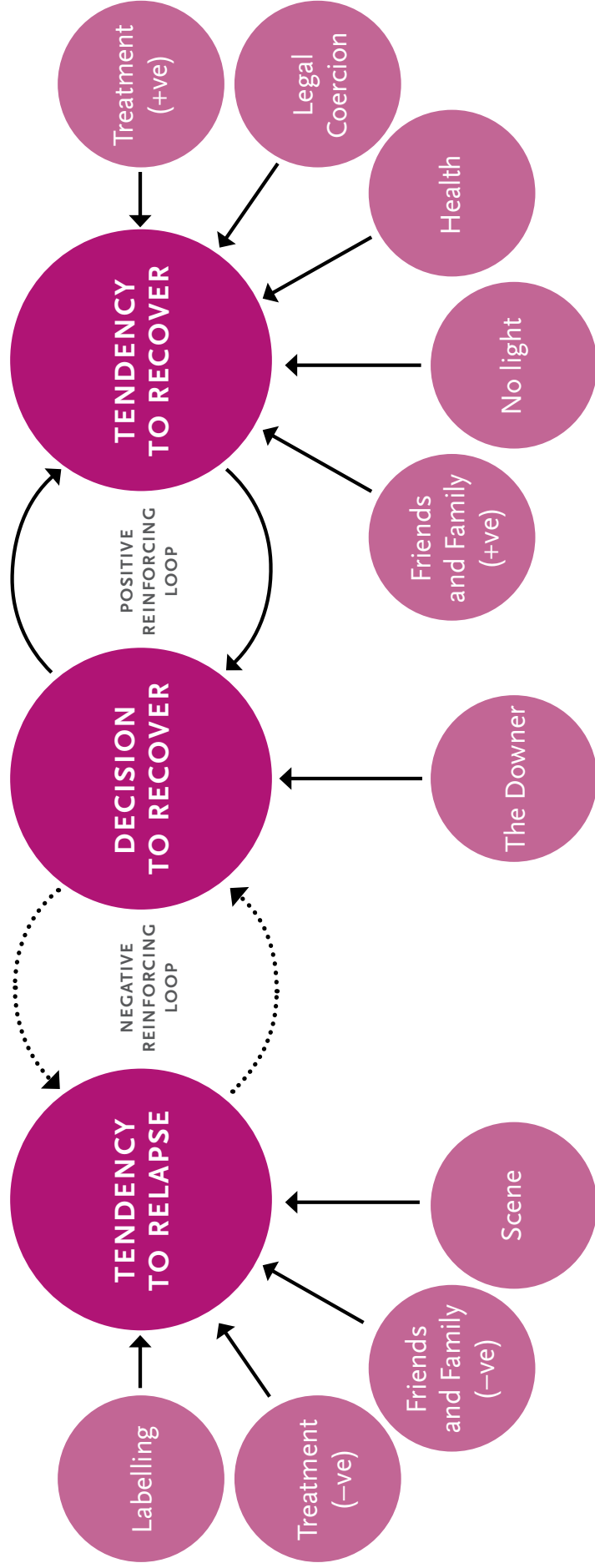
- *Labelling* — the stigma that many individuals with problem drug or alcohol use experience. Many participants described feeling stigmatised in a variety of ways and by various people.
- *Treatment* — the negative incidents or pressures that individuals experienced while in treatment that they felt acted as a barrier to their recovery and/or as a disincentive to try and recover (again). In some cases Treatment was a positive factor and supported the Tendency to Recover.
- *Friends and Family* — the people within individuals’ networks that have a negative impact on their resolve to instigate recovery. In some cases this was a positive influencing factor and strengthened participants’ resolve to instigate recovery.
- *Scene* — the environment in which individuals live, work, take drugs and drink, as well as their general circumstances and how they impact on their using behaviour.
- *The Downer* — the negative aspects of problematic use, including the mental and physical effects experienced when the effects of drugs or alcohol wore off.
- *No Light* — the end point for many, when the experiences and lifestyles of problematic use had reached the lowest point and there seemed little hope.
- *Health* — the physical and mental health issues that individuals experienced as a result of problematic use.
- *Legal Coercion* — the legal obligations individuals may be subject to such as Drug Rehabilitation Requirement (DRR).

 See page 98 for Appendix B



Fig 7. The Struggle sub-system

- A** → **B** Influence acts in the same direction: if **A** increases, **B** increases; if **A** decreases, **B** decreases
- A** ... **B** Influence acts in the opposite direction: if **A** increases, **B** decreases; if **A** decreases, **B** increases



FACTORS WEAKENING DECISION TO RECOVER

FACTORS STRENGTHENING DECISION TO RECOVER

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## Tendency to Relapse, Decision to Recover and Tendency to Recover

As a sub-system, the Struggle describes how individuals battle with the conflicting impulses to move away from problematic use on the one hand or fall deeper into it on the other. For example, an individual might decide one day that they want to seek help and may begin to speak to someone to find help or treatment. But as this sub-system demonstrates, there are multiple factors, both internal and external, that might influence the individual's resolve or their ability to follow it through.

According to this sub-system, the Decision to Recover is in the middle of a tension between the Tendency to Recover and the Tendency to Relapse. If the impetus to the Decision to Recover, represented in the map by the Downer, triggers a strong decision then it will increase the Tendency to Recover and this will in turn strengthen the decision. This is further aided by the factors such as Friends and Family and Health, which tend to strengthen that Decision to Recover. Success breeds success in a positive reinforcing loop.

If, however, the trigger is relatively weak, the pressure of factors such as Labelling and the Scene will weaken the Decision to Recover and will increase the Tendency to Relapse. This in turn will weaken the Decision to Recover. This becomes a vicious cycle or a negative reinforcing loop.

The smaller circles represent the key, user-identified factors that may intensify the strength of the two reinforcing loops. However, these examples are by no means comprehensive: people will have their own personal set of factors, which is why a personalised approach to emerging recovery is so important. When considering the Tendency to Relapse the stronger the influencing factors are, the harder it will be to get out of the relapse dynamic. When considering the Tendency to Recover, the influencing factors can be seen to counteract the negative factors and strengthen the recovery dynamic.

### The Tendency to Relapse

Individuals often oscillate within the Struggle where they might sometimes feel like giving up and getting clean and move towards the Tendency to Recover, but then something might happen (perhaps unexpectedly) that would move them towards the Tendency to Relapse.

*“The first time I got off it, I actually just got it in my head — that is it, and I done it and stayed off it for a year. But then something happened with my children and I went straight back down that road again.”*

— Workshop Participant

**Figure 7** illustrates specific factors which further influence the Tendency to Relapse; Labelling, Treatment, Friends and Family and the Scene. In many ways these factors are the external reasons for individuals seeking the Escape detailed in the Hold sub-system. Interestingly, within the Struggle sub-system, many of the factors can be both supportive to the Decision to Recover to instigate recovery, feeding the Tendency to Recover, as well as detrimental to it, feeding the Tendency to Relapse. In **Figure 7** we have apportioned factors according to whether they were more often described as a help or hindrance to recovery.

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## WHAT IS A REINFORCING LOOP?

A reinforcing loop is a feature of a system where the output of that system sends a signal back into the system which further increases its output. This can be negative or positive. For example, the more you get into debt the more interest payments increase your debt. On the other hand, the more savings you have in the bank, the quicker they grow.



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## **Friends and Family**

Friends and Family are two of the most influential factors in both supporting moves towards recovery and sustaining it, as well as influencing the likelihood of relapse or preventing the initial steps towards recovery. This illustrates the significant impacts social networks can have on an individual's behaviour and health.<sup>145</sup> Participants more often than not described how Friends and Family were influential in their first experiences of drugs and alcohol. Some 30 per cent of respondents said that all of the people they knew took drugs and a quarter said that people in their support networks took drugs problematically.

*“Friends and family: they’re the ones that started me out.”*

— Workshop Participant

*“My mum was doing loads of coke and pills, my sister was the same — half my family’s on heroin. I wasn’t really into it that much but then my brother started giving it to me when I was in about year 5 at school.”*

— Workshop Participant

*“My parents were dealers... so for me drugs was a normality.”*

— Workshop Participant

For those participants who identified themselves as alcoholics, they noted how drinking had started out as a social event, drinking with friends in pubs.

*“I started drinking socially but as I got more into the addiction, I stayed at home so people wouldn’t know how much I was drinking.”*

— Workshop Participant

For women, partners or spouses were the most influential factor to their problematic use and its escalation.

A third of respondents said that all the people they knew used alcohol, with one in five respondents suggesting that people in their support networks used alcohol problematically. This was particularly true for participants who were also homeless.

Conversely, Friends and Family can have significant, positive impacts.

*“My daughter saved my life...at the time I was doing about £120 worth of heroin, £100 worth of crack, I was buying Valium off the internet; I was probably doing about 5, 6 milligrams a day. I’d been told I couldn’t have children, been told that I had completely screwed my body up, I’d had to have several abortions because of when I was on the game — people don’t treat you particularly well to be honest... literally saved my life.”*

— Women’s Focus Group Participant

*“My kids were totally disgusted with me.”*

— Workshop Participant

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145 Rowson, J., Broome, S., and Jones, A. (2010), op. cit.

## The Scene

The Scene describes individuals' environments and can have a damaging impact on their ability to stay clean.

*"Moved down to Worthing to get away from things but like, when you're in the circle of drugs and that and you still want it, you find the people that you want to find to get the drugs and you start hanging round with them."*

— Workshop Participant

For women, their living situation with abusive or drug-dependent partners, and reliance on sex work to fund their habits meant they felt little hope for escaping their situation. For others, the lack of or a perception of a lack of opportunities in their community fed the reinforcing loop back to the Tendency to Relapse.

*"If I had a job it would be different, but like, because I haven't got a job at the moment, there's nothing better to do, there's nowhere for us to go or to do."*

— Workshop Participant

*"I take drugs as well 'cos what has this place got to offer me?"*

— Workshop Participant

## Treatment and Labelling

Even for those in Treatment there is an actual as well as perceived lack of opportunity to do anything other than address the medical aspects of their problem drug use (for example, to foster social and economic integration). Almost three quarters of participants in our survey had skills or a trade that they felt could help get them into employment or training, and only one in seven had never been employed. However this potential was difficult to realise, due to a combination of limited opportunity and support in existing service provision, low confidence, social isolation, and the stigma ('Labelling' in Figure 7) associated with substance misuse.

*"Five months now I've been in recovery, five months clean and serene. I feel better but I keep saying to myself what a bloody waste I've done 25 years of my life. I could have been in the Navy, I could have had a job, been a cook in the Navy but I messed it up for the drink."*

— Workshop Participant

Almost 40 per cent of survey respondents had not been employed for many years. The majority (83 per cent) suggested they faced additional (due to drug use) and significant barriers in getting (back to) work, which included breaking out of the 'benefits trap'. Allied to a lack of confidence, stigmatisation (Labelling), chequered employment history, health issues, criminal records, and addiction, the jump required to become financially independent appeared overwhelming for many respondents. Only 5 per cent were in any kind of training, and 5 percent were receiving some sort of education. These factors make it hard for users to be hopeful about the rest of their lives, and overwhelming difficulties can weaken the Decision to Recover, and hence strengthen the Tendency to Relapse.

These issues were echoed in the workshops and can be seen to account for the high level of relapse at the two project sites as well as the high number of individuals not completing their treatment as originally intended. Having hope or a belief that life can and will get better is critical to recovery and yet the evidence suggests that there is little to promote this confidence, with little dedicated activity in services or visible role models of people in recovery.



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*“It comes down to faith; faith that life will get better.”*

— Workshop Participant

In Crawley, where 15 per cent of the population are from Asian/Asian British Indian and Asian/Asian British Pakistani groups,<sup>146</sup> the influence of family and community, and of Labelling, is particularly strong. Research suggests that in South Asian communities ‘the stigma attached to the use of drugs, rather than being directed at the individual only, is also felt among the family, the extended family and family friends.’<sup>147</sup> This can have both a positive and negative influence on recovery. An individual may seek to hide or deny problems with drugs or alcohol use to prevent shame being brought on the family; or alternatively, strong families and communities who are co-affected by an individual’s drug use can be instrumental in enabling access to treatment or in supporting them in their recovery.

*“My uncles, even my mum went there and said he needs help.”*

— Interviewee

*“My neighbours, they’re helping me and still helping me.”*

— Interviewee

### **No Light**

Little was said about No Light beyond the fact that this was in some ways the final, ultimate Downer, when the experiences and lifestyles of problematic use had reached the lowest point and there seemed little hope. However, this variable is potentially key as participants described how reaching this point often encouraged them to seek help; the only alternative available to them was often perceived to be death. Finding ways to engage people at this point may produce significant results in provoking a Tendency to Recover.

*“I know if I have one drink, I’m gone.”*

— Workshop Participant

### **Health**

Mental and physical health issues can pre-date problem drug and alcohol use, although the development of acute health issues often goes hand in hand with the development of problematic use.

*“The major thing that happened to me — I started to have fits. Stiff fits, I can’t explain them... It actually became normal. I’d have a fit and know how long it was going to last depending on what I was drinking.”*

— Workshop Participant

These health issues ranged in severity but all were considered to have a significant impact on an individual’s resolve to instigate recovery. Specifically, survey responses revealed that within the last few weeks, more than 60 per cent experienced general anxiety, 80 per cent slept poorly, 54 per cent had low self-esteem, 61 per cent felt depressed and one third felt paranoid. One in six had suicidal thoughts, 13 per cent had self-harmed, 8 per cent had taken a deliberate overdose, and 6 per cent had attempted suicide.

For those participants who had received help for their particular health issues, recovery seemed a far more hopeful and viable possibility and so strengthened their Tendency to Recover.

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<sup>146</sup> See <http://www.crawley.gov.uk/stellent/groups/public/documents/report/into10668.pdf>

<sup>147</sup> Fountain, J. (2007) *Issues surrounding drug use and drug services among South Asian communities in England*, London: NTA.

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While the influencing factors and dynamics within this sub-system represent only a handful of the influences on a person's resolve and ability to instigate recovery, they demonstrate the complexities involved in the journey. The balance and strength of the loops depends on a wide variety of internal and external factors which can act independently or together, can influence one another, and can pull the individual towards the Tendency to Relapse and the Tendency to Recover. No two journeys to recovery are exactly the same.

Mapping out and thinking through the various components that inform this complexity means that a personalised response can be delivered. This can take into account and monitor the variety of needs and pressures, the existing resources and assets available and offer a way of prioritising efforts to address the needs of individuals with a raft of needs. It is the relative strength of these elements in relation to the Tendencies to Recover or Relapse that mean that for most, this sub-system can be the longest part to a person's recovery and has a close relationship to all other sub-systems at all points through a person's journey.

## The Recovery

This sub-system illustrates one possible route to recovery that represents the strongest account given in the research. There is an emphasis on recovery with formal treatment in this account as a majority of those involved in the research had some experience of accessing treatment services. It should be noted that this sub-system is not being presented as an ideal model, but the frame around which to present the research findings. The components of this sub-system are based on the terminology used by workshop participants.

- *Treatment* — the range of formal and informal treatment services and support. This is not confined to formal treatment services.
- *Making a Plan* — the development of a whole person recovery plan or informal strategies such as going cold turkey.
- *Rest of my Life* — the individual's ability to picture and plan for a goal or set of goals and future life. Hope and a belief in the possibility of achieving these goals are generated through the mapping process and a trust in the support mechanisms to enable the individual to reach their goals. They are also made more achievable by providing greater visibility of others in recovery.
- *Breaking the Routines* — the development of skills, capabilities, tools and processes to enable the individual to cope with the variety of pressures and factors that influence their using behaviours.
- *The Baggage* — the feelings and experiences of the past that will surface as the individual stops using drugs and/or alcohol to block them, and that will need to be dealt with. In this sub-system, the Baggage can be seen as part of a balancing loop that may have a delay effect on a person's recovery and may cause the person to relapse as they struggle to weaken its influence and develop the tools needed to cope without drugs and/or alcohol.

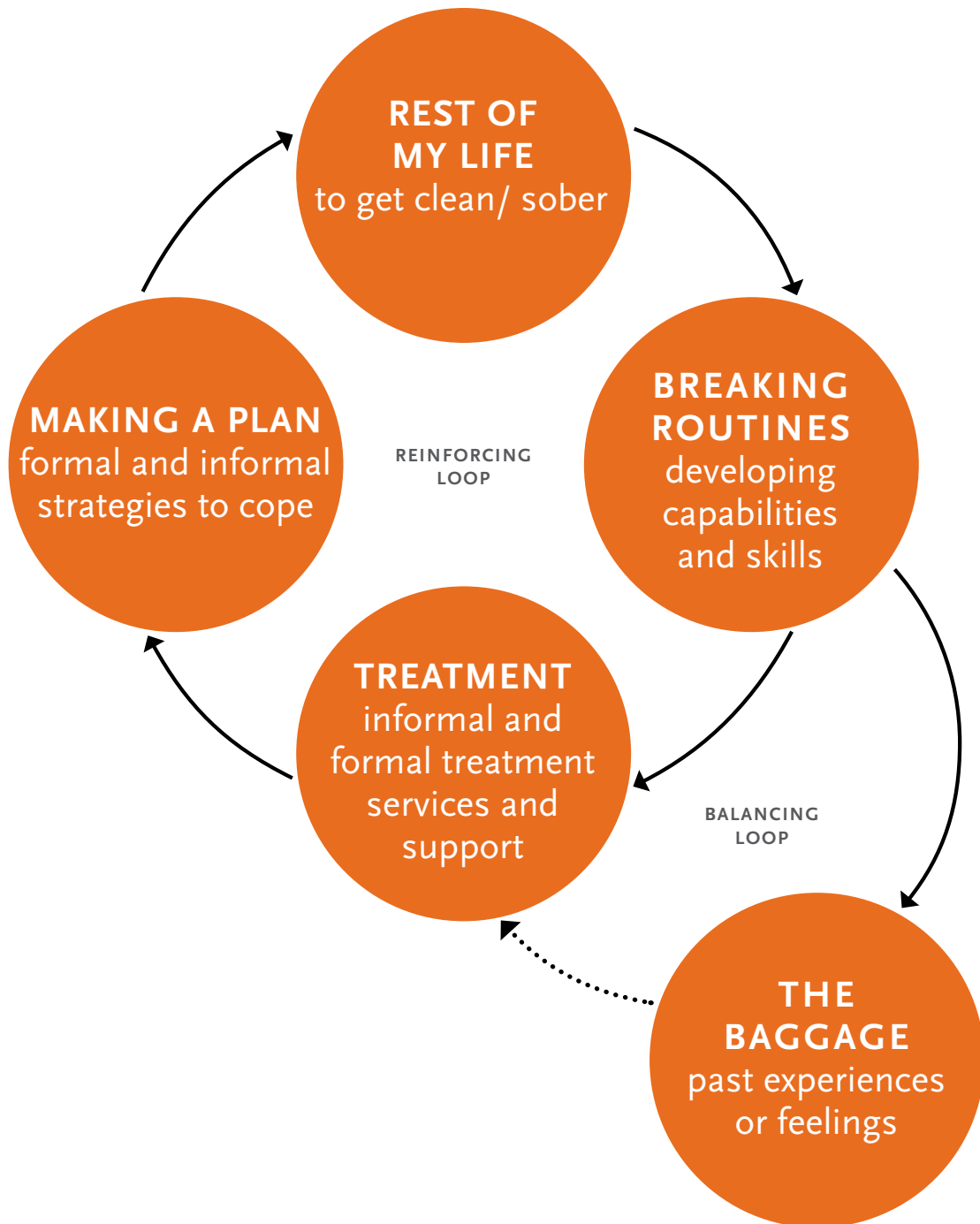




Fig 8. The Recovery sub-system

**A** → **B** Influence acts in the same direction: if **A** increases, **B** increases; if **A** decreases, **B** decreases

**A** ⇢ **B** Influence acts in the opposite direction: if **A** increases, **B** decreases; if **A** decreases, **B** increases



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## Treatment

There are a range of entry points to the Recovery sub-system and it is the ease at which individuals are able to access these gateways and the response that they receive when they get there, that can have the most impact for those at the very early stages of their recovery journey. Predominantly participants discussed treatment in terms of the traditional drug and alcohol services which is reflected in the quotes below. However, we recognise that recovery is not dependent on formal treatment.

All but 5 per cent of survey respondents reported that they were registered with a GP and this was often the first point of contact in seeking help with their drug and alcohol problems. Overwhelming, the experiences of workshop participants was negative.

*“When I first went to the doctors they were like, you’re too young, you don’t have an addiction. And I just kept getting turned away.”*

— Workshop Participant

*“He told me to pull myself together.”*

— Workshop Participant

When workshop participants felt the GPs got it right, this made an enormous difference to their recovery.

*“The doctor’s tone of voice changed — they were determined to get the truth. And they did eventually.”*

— Workshop Participant

GP training in problematic drug and alcohol use is predominantly offered at the post-graduate level through the Royal College of General Practitioners (RCGP) certificate in Drug Dependency,<sup>148</sup> while little is offered to students during medical school. This can lead to a patchwork of understanding and experience that can often be determined by exposure to patients with the related problems. Our research suggested that this can mean that many can feel ill-equipped to support an individual with their drug problems. This may also mean that GPs are susceptible to the populist and stigmatising misunderstandings about drug use and users which are then reflected in their reactions to those seeking help.

Whatever the reasons, these responses can have a lasting and damaging effect on individuals who might want to address their drug use. Such effects extend to specialist treatment providers as they are often seen as ‘fellow professionals’ akin to GPs.

When participants and survey respondents discussed formal Treatment, they reported a mixed experience. More than half of the survey respondents who had received Treatment had not finished their programme as originally intended because they were either not ready to stop using (16 per cent), had started using again (22 per cent), the treatment model had not suited them (13 per cent) or they had moved out of the area (13 per cent). For some, the experience of being in Treatment diminished their Tendency to Recover. Workshops participants told us how they had to increase their drinking to reach the required level on the breathalyser that qualified them for Treatment.

*“It was unbelievable the amount I was drinking just to get in.”*

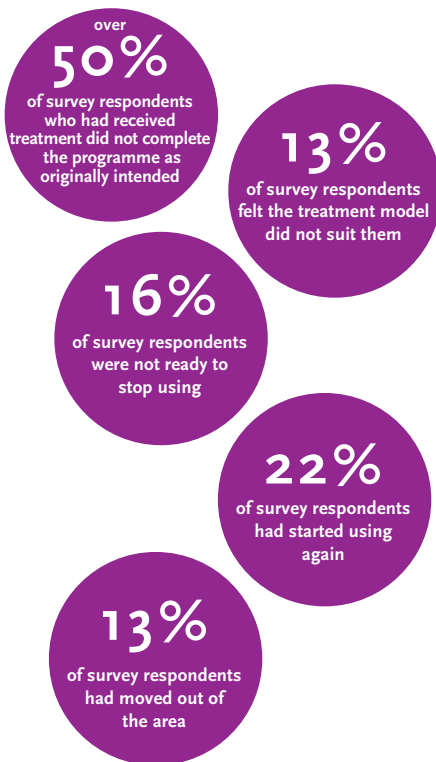
— Workshop Participant

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*“Wherever you go you get judged. GPs especially — they’re like it’s all self-inflicted so just get on with it.”*

— Workshop Participant

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When asked what kind of support they received that was important to them, 35 per cent said ‘someone to talk to/company’, and 21 per cent said some form of emotional support. Other forms of support included: support with their care plan (15 per cent); practical, day-to-day help — often cleaning and food (16 per cent); and accommodation (12 per cent). Only 2 per cent received help in getting work or onto training, and 1 per cent received help with improving relationships with children/family/friends.

*“[My recovery] has a lot to do with my brother.”*

— Workshop Participant

Half replied that they could access support when they needed it, with a further 29 per cent saying they could get support at the right time sometimes. Those who were unhappy with life and those of no fixed address were less able to access support when they needed it.

When asked what would make the most difference to helping them achieve their goals, a third of respondents pointed to better service provision, with two main goals: to address their drug and alcohol problems; and to get into education, training or employment. Respondents meant a broad range of things by ‘better service provision’. Generally, this included more accessible staff that were knowledgeable across a wide range of experiences and services (24 per cent); better access to services (40 per cent); more accessible service locations (22 per cent); and an increased range of services and activities to support recovery (25 per cent).

**Facilitator:** *“What is it about now that’s kept you clean for the last five months?”*

**Workshop Participant:** *“It’s going to meetings and things like these groups helps. This area actually...It’s took me to come all the way down south to get it sorted.”*

Issues around access are particularly acute for individuals from ethnic minority groups where language, stigma, trust<sup>149</sup> and social customs can act as significant barriers to seeking and receiving Treatment.

*“They don’t want to come forward because they’re scared... there’s no Asian there... there’s no-one working there that they can talk to. OK, you can get a translator but I wouldn’t be comfortable, you know if my wife came there she wouldn’t be comfortable with a man translating... [Having Asian people in the services] would help a lot. Do you know why? Because they’ll come forward. At the moment they’re suffering. Loads of families.”*

— Interviewee

Ultimately, the issues uncovered around Treatment come down to access in the broadest sense and are common across all groups.

- *Where* treatment services are located. This is especially true for rural residents, those unable to reach services based centrally due to transport costs or lack of transport, those with childcare needs, those in full-time employment, or for those who do not want to be seen entering known treatment premises.
- *How* to find information and advice about substances and treatment options.
- *Who* supports the recovery journey, from the first person asked for help, to services staff and friends and family.
- *When* services, staff and other support structures are available.

<sup>148</sup> See <http://www.rcgp.org.uk/default.aspx?page=6962>

<sup>149</sup> Fountain, J. (2007), op. cit.

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As our findings suggest, for some individuals, Friends and Family could provide the necessary support to sustained recovery, while for others having somewhere to live would be the most significant support. Each individual will have a different composition of components available to them. Understanding formal and informal forms of support in personalised terms assists in mobilising that support and addressing significant gaps.

### **Making a Plan and The Baggage**

For some, Making a Plan comes before any formal Treatment or support. For those entering formal treatment it is part of their initial assessment process and for others, it is something that is developed and redeveloped along their recovery journey. For some it is a D.I.Y. response to the Desire to initiate recovery. It may mean abruptly curtailing their drug use (cold turkey) or withdrawing from the negative influences of 'the Scene'.

**Facilitator:** *"You came off it yourself?"*

**Female Workshop Participant:** *"Yeah, I found it took about 3-4 weeks. But I had Sam to help me a lot of the time."*

**Male Workshop Participant:** *"I had just finished, just done my rattle so I was quite supportive."*

**Female Workshop Participant:** *"And I was just starting just as he was coming out the other end of it, so I had him to help me through the main bit. He knew what I was going through and how I was feeling."*

Those who have sought help for their problem drug and alcohol use and received some form of Treatment (providing it is a positive experience) will be supported in developing a *care* plan to some extent.

This will strengthen their capacity to see a different future with a better life and help to Break Routines that have built up previously in the Hold. New routines will strengthen their Tendency to Recover by building and strengthening the resources needed to sustain recovery. However, as described above, this can be slowed down by having to deal with psychological Baggage, which can contribute to the Tendency to Relapse often seen in the recovery journey.

Of those survey respondents in formal treatment, two thirds had some kind of care plan. Those with low basic skills (reading, writing, and maths) were less likely to be satisfied with their involvement in treatment decisions, as were respondents who saw their drug and alcohol use as particularly problematic. More generally, three quarters of respondents wanted more input into treatment decisions. Cannabis users, (especially those using skunk), in particular wanted more input into treatment decisions, although those with debt problems were less likely to want more involvement.

When thinking about designing services that would meet their needs, respondents frequently cited improved support across a number of domains, including problem drug and alcohol use, housing, family relationships, health and financial advice. However, exploring issues to address individual cases reveals a very broad range of complex and inter-related problems. The skill set and knowledge of keyworkers and the coordination and ability to provide personalised support across a range of services is challenging. The reasons given for this often reflected a feeling that keyworkers lacked empathy or were unable to fully appreciate the realities of substance misuse because they had no experience of it.

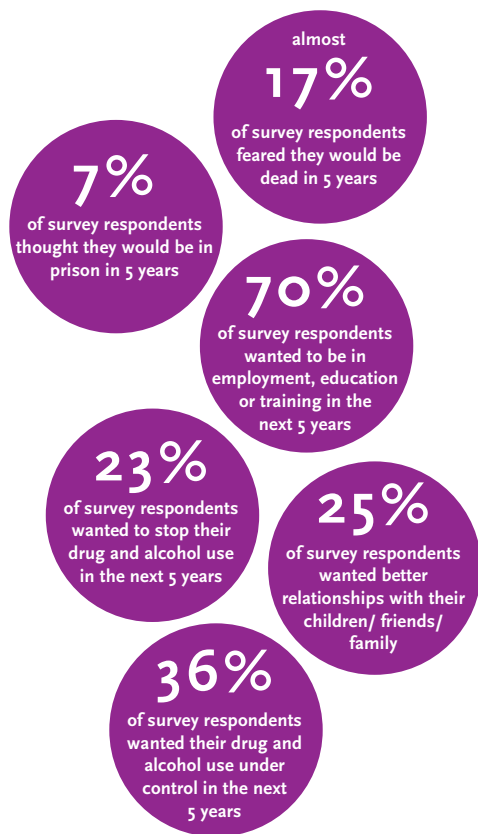
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*"I didn't like the taste or the smell of alcohol. But it's to do with the percentage of the alcohol, to get that hit. And the suppression of all your feelings. And that's the trouble when you stop any substance. You get all your feelings back. And when they come back you get all the anxiety and depression."*

— Workshop Participant

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*“When you go to Addaction or KCA and you try to explain these things you do get the impression that the person on the other side of the desk has only ever read it out of a book. And that is so patronising because they’re saying you shouldn’t be feeling like that and you’re like, hang on, you haven’t got a clue.”*

— Workshop Participant



The reality is that often a number of staff within treatment services have personal experience of problematic drug and alcohol use. However they are rarely allowed to disclose this information to their clients leading to this perception.

Current funding channels do not easily allow joint commissioning or pooled budgets that would ensure that the range of individual needs could be addressed in a more streamlined manner. Learning from the current Drug System Change Pilots will be key to exploring how coordination of services and support around the user can best be achieved. Generally, there is a clear indication of the desire and need to personalise The Recovery sub-system. In order to do so, it is necessary to expand the range of available capabilities, skills, resources and assets and mobilise them for individual and collective support.

### The Rest of my life

When asked where they saw themselves in five years, a third of survey respondents felt they would be in some form of employment, education or training. A quarter hoped that they would have improved relationships with their children/family/friends. Almost a quarter hoped to improve their housing situation over this time. These respondents could see the Rest of My Life, but could not reach this space in the system for lack of positive connections (despite the presence of Friends and Family) that feed the reinforcing loop of their Decision to Recover and Tendency to Recover (see **Figure 7**).

More negatively, one in six feared they might be dead, a quarter suggested they would still be using drugs and alcohol, and 7 per cent felt they would probably be in prison.

*“I’m either going to get well or die, I didn’t have any other choices. I was right rock bottom. I had no housing; I was living on the streets, doing anything to get a drink.”*

— Workshop Participant

One in ten found it impossible to offer any opinion as to where they might be in five years and could not look beyond the here and now. This indicates a strong Tendency to Relapse and/or difficulty in escaping the Hold, and no clear way of reaching the Recovery sub-system and connecting to or visualising a viable future.

When asked where they would *like* to be in five years, 70 per cent said in employment, education or training. Clearly, in terms of aspirations, users can connect with Rest of My Life. Over a third (36 per cent) said that they would like their drug and alcohol use ‘under control’, compared to 23 per cent who said they would have wanted to stop their drug and alcohol use. In addition, 1 per cent said they would like to be ‘in recovery’ and two percent said ‘in treatment’. The differences in personal outcomes reflect the need for personalised approaches and an acceptance of the diversity of goals users have. The findings may also indicate that ‘recovery’ is not yet a ‘live concept’ for many users.

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They are unaware of it and do not use its language, particularly for those not in treatment, although the supportive factors they describe correlate strongly to the ideas and components of recovery capital, as we come to below.

Over half wanted to have improved relationships with their children/family/friends, which can support Tendency to Recover through acting for the sake of Family. Respondents also wanted improved health (18 per cent), finances (13 per cent), and housing (58 per cent). This indicates the need for a personalised, whole-person approach, if recovery is to be maintained.

### **Breaking routines**

Those who are unhappiest among survey respondents — who have some of the greatest problems, weakest support networks, and who are more ‘by themselves’ — tend to want more control and input over their own treatment. However, they are also in a relatively bad position to do so given their low personal, social and community recovery capital. For instance, one in five survey respondents reported reading difficulties, with the same proportion having writing difficulties, and trouble with basic sums.

*“It’s a multitude of what you’ve learnt along the way and your acceptance of what you’ve learnt otherwise you would still be out there. We do suffer with our addiction.”*

— Workshop Participant

Such individuals will need to develop a range of capabilities and skills or build upon those they might already have, in order to sustain their recovery and reach their end goals. Breaking habits and routines is one of the most difficult aspects of the Recovery sub-system. Habits are intransigent, and their tenacity varies from one person to another. Successfully changing habits depends upon a variety of other factors, including those described in the Struggle.

*“I don’t know what stopped me. Something just went in my head. AA meetings have helped but it’s not what stopped me, no way. I think it were more the morning afters. I were embarrassed. It were just getting to me and then something just went in me head.”*

— Workshop Participant

The self-control needed to Break Routines comes from training: exercising the brain to practice self-control. It is not something that is innate. It is made easier through the right commitment devices: the social relationships and belonging to social institutions that form part of the notion of recovery capital.<sup>150</sup>

A recent RSA report on behaviour change found that participants from the general public responded well to learning that there were sound neurological reasons why it is hard to change habits, and that it was not merely a matter of weakness or laziness. Participants were particularly receptive to the idea that working on habits means changing the context within which habitual behaviour arises, rather than relying on willpower alone. Participants seemed to find this knowledge both a relief and an inspiration, and such an approach should be considered in the context of recovery.<sup>151</sup>

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150 RSA — Home Office Drugs Policy Seminar — What do advances in neurobiology, behavioural economics and social psychology mean for drug strategy?, September 2009.

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151 Grist, M. (June 2010) *Steer: Mastering our Behaviour through Instinct Environment and Reason*, London: RSA.



over  
**50%**

of survey respondents  
wanted better  
relationships with their  
children/ friends/  
family

**1%**

of survey respondents  
received help with  
improving relationships  
with children/family  
/friends

**16%**

of survey respondents  
wanted practical, day-to-day  
help — often cleaning  
and food were  
important

**21%**

of survey respondents  
said emotional support  
was important

**50%**

of survey respondents  
said they could access  
support when they  
needed it

**15%**

of survey respondents  
thought support with  
their care plan was  
important

almost  
**50%**

of survey respondents  
were a parent of a child  
under 16 years old

**35%**

of survey respondents  
thought 'someone to  
talk to/company' was  
important support

friends  
+  
family.



**50%**

of survey respondents said they had problems with debts, with the vast majority receiving no help with debt problems

**40%**

of survey respondents lived alone

**80%**

of survey respondents with access to a computer used Facebook

over  
**14%**

of survey respondents were of no fixed address

**85%**

of survey respondents had a mobile phone

over  
**50%**

of survey respondents wanted better relationships with their children/ friends/ family

more than  
**50%**

of survey respondents had health problems due to alcohol

After





**28%**

of survey respondents said they get most support from friends who do not use drugs

**8%**

of survey respondents said they got most support from NA / AA

**36%**

of survey respondents said they get most support from their Keyworker

**38%**

of survey respondents said they get most support from friends who use drugs

**42%**

of survey respondents said they get most support from their family/partner

**16%**

of survey respondents wanted practical, day-to-day help — often cleaning and food were important

**21%**

of survey respondents said emotional support was important

**1%**

of survey respondents received help with improving relationships with children/ family /friends

**50%**

of survey respondents said they could access support when they needed it

almost

**50%**

of survey respondents were a parent of a child under 16 years old

**15%**

of survey respondents thought support with their care plan was important

**35%**

of survey respondents thought 'someone to talk to/company' was important support



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## SECTION 5. *Applying the concept of Recovery Capital*

This section explores our findings in relation to the concept of recovery capital and integrates these developments with systems thinking. The result is a Whole Person Recovery System which we suggest offers an improvement model for any commissioner as they move towards a greater focus on recovery outcomes.

As our research shows, for most individuals with drug and alcohol dependencies, problems are often multi-layered and complex. They relate to the range of skills or capabilities a person might possess, their access to and relationships with different networks within their social sphere, and the availability and access to resources and opportunities within their community and surrounding environment.

Research has shown that recognising a person's possession of, or access to, such skills, resources and assets can be indicative of a person's capacity to overcome problematic drug use.<sup>152</sup> Granfield and Cloud<sup>153</sup> discuss these variables as recovery capital: 'the breadth and depth of internal and external resources that can be drawn upon to initiate and sustain recovery from AOD [alcohol and other drug] problems.' They suggest that people who have access to recovery capital are better able to address problem drug use than those who do not.<sup>154</sup>

It is useful for us to conceptualise the research findings as components of recovery capital and therefore variables of a whole system. The various components of recovery capital that emerged from the findings are described below. As these findings are discussed in detail in the previous section, the descriptions here serve as brief reminders.

### Personal Recovery Capital

#### 1. Housing

A significant number of survey respondents and workshop participants had problems with housing. Safe and secure accommodation is a key element of personal recovery capital and without it individuals are more likely to be part of networks where drug and alcohol use is prevalent and are more likely to use problematically as a coping strategy.

#### 2. Physical and mental health

A significant number of survey respondents and workshop participants suffered from a range of issues related to their physical and mental health that were often a result of prolonged drug or alcohol use.

Physical and mental health has a substantial impact on using behaviours, often as a result of individuals attempting to self-medicate to escape symptoms. This can lead to individuals being trapped in the sub-systems described above.

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### **3. Purposeful activity: Education, training and employment**

The statistical link between unemployment and drug use is clear, yet whether unemployment alone is a significant determinant of the onset of drug problems is unresolved. In preventing relapse, the influence of employment is far less uncertain.<sup>155</sup>

A focus on purposeful and meaningful activity was generally considered to be lacking from current service provision, which meant that individuals felt poorly equipped to reintegrate and contribute to their communities and therefore sustain their recovery.

## **Social Recovery Capital**

### **1. Peer support**

Peer support is significant at all levels of recovery. As an umbrella term, peer support includes a variety of activities outlined below.

- a. Peer mentoring: a one-to-one relationship in which one individual supports another in goal setting within a defined timeframe.<sup>156</sup>
- b. Befriending/buddying/listening: a less formal social relationship between two or more individuals that can last over a longer timeframe.<sup>157</sup>
- c. Advocacy: taking action to help people say what they want, secure their rights, represent their interests and obtain services they need.<sup>158</sup>
- d. Mediation: dispute resolution between two individuals or an individual and a service.
- e. Peer advice: offering advice based on lived experience.
- f. Education and training: developing individuals' knowledge and skills base through education and training.

Peer support can be formal and informal and different elements of this support are needed at different points of an individual's journey.

### **2. Friends and Family**

Friends and Family can be both negative and positive influences on an individual's using behaviour and recovery journey. Support through social networks is 'important during life crises because it affects the options, resources, information, and supports available to people as they attempt to resolve their problems. The possession of social capital helps facilitate particular ends, whether it is in acquiring employment or whether it is overcoming a major life obstacle.'<sup>159</sup>

Conversely, friends and family can also be detrimental to an individual's recovery journey and it is often only once an individual has broken ties with these networks or once the whole network has recovered, that they are able to sustain their recovery.

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152 Cloud, W. & Granfield, R. (2008) 'Conceptualizing Recovery Capital: Expansion of a Theoretical Construct' in **Substance Use & Misuse**, vol. 43, no. 12-13, pp. 1971-1986.

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153 Granfield, R., & Cloud, W. (1999) **Coming clean: Overcoming addiction without treatment**. New York: New York University Press.

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154 Cloud & Granfield (2008), op. cit.

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155 South et al. (2001), op. cit.

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156 See <http://www.mandbf.org.uk>

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157 *ibid.*

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158 See <http://www.actionforadvocacy.org.uk>

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159 Cloud, W. & Granfield, R. (2008), op. cit.

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## Community Recovery Capital

### 1. Stigmatisation and negative labelling

There is a natural aspect of human functioning which is to label and to categorise the social and physical world; to fix everything with an identity which reduces complexity and provides order to guide our understanding of the world. These labels are often value driven and loaded with judgements that are rooted in historical ideas and beliefs. As the world and our understanding of it becomes more complex, it has been argued that there has been a shift from “stable identities based on familiar social class hierarchies” to “multiple, fragmented and more uncertain identity projects based on ‘life-style’ and ‘consumer choices’”.<sup>160</sup>

Such labels and associated stigma generated by attitudes to what are deemed to be lifestyle and consumer choices present problem drug users with significant barriers to all forms of recovery capital. Dubbed ‘Labelling’ by participants in our survey, stigma influences how problem drug and alcohol users feel about themselves and their environments, which can drive social segregation, which in turn diminishes the stock of and access to community recovery capital. Thus a negative reinforcing loop forms.

The close association between drugs and crime is a particular driver of stigma. Almost all survey respondents (95 per cent) had committed a criminal offence and half had received a prison sentence. Almost three quarters said their sentence was related to taking drugs and 30 per cent said their sentence was related to taking alcohol. Many of these respondents who were trying to sustain their recovery by, for example, getting a job, felt doubly stigmatised due to long breaks in career histories as a result of drug and alcohol use alongside a criminal record.

As sustained recovery depends to some extent on a supportive community, sustainable recovery will remain difficult to achieve while levels of stigma associated with problem drug use and criminal records are high.

### 2. Community resources

There are huge variations in the quality and quantity of community resources from one area to another. This includes transport links, community activities, public spaces as well as treatment and support services, and often have costs attached.

Having something to do and somewhere to go was extremely important to people in recovery. One participant for example had been given free gym membership which she felt was supporting her recovery. Others described how they had little to do in their area but stay home and watch the television which increased their feelings of isolation and therefore the risk of relapse.

For those in early recovery, treatment and support services were central to them. However, there was a common complaint about the lack of access to these services especially during evenings and weekends, as well as a lack of choice in provision of services.

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<sup>160</sup> Wetherell, M. (ed.) (2009) *Identity in the 21st Century. New Trends in Changing Times*, Basingstoke: Palgrave Macmillan.

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<sup>161</sup> See [http://www.ccar.us/about\\_ccar.htm](http://www.ccar.us/about_ccar.htm)

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<sup>162</sup> Cloud, W. & Granfield, R. (2008), *op. cit.*



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Visibility as well as availability of services and support structures is important for individuals seeking help but also for other agencies, organisations and services. Often there are resources that already exist but remain unknown and under-utilised which can have significant consequences. The local police, for example, at one of the project sites were unaware of the peer support networks available in the local town. This meant that the police often felt they had few options when faced with a problematic street drinker than locking them in a cell. Increasing their awareness of available support means they will be more likely to signpost that street drinker to for example, a local EXACT group or call upon EXACT members to support them.

### **3. Local Recovery Community**

Participants felt that aftercare was particularly poor in both sites of the project and contributed to high levels of relapse. Recovery Communities have existed in America for more than a decade and while there is evidence of these developing in the UK, they are less well developed.

Recovery Communities put a face on recovery, sharing stories of hope, providing role models and promoting recovery. People in recovery provide end-to-end support to others in recovery or those seeking support, engaging the wider community to reduce levels of stigma that can perpetuate cycles of disadvantage and hopelessness.

#### **THE CONNECTICUT COMMUNITY FOR ADDICTION RECOVERY (CCAR) MISSION STATEMENT**

**The Connecticut Community for Addiction Recovery (CCAR) organises the recovery community (people in recovery, family members, friends and allies) to put a face on recovery and to provide recovery support services.**

**By promoting recovery from alcohol and other drug addiction through advocacy, education and support services, CCAR strives to end discrimination surrounding addiction and recovery, open new doors and remove barriers to recovery, maintain and sustain recovery regardless of the pathway, all the while ensuring that all people in recovery, and people seeking recovery, are treated with dignity and respect.<sup>161</sup>**

Having initially been conceived as a list of discrete components, Granfield and Cloud suggest that recovery capital exists on a continuum with both positive and negative sides where positive elements strengthen and support a person's recovery and negative elements impede it.<sup>162</sup> Where the positive elements of recovery capital are lacking, problem drug use offers a stop-gap; a way of covering over inadequacies either of the individual's capabilities (for example, low self-esteem, emotional health or coping strategies), of social networks (for example, all members of friend network with problematic drug or alcohol use), or those of the local community (for example, lack of employment opportunities, high levels of stigmatisation and low levels of attachment).

Fig 9. Recovery Capital Poster<sup>163</sup>



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## A Systems Approach to Developing Recovery Capital

Our research supports the concept of recovery capital (and negative and positive recovery capital) but seeks to extend the model. It is helpful to move from considering the dimensions of personal, social and community capital as scalars (measures that have quantity but no direction) as suggested in **Figure 9**, to vectors (measures that have magnitude and direction).

However, in this case, such vectors are interdependent and must be understood in a system. Systems often work to protect their integrity, maintaining the relationships and consequences upon which they are constructed. In the case of problem drug use, the user-generated systems in **Section 4** illustrate why recovery can be so difficult to initiate and sustain when considered as a system.

This thinking adds a valuable dimension to drug strategy and its implementation as the understanding of recovery capital and how to foster it develops. Understanding how both positive and negative dimensions interact with one another, where the reinforcing or balancing loops might exist, and where there are gaps and opportunities for development, we believe will lead to more informed, tailored plans and support at the right time, and ultimately in more success in helping problematic drug and alcohol users move into sustainable recovery. As the system is centred on the individual, it means recovery plans fit the person and not the other way round.

**Figure 10** further illustrates the dynamics *between* the three sub-systems. Despite the appearance of a linear progression through distinct phases, it is not the case that an individual moves neatly from one phase to another.

For example, a long term problematic user will have moments of Struggle and encounters with some features of Recovery and a recovered person will be subject to the forces at work in the Hold. An individual could be in Treatment (part of the Recovery sub-system) but also in the Hold. The user-generated system map should be understood as a representation of the tangle of forces the user is caught up in and as a prompt for planning and organising the required support and treatment.

It is important to emphasise the *visual* representation of the system as a way of making sense of complex relationships. We believe that such visualisation acts not only as an accessible tool to plan care and/or support, but also as a prompt for reflexivity and to start to change the subjective perception of individuals within systems and communities.<sup>164</sup> A visual systems method allows a whole person approach to be taken, mapping all forms of support required to assist an individual into recovery in ways that are easily understood and that more obviously place problem drug users within their communities.

However, this user-generated system itself exists within a complex system of systems. With this in mind, we turn to look at what an overarching system of personalised recovery might look like.

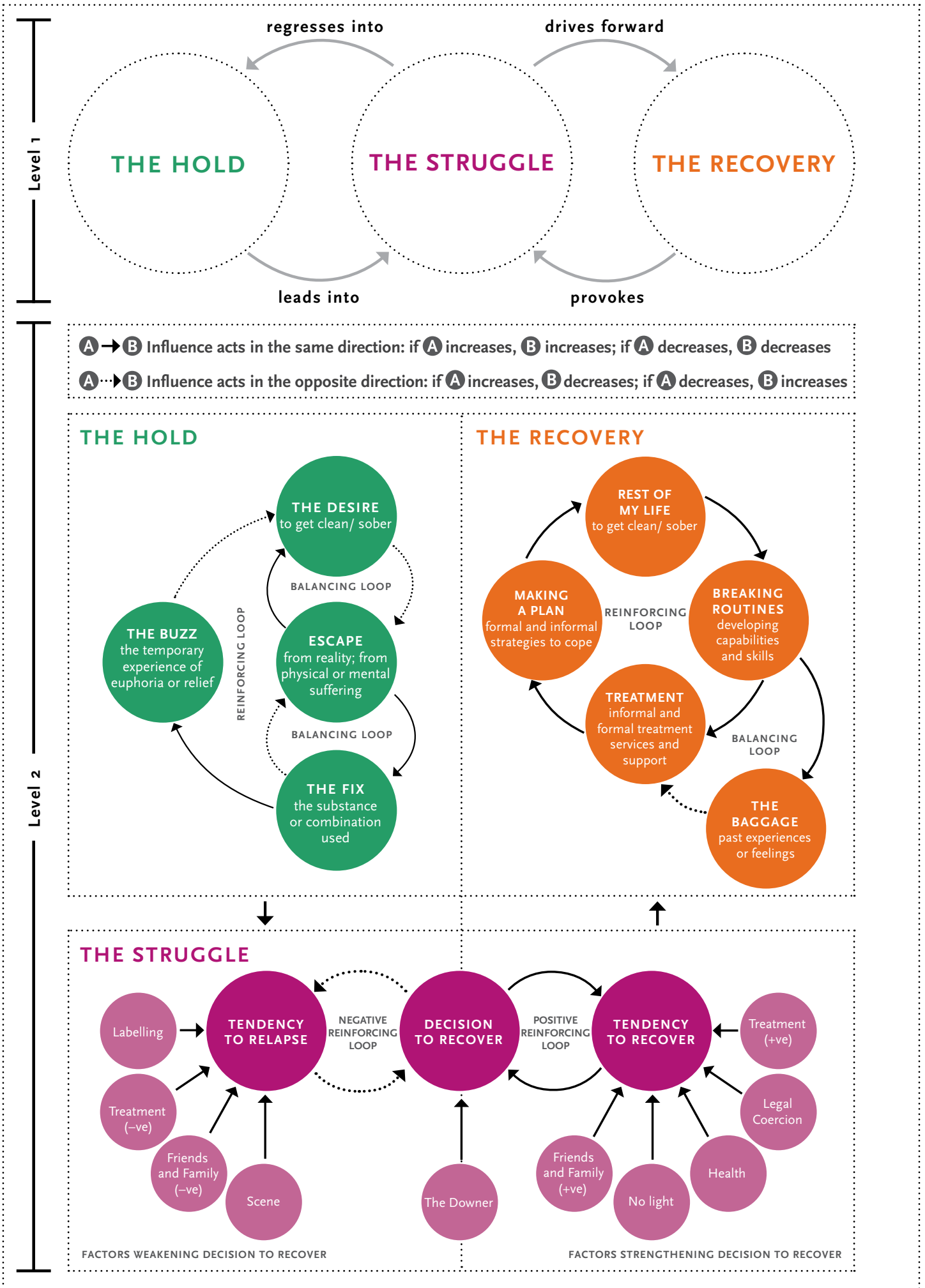
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<sup>163</sup> Developed by Stephen Bamber, Director of the Recovery Academy.

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<sup>164</sup> Rowson, J., Broome, S., Jones, A. (2010), op. cit.

Fig 10. Different levels of the user generated systems map





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## Towards a Whole Person Recovery System

Despite the many developments across the field: increased uptake in treatment, requirements for user involvement in commissioning and a greater emphasis on recovery outcomes, current treatment systems continue to suffer from a series of inadequacies that prevent whole scale shift towards our broader understanding of personalised recovery. Two of these inadequacies relate closely to this project. Firstly, a failure to sufficiently capture user experiences and use them in meaningful ways to meet the needs of the user; and secondly, a narrow framing of ‘the problem’ and ‘the solution’ by commissioners and service providers.

The user-centred research of this project, alongside wider research on recovery capital and the emerging evidence around recovery, means that we can start to address these deficiencies by envisioning a whole system approach to personalised recovery. This is what we call the Whole Person Recovery System.

The Whole Person Recovery System (see **Figure 11**) is the result of a combination of the approaches, concepts and research employed throughout this report. It aims to explain how different aspects of the recovery process operate as sub-systems, interact and sustain each other and form the system for Whole Person Recovery. As a whole system, it provides a ‘consistent ontology’<sup>165</sup> for recovery and guides the use and further development of the sub-systems. For example, treatment and support can be understood and implemented in a way that benefits the system as a whole. In this way, we can create a mutually reinforcing system of recovery.

**Figure 11** offers a high level improvement model for commissioners and practitioners as they reshape the services in their area to become recovery-oriented, and can be considered a ‘meta-model’ for managing a recovery system.<sup>166</sup>

## The Whole Person Recovery System

As we have discussed above, systems maps are rarely used to describe linear processes but demonstrate the dynamic relationships between various components that make up the whole system. However, for the purposes of this report it is necessary to concentrate on and present the *main* relationships within the system rather than *all* of the relationships. This enables us to describe how the system can work and demonstrate the impact that each component of the system has on the whole. In this recovery system there is a virtuous cycle of activities which sustain the recovery process and which enables the system as a whole to function well beyond the sum of the parts.

In this presentation of the Whole Person Recovery System, the reader should commence at one component in the main loop. The direction of the arrow indicates how the components reinforce and support one another. Each component should also be understood as a sub-system which generates an outcome. That outcome is the component of this system. For example, *Increasing Participation in Society* will be the outcome of various activities that may build a person’s confidence, decrease local levels of stigma, or open up opportunities for an individual to participate in society.

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165 Goldspink, C. (2000) ‘Modelling social systems as complex: Towards a social simulation meta-model’ in *Journal of Artificial Societies and Social Simulation*, vol. 3, no. 2.

166 *ibid.*

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Each sub-system/series of activities must be tailored to the individual and the local community. For this reason we have not provided the detail of each sub-system in this report. However in the **Section 6** we provide a description of the ideas we will be piloting in Bognor Regis and Crawley that will generate the outcomes of some of these sub-systems needed to activate the whole recovery system.

In **Figure 11**, the dark grey circles primarily describe the activities which the recovering person needs to engage in for a successful recovery outcome. Engagement in different activities might be strong, weak or absent, but their relative importance will depend on the priorities and goals set by the individual. In this way the system is personalised and can be seen to be as much within the individual as involving them.

For the outcomes of each sub-system to be realised to their full potential they need to be supported by social networks and the wider community. The light grey circles of the system generate this support. For example *Generating Local Recovery Capital Sources* will engage a variety of community members in activities aimed at producing recovery capital helping to reduce stigma and develop a supportive community in which those in recovery feel better able to integrate and contribute.

To explain this system in more detail, let us start at The Hold, the basic structure of addiction. This is expanded in the diagram to remind the reader of its full explanation, as described earlier in **Section 4**. From here, Laub and Sampson<sup>167</sup> suggest that there is a range of life events that trigger and harden the resolve to get out of the grip of the Hold. They include:

- attachment to a conventional person (e.g. spouse);
- stable employment;
- transformation of personal identity;
- ageing;
- inter-personal skills improvement; and
- life and coping skills improvement.

The model indicates that triggers arise from an *Improving Position of Health or Wellbeing* which in turn is fed by *Increasing Participation in Society*. Participation is greatly helped by the *Acquisition of Recovery Capital*, which sits within three distinct domains (personal, social and community, as described above).

Recognising the value of recovery capital is enhanced by *Engaging in Recovery Actions*, which also bring out the need for *Developing Recovery Capital*. This in turn is made easier if the person can already recognise that they have untapped resources to start the process from. Mapping available recovery capital in all its forms with users assists this process and there are emerging tools in the field to enable this to happen in the community as well as part of a treatment process.<sup>168</sup> Interest in this will arise as the person *Prioritises the Engagement in Recovery*. And so, to complete the loop, the prioritisation is nourished by an increasing *Resolve to get out of the Hold*.

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<sup>167</sup> Laub, J.H. and Sampson, R.J. (2003) **Shared Beginnings, Divergent Lives: Delinquent Boys to Age 70**, Cambridge, MA: Harvard University Press.

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<sup>168</sup> Tools are being developed by Dr David Best, Chair of the UK Recovery Academy, Chair of the Scottish Drugs Recovery Consortium and a researcher at the University of the West of Scotland. He is currently involved in researching recovery pathways and in developing training manuals in recovery approaches to treatment.

Fig 11. The Whole Person Recovery System

A → B Influence acts in the same direction: if A increases, B increases; if A decreases, B decreases

A ⇄ B Influence acts in the opposite direction: if A increases, B decreases; if A decreases, B increases



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These linkages describe the dark grey loop, which is the core dynamic of recovery. However, any and all of these stages must be helped and enabled by other influences (represented by the light grey factors) entering into the system. We consider the main factors to be:

- generating situations which increase the chances of experiencing triggers;
- developing local opportunities that increase the scope for participation in society;
- developing local sources of recovery capital, especially in the social and community domains, to enable individuals to build their own recovery capital;
- providing suitable treatment and support services aligned to people engaging in recovery actions;
- providing recovery diagnostic tools that help users and their supporters to better understand their options, and to take inspiration from recovery role models; and
- developing social relationships and community contexts which encourage the prioritisation of recovery.

In summary, the whole system recovery approach proposes that first there is a set of activities that to varying degrees will need to be undertaken by someone moving into recovery. Second, that if any activity in this set is weak or missing, then an individual will have less chance of recovery. Third, that although any activity may have effects on any other, there is a main sequence of activities which is likely to be optimally and mutually strengthening. Fourth, that recovery is greatly helped and in some cases is only possible, with the appropriate support and enabling conditions.

As a whole person recovery system we are able to visualise the relationships between the various component parts that provide the foundations on which to operationalise the system and begin moving towards a user-generated holistic response to recovery. The following section introduces the processes taken to develop the activities and ideas locally that will be piloted in the final phase of our project. These will be integral to testing the system and in beginning to generate the recovery capital needed to support long-term recovery.

## Operationalising the Whole Person Recovery System

The work of the DAAT, EXACT and a host of other local partners means that we are not starting from scratch in Bognor Regis and Crawley. There is an array of existing recovery capital spanning treatment services, mutual aid group, and community organisations. However, many of these recovery capital components operate in isolation: former and current users involved in the research reported on the disjointed nature of local support and services which has made it difficult to find a pathway of recovery.

The research and user generated systems in this report were based on research by users with users. These systems and research findings were the evidence and stimulus that fed into our Design Symposium (see **Appendix C**) and that triggered ideas for whole person recovery. These ideas were in turn re-engineered to fit the local context in Bognor Regis and Crawley.

Before we describe the ideas that constitute the pilot phase of the project, there are three points to draw attention to. Firstly, in both the Design Symposium and the re-engineering of the ideas in our local workshops, the majority of ideas fell directly into the Recovery sub-system. While components of these ideas connected to factors within other sub-systems, a dominant message from all stages of the research and design was that the existence and availability of, access to and coordination of post-treatment support was limited.





Users described their experience of leaving treatment as like “coming out of prison” or “falling off a cliff”. Difficulty in connecting to components of recovery capital required for social and economic reintegration drove a Tendency to Relapse. Consequently, most of the ideas for the pilot phase are situated within the Recovery sub-system.

Secondly, our user-centred approach meant that our project had focused on empowering marginalised groups to work together, have their voice heard, and their ideas taken seriously and progressed. Consequently, this created expectation and momentum that in some ways did not align with the obligations and constraints of service providers. At an RSA seminar on recovery capital,<sup>169</sup> the point was made by a leading service provider that an unhelpful, often combative polarisation sometimes exists between users and peers on one side, and treatment service providers and the public sector on the other. A user-centred approach must take care not to exacerbate such dynamics.

To rebalance empowerment, to create common understanding and interests in the pilot phase, and to bring together the necessary resources and stakeholders required to implement our ideas and to take account of our systems, we have created a local Recovery Alliance in Bognor Regis and Crawley. The Alliances include:

- EXACT: peer led recovery support group
- Drug and alcohol service providers
- Adult and young people's social services
- Health-related organisations
- Mental health organisations
- Local voluntary and charitable organisations
- Local media
- Fellows of the RSA and local community members
- Faith groups
- Schools, universities and educational centres
- Volunteer groups
- Local councillors and cabinet members
- Service commissioners
- Homeless shelters
- Unemployment support groups
- Local businesses
- Family and carer groups
- Criminal justice agencies including local police and probation

Members of the Recovery Alliances have taken the lead on re-engineering ideas from the Design Symposium and contextualising them to reflect local conditions. Despite the mix of stakeholders, the voice and experience of the user remains at the heart of the Recovery Alliance. An obvious gap in Recovery Alliance membership is other actors within the criminal justice system. Innovations such as the Family Drug and Alcohol Court show that engagement of users through such settings can help empower users and join up services and other support quickly.<sup>170</sup>

Thirdly, the journey to the ideas is at least as important as the ideas themselves. The following ideas have been constructed through carefully built confidence and relationships and have common ownership, credibility, buy-in from the necessary stakeholders, and momentum as a result. Some ideas are quick wins, small-scale useful projects designed to keep momentum, demonstrate progress and build further partnerships. Others are longer-term and more ambitious.

It is quite possible that these ideas could have been landed upon by an individual or small group working in isolation. Such an approach, however, would make these ideas much more difficult to implement. It would run the risk of fuelling polarisation between different stakeholders and of failing to bring in all parts of the community to work on understanding and supporting recovery. This approach reflects the RSA's interest in pursuing methods that generate outcomes through process as well as final interventions.

<sup>169</sup> RSA Recovery Capital Expert Seminar, 2010, [Online], Available: <http://www.theRSA.org/projects/our-projects/reports/the-potential-of-recovery-capital>

<sup>170</sup> RSA — Home Office Drugs Policy Seminar — User centred drug services, April 2009; Harwin, J. (2009) *The Family Drug & Alcohol Court (FDAC) Evaluation Project Interim Report*, [Online], Available: <http://www.brunel.ac.uk/doc/1321/FDACIRAugust200920090914.pdf>





Services  
&  
treatment





## SECTION 6. *From recovery thinking to action*

In this section we outline the ideas being taken forward in the final pilot stage of the project. These ideas aim to operationalise the parts of the Whole Person Recovery System that the local Recovery Alliances determined were most important to their area. The evaluation framework for each idea will be developed as part of the idea scoping phase and a report will be published next year analysing their progress and impact. The pilots began in autumn 2010.



**Fig 12. Operationalising the Whole Person Recovery System**

Figure 12 illustrates the parts of the Whole Person Recovery System that are operationalised by the nine ideas that are discussed in this section. These ideas will be piloted in the final phase of the project.

<b>Idea 1:</b> Recovery Network Mapping Project site: Bognor Regis and Crawley	<b>Idea 4:</b> Training for GPs Project site: Bognor Regis	<b>Idea 7:</b> Small sparks Project site: Bognor Regis, Crawley
<b>Idea 2:</b> Recovery Toolkit and Journal Project site: Bognor Regis, Crawley	<b>Idea 5:</b> KeyRing Support Project site: Crawley	<b>Idea 8:</b> Individual Budgets Project site: West Sussex
<b>Idea 3:</b> 24/7 peer led radio service Project site: Crawley (short term), West Sussex (long term)	<b>Idea 6:</b> 'The Hub' drop-in Project site: Bognor Regis	<b>Idea 9:</b> Recovery Communities Project site: West Sussex



**A → B** Influence acts in the same direction: if **A** increases, **B** increases; if **A** decreases, **B** decreases  
**A ↔ B** Influence acts in the opposite direction: if **A** increases, **B** decreases; if **A** decreases, **B** increases



## **Idea 1: Recovery Network Mapping**

**Project site: Bognor Regis, Crawley**

Each Recovery Alliance will develop a resource map for their locality that will include key individuals, RSA Fellows, third, private and public sector organisations, and services and agencies.

The resource map will visualise the existing local landscape and provide an opportunity for the Recovery Alliance members to identify where there are gaps and where there may be opportunities to expand the Recovery Alliance. Most importantly, the resource map will identify the depth and breadth of peer support available. Appearing on the map will be linked to membership to the Recovery Alliance and to signing up to Recovery Alliance principles of understanding, supporting and championing recovery.

The resource map will be available in online and offline formats and will be disseminated to all local stakeholders, providing a useful tool to users, peer groups, new arrivals to the area, GPs, police and other organisations or agencies who currently have little knowledge of what exists to support recovery. The online version of the resource map will be linked to the peer led radio service and recovery journal and toolkit detailed below.

## **Idea 2: Recovery Toolkit and Journal**

**Project site: Bognor Regis, Crawley**

The Recovery Alliance will create a resource for anyone seeking information, advice, guidance or support for their substance using. The Recovery Toolkit and Journal will include:

- the Recovery Network Map (see **Idea 1**) with contact details for all points on the network and peer review information;
- a recovery capital tool for individuals to consider their goals and what resources and assets they have and need in order to reach those goals. This tool will help construct a recovery plan based on the systems described above and will complement formal care and treatment plans co-produced by service providers and users;
- a space for individuals to keep a record of their personal journey. This space will be a useful tool for individuals in demonstrating and reflecting on the distance travelled in their recovery to themselves, their peers and other services or agencies, which will act as both a reflexive tool to reinforce recovery, and as an evaluative tool for our pilot stage; and
- a calendar to keep a record of appointments and meetings related to their recovery.

This toolkit will be available online and be linked to the website being developed for the peer led radio service (see **Idea 3**).



### **Idea 3: 24/7 peer led radio service**

**Project site: Crawley (short term), West Sussex (long term)**

In the current climate it is difficult to imagine creating a service able to provide 24-hour support, seven days a week, yet our research showed that for many, this is what they need. The Radio service website will be designed and developed by experts by experience with the support of RSA Fellows and offers the possibility of 24-hour support in a cost-effective way. Local businesses have been approached to sponsor the service and provide initial seed funding. Support can be delivered in a variety of ways and does not depend on access to a physical building. This radio service will provide:

- stories of hope and recovery, working up to 24 hours a day coverage, but initially working on a 'night owl network' basis to provide support and interaction through the night when mainstream services are not accessible;
- interviews and programmes developed by local experts by experience on a variety of topics around recovery;
- harm minimisation information and guidance from experts;
- information, advice and guidance about local services and the opportunities available; and
- fun activities, music and local community announcements.

The radio service will be peer led and will provide a pathway to employment through training and development of skills in broadcasting, interviewing, DJ-ing, presenting, and producing, with the possibility of gaining the NCFE qualification (or similar) for radio production. Initially the service will be made available through a dedicated website which will act as a portal to accessing a series of pre-recorded podcasts that are linked to online and offline content that will be accessible through the member organisations of the Recovery Alliance.

### **Idea 4: Training for GPs**

**Project site: Bognor Regis**

GPs are often the first port of call for people seeking help for problematic drug and alcohol use. The vast majority (95 per cent) of our survey respondents were registered with a GP. However, two issues often mean that those seeking help have a poor experience:

- GPs receive a small amount of training in substance misuse and are often unaware of the services or support resources available locally. This means that they can feel unable to treat the individual or to refer them on to a specialist service that might meet the individuals' needs.
- Research respondents felt GPs can be strongly influenced by the stigma associated with substance misuse, which creates unhelpful tensions between patient and professional when seeking help. As the first point of contact for many, users need a trusting, welcoming relationship with their GP. A poor experience with a GP can affect whether someone will seek further help, how they feel about the professional services, and ultimately fuel a Tendency to Relapse.

Arun EXACT, supported by the Recovery Alliance, will develop a short film targeting all health practitioners including chemist/pharmacy staff, GP surgery receptionists, GP practice managers, and frontline staff. The film will show experts by experience talking about their positive and negative experiences with GPs and how this affected their recovery journey. The film will be accompanied by the Recovery Network Map (see **Idea 1**).

A short survey will be developed to evaluate the impact of the film on the attitudes of health practitioners and will seek to understand whether a more detailed training pack would be beneficial to developing understanding and awareness of local issues further. A local launch event will be held to encourage local health practitioners to engage in the training pack and engage in the Recovery Alliance.



## Idea 5: KeyRing Support Project site: Crawley

The Crawley Recovery Alliance is keen to explore the KeyRing model of support as a way of managing the high levels of diversity across the thirteen estates of the town. KeyRing is a model of community-based supported living which sets up networks of ten individuals in a community: nine are people who need support while the tenth is the network support coordinator (often a volunteer from the local community). KeyRing describe their model thus:

*“The volunteer sees Members regularly and helps the group work together. The volunteer is like a good neighbour who will help out if difficulties arise. Because the volunteer lives in the community, they know what’s going on and are able to help members make links... KeyRing believes that community connections are very important [and] encourage people to make good links in their neighbourhood.”<sup>171</sup>*

The Crawley Recovery Alliance will explore how it can learn from existing KeyRing networks, how such a model might create recovery capital, and how the model might be tested and replicated across the town’s diverse estates. It will explore how it might link to the current International Treatment Effectiveness Project (ITEP) rollout (see below).

### INTERNATIONAL TREATMENT EFFECTIVENESS PROJECT (ITEP)<sup>172</sup>

The NTA developed a manual for care planning in collaboration with the Institute of Behavioural Research (IBR) in Texas and several service providers in north-west England and London in order to improve treatment effectiveness. The manual was designed to be used by trained keyworkers with their clients and contained two approaches to care planning — node link mapping and a brief intervention aimed at changing thinking patterns.

The initial pilot project was found to have had a positive effect in several areas. ‘Clients’ engagement with treatment was found to be higher in those services where mapping was used, compared to services where mapping was either not implemented, or was to a very small degree<sup>173</sup>. ITEP is now being rolled out across the UK.

Research has suggested that drug use occurs within a complex ecology (such as our systems maps), and that consequently, intensive treatment and recovery support is needed for all people in the system simultaneously if treatment intervention was to be effective.<sup>174</sup> Available resources as well as the individual trajectory of recovery journeys may mean this is not possible, although KeyRing networks could be encouraged and supported into and through treatment simultaneously, offering mutual support to each, and potentially forming a pooling mechanism for individual budgets (see Idea 8).

We will explore whether KeyRing groups work best when all user members are at a similar stage in their recovery journey or when group membership has a mix of users at various stages of their recovery journey.

171 See <http://www.keyring.org/site/KEYR/Templates/General.aspx?pageid=9&cc=GB>

172 Campbell, A., Finch, E., Brotchie, J. and Davis, P. (July 2007) **The International Treatment Effectiveness Project Implementing psychosocial interventions for adult drug misusers**, London: NTA.

173 *ibid.*

174 Halpern, D. and Bates, C., Mulgan, G., and Aldridge, S. with Beales, G., and Heathfield, A. (February 2004) **Personal Responsibility and Changing Behaviour: the state of knowledge and its implications for public policy**, London: PM Strategy Unit.



## **Idea 6: 'The Hub' drop-in**

**Project site: Bognor Regis**

Arun EXACT will explore potential sites for a peer-led central drop-in café. The primary feature of The Hub is to have early and late opening hours and be open at weekends; it would provide support during the periods between triage and treatment, and provide refreshments.

In the short term The Hub would seek to develop close links with existing services and initiatives such as the Friends and Family Project, Working Link, and health and wellbeing trainers. In the medium term, the Hub will seek to set itself up as a social enterprise, and perhaps as a Community Interest Company (CIC). It will seek to provide training for those in recovery to become accredited mentors who could provide fast response support to those in need.

The Hub will seek to provide a support service to anyone suffering as a result of drug and alcohol use, including friends and families of users. Existing services, criminal justice agencies and GPs will be encouraged to signpost individuals to The Hub for peer support.

In the longer term, The Hub aims to operate a volunteering programme supporting local community initiatives, which will assist pathways to employment by providing relevant experience. It will work with Working Links to provide preparation for work (such as interview skills), and will encourage employers to conduct interviews at The Hub.

The Hub will be positioned as the face of recovery for Bognor Regis and over time will aim to bring in people from a cross section of the community to foster access to recovery capital and expand membership of the local Recovery Alliance.



## **Idea 7: Small sparks**

**Project site: Bognor Regis, Crawley**

Many local authorities run 'small sparks' schemes: a form of community chest that give local people small grants (typically £50-£500) for local activities and groups. In each of the project sites, our working proposal is to receive applications for grants from individual users seeking to spark the next stage in their recovery journey or access to a particular component of recovery capital. Our research uncovered many stories of recovery that had faltered on seemingly small details: lack of transport costs to get to appointments or job interview, or a lack of funds available to reintegrate socially (for example, through a leisure pursuit or local club). Our survey found that when users were asked for their ideas about what would help them, many suggested small-scale forms of support. This chimes with the experience of an existing Drug System Change Pilot, which suggested that users often make conservative choices for small-scale forms of support that can make significant impacts.<sup>175</sup> Small sparks awards will be made quickly to cover the costs for such items as a monthly travel pass, or group membership.

Applications will be made verbally in person to an informal panel of Recovery Alliance members, dominated by users in recovery. It will be for panel members to decide on the appropriateness of the application and size of grant. A grant ceiling is to be decided, but the only condition of the grant will be that users will have to come back in person and describe the impact of the grant.

By focusing on control, connection, support, and developing capacity and expertise, these ideas span our systems. They operate on personal, social and community levels and therefore support the growth of and access to recovery capital across all domains.



## Idea 8: Individual Budgets

Project site: West Sussex

Self-directed services are in some ways the ultimate ambition of personalisation and are key to a user-centred system. To make individual budgets possible however, commissioning, brokerage and services need to be structured so that they are flexible enough to accommodate the broad range of needs that face users. Individual budgets will not be required, or wanted, by all. In our research, just over a quarter (27 per cent) of survey respondents wanted to be in charge of a personal budget. However, for this minority, individual budgets present an opportunity to take control of their recovery and receive the tailored support they require.

The RSA will be working with West Sussex DAAT to scope the opportunity to design and implement an individual budgets pilot available to users interested in this option. Implementing individual budgets will not be straightforward. There are issues of how to disinvest in services to provide personalised, flexible options with a core range of services preserved, as well as workforce modernisation issues (as described earlier) and limited choice.<sup>176</sup> The design will be informed by the forthcoming report from the Department of Health on the two-year Drug Systems Change Pilots.<sup>177</sup> We will also be scoping ways for users to pool their budgets with others to increase purchasing power and confidence in decision-making. KeyRing networks may be one route through which such collaboration could take place (see **Idea 5**).

## Idea 9: Recovery Communities

Project site: West Sussex

The Recovery Alliance at each project site is critical to the success of these ideas. At a time when funding is likely to be scarce, greater awareness of existing resources and the pooling of those resources is the most viable way forward. Recovery Alliance members are investing in the future of their communities.

Each Recovery Alliance member will be an active part of this final project phase, informing the implementation plan for pilots; monitoring the pilots in their respective organisations; updating the communal website; and feeding into the evaluation of the pilot. Recovery Alliance members will be the local recovery champions for their area, mobilising their networks to accelerate the creation of broad recovery communities aimed at bringing the conversation about and support for tackling substance misuse in from the margins. A list of current Recovery Alliance members is given in **Appendix E**.

175 RSA — Home Office Drugs Policy Seminar — User centred drug services, April 2009.

176 RSA — Home Office Drugs Policy Seminar — Will localism drive the national drugs strategy?, January 2009.

177 See <http://www.nta.nhs.uk/who-healthcare-scp.aspx>



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## SECTION 7. *Conclusions and reflections*

The rhetoric of the new coalition government gives us reason to brace ourselves for an era of dramatic change. What this means for the drug and alcohol field is unclear at the time of writing. Yet the drug strategy consultation document<sup>178</sup> gives us hope that it will involve better cross government working, a greater convergence of drugs and alcohol policy at a strategic level, and increased emphasis on recovery outcomes.

Such developments would be welcomed. This final section offers conclusions and recommendations before reflecting on the approaches used in the project and their implications for those seeking to realise the ambitions laid out in the preceding discussions. We hope this report offers practical steps that will be needed in making recovery a reality for the individuals and communities suffering from the problems associated with drug and alcohol use.

### A whole person systems approach

In many ways, our understanding of recovery remains conceptual even as we begin to understand it in relation to recovery capital in its personal, social and community forms. This is largely due to how we currently only think about recovery capital as scalar values, for example, high levels of access to funding, low levels of human capital in the form of qualifications, or medium levels of stigma in social and economic institutions.

Even the more recent work by Cloud and Granfield,<sup>179</sup> which extends the thinking around recovery capital to visualise the various components on a continuum; as vectors of recovery that have negative/positive value and direction,<sup>180</sup> provides little beyond the concept.

Our work seeks to move beyond this to understand recovery as a *system* of those vectors in order to understand the forces and interdependencies at play in provoking and sustaining recovery at an individual and collective level. Only then can we begin to develop the activities, structures and institutions needed to support that system and meet its ambitions. Critically, the system is constructed from a user-perspective and so describes the lived experience of improved quality of life and empowerment that characterises recovery.

The process of recovery can occur without professional input, and where professional input through treatment services is involved, its role is far from clear.<sup>181</sup> Our Whole Person Recovery System allows DAATs to see their role as fostering recovery capital and enabling access to it for individuals, services, families and friends and the general community. This organising framework is the foundation stone for commissioning, planning and supporting a recovery-oriented system of care and social and economic integration.

Addressing problem drug and alcohol use is complex. A systems approach is capable of holding, simplifying, and visualising this complexity. Moreover, a system from the point of view of the user, rather than from the top-down structures of government, means that users will not be required to navigate the complex systems of policy and consequential service provision that often act as barriers to seeking support or entering and completing treatment.

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In addition, a new national drug strategy that is modelled on user-generated systems will be able to join up policies and practices in ways that will be more effective at enabling recovery. This will be particularly important as more government departments become involved in delivering the forthcoming drug strategy (including the Department for Work and Pensions, the Ministry of Justice, the Home Office and the Department for Education).<sup>182</sup> A strategic vision, aligned targets and an understanding of the dependencies within the entire system will ensure that silo working is prevented and that the impact of difficulties within one part of the system on all other parts can be anticipated earlier and the disruption and potential damage limited. A whole person recovery approach joins up the domains of recovery capital: the relevant different policy and service areas. Doing so addresses the insularity of the drugs agenda, and places recovery at the very heart of drug policy and public discourse. This is key if stigma and social and economic exclusion are going to be overcome.

### Independent user-centred institution

A clear message from the research and action is that independent user groups — of which EXACT is an example — are potentially important to improving recovery oriented services. They offer a better way to broker personalised services, and support users at any stage of their recovery no matter which pathway they choose (i.e. with or without formal treatment), and ensure where they exist, service user groups have a meaningful involvement in shaping service provision. But how should such independent user-led groups be funded? If funding for brokerage of personalised support comes from the local authority, this creates dependency and obligations that may undermine their role. Alternatively, if funding comes from top-slicing individual budgets, this means less money is available for budget holders.<sup>183</sup>

### Learning from existing models

In the Criminal Justice System (CJS), Independent Monitoring Boards (IMB) are appointed by the Secretary of State to every Prison and Immigration Removal Centre (IRC) in the UK, as required by the Prisons Act 1952 and the Immigration and Asylum Act 1999.<sup>184</sup> IMBs are made up of members of the community in which the Prison or IRC is located. They have a remit that ensures that those held in custody receive just and humane treatment and are able to access programmes that will prepare them for release and that any concerns are reported directly to the Secretary of State or those with delegated authority. They also ensure that the standards and requirements placed on the institution are upheld and reports are made on the impact to those in custody.<sup>185</sup> The statutory role of IMBs ensures that they have a prominent position within the CJS and guarantees that the individual rights of those in custody are advocated and that their concerns are dealt with appropriately.

In this way, IMBs offer a model on which independent user-centred groups such as EXACT can develop. As outlined earlier, every service is required to create a service user group but the extent to which the service users are given (or have the perception of being given) the legitimacy to advocate their needs and concerns and those of fellow service users varies enormously. This is intrinsically connected to the historical power dynamics that have prevented meaningful service user involvement in the past.

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178 Home Office (August 2010), op. cit.

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179 Cloud, W. and Granfield, R. (2008), op. cit.

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180 *ibid.*

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181 Best, D. and Laudet, A. (2010), op.cit.

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182 Home Office (August 2010), op. cit.

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183 RSA — Home Office Drugs Policy Seminar — User-centred drug services, April 2009.

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184 See <http://www.imb.gov.uk>

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185 *ibid.*



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IMBs receive funding from the government<sup>186</sup> which, during this cold financial climate and vast spending cuts, would be unlikely to extend to new institutions such as we are proposing. With this in mind we are exploring social enterprise models, seed-funded by local authority, RSA and other (in-kind) support to enable the local EXACT groups to stand on their own feet and establish themselves as an independent body.

## Meeting the challenges of personalisation

When the Whole Person Recovery Project began in 2009, personalisation was at the forefront of the debates around the future of public services although few initiatives were being piloted beyond those in social care. There was a need, if not an appetite to extend these pilots into other areas of social policy, particularly drugs and alcohol where user-centred approaches had been slower to develop but where it was believed significant impact could be made.

This project set out to be part of the extension of personalisation into the drug and alcohol field. What we found was that it is not only right and possible to embed users fully in the design and development of the services that will meet their needs but that by doing so service users develop a greater sense of efficacy, have more hope for successful recovery and can relatively quickly become part of supportive networks essential to recovery.

Likewise, local service providers and commissioners benefit from a greater understanding of the vast range of needs of service users, can support the development of more tailored responses and reap the efficiencies that this brings about. In short, there is greater empathic capacity.

The recognition of these benefits is important as we move towards a greater focus on recovery and recovery outcomes. Recovery is a personalised journey, centred around the user: no two journeys to long-term recovery are identical. Consequently, personalised services and recovery are natural allies.

This does not mean that embedding a user-centred approach is straightforward. As outlined in the earlier sections there are multiple levels of complexity related to the user-centred approach as well as the intricacies of the problems related to drug and alcohol use. Earlier we outlined some of the key challenges to embedding user-centred services. Here we outline the ways we believe these begin to be overcome.

## Stigma

It is human nature to label others; we all do it whether we are aware of it or not. For most problematic drug and alcohol users these labels are often extremely negative and stigmatising. As our research has demonstrated, this can have a dramatic effect on an individual's using behaviour, often making it worse. It can reduce their likelihood to seek help and their ability to sustain recovery by gaining employment or joining networks beyond those with experience of problematic drug and alcohol use.

EXACT will be the face of Recovery in West Sussex, providing positive role models and visibly contributing to their communities. EXACT will lead and take part in activities that will promote community cohesion and recovery.

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In addition the newly created Recovery Alliances at each site will encourage the engagement of a much broader range of community stakeholders. The Recovery Alliance provides the space for members to increase their awareness of substance misuse and develop a more balanced understanding of the issues and ways to address them.

## Heterogeneity

There is no one size fits all model of recovery and nor should there be given the findings of our research. Individuals should be treated individually, taking the time to understand the negative and positive recovery capital factors that influence that person's using behaviour and their ability to initiate and sustain recovery.

This project has shown that developing relationships with existing organisations or community members with links into particular groups offers a better opportunity to reach those considered harder to reach and understanding their particular needs. During this project we were fortunate to link with the mental health charity Rethink for example, whose workers were trusted members of Asian networks in Crawley, and so facilitated our research. In moving forward, the Recovery Alliances will guarantee a commitment from local services, agencies and community members in working together to understand and meet the needs of individuals and groups in far more personalised ways.

## Participation and sustainability

Service users can feel poorly equipped or poorly informed about ways in which to get involved in the process of service development. Often there are financial or time constraints which might prevent their involvement, for example, childcare costs or travel expenses.

We found that the service providers involved in this project have already begun to make welcome advances in developing their service user involvement. In addition and as outlined earlier, establishing EXACT as an independent body such as the Independent Monitoring Boards within the criminal justice system, will ensure that user involvement remains a priority in designing, delivering and reviewing services and in commissioning future services.

The EXACT groups offer support to the range of priorities that a user may have such as family commitments, accessing education and training or finding employment and in finding accommodation, none of which may be straightforward and could potentially negatively impact on an individual's recovery. The end to end peer support provided by these groups ensures that people, particularly those in early recovery, have the support they have told us they want and need.

## Power imbalances

The inherent power imbalance of traditional treatment models between the service provider and the service user is one of the most difficult challenges to address as it often requires cultural, attitudinal and institutional change.

We have found that the process and methodology of this project has helped to accelerate the changes needed to reframe the power dynamic. Through multi-stakeholder group sessions the project began to form and activate networks that reflect the whole system needed to develop new ideas and solutions.

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<sup>186</sup> While the funding may be drawn down from the government the IMBs remain entirely independent and cannot be instructed by the Secretary of State or even the IMB Secretariat.

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In these ways, we have moved forward through what Kahane calls generative dialogue,<sup>187</sup> built on all participants being able to understand the whole system and reflect on their role in it. The journey to arriving at these ideas is as important as the ideas themselves.

In continuing to address this challenge, the Recovery Alliances will continue this process, building on the multi-stakeholder engagement, and co-producing a shared sense of purpose through the creation of a Charter and developing a shared understanding of what recovery is and the varied support that individuals might need in beginning on the road to recovery and sustaining it long term.

## Mismatched expectations

Expectations of the treatment system and provision are often mismatched between service users and providers. These are often related to user's uninformed and unrealistic expectations and demands around the options for treatment, time frames and waiting lists and financial constraints. The mismatch may also be related to practitioners' understanding of available resources, organisational targets and a misunderstanding of an individual's personal needs. There also may be differences in terms of the overall goals of treatment. A main benefit of the Recovery Alliance is that in collectively taking forward the ideas detailed in the previous section, they will develop a greater understanding of where capabilities, resources and assets currently exist; where they can be joined up or strengthened through direct collaboration; and how they might interact with one another. The tools that will be developed to capture this richer knowledge will be shared through the members' wider networks and the wider community to ensure that myths are busted and expectations are more closely aligned to reality.

There will always be some expectations that will continue to be difficult to meet: a common condition of addiction, for example, is the desire to have everything immediately. In a system as complex as the ones described in this report this may not be possible. But by ensuring that as many influential networks in a community have a full and shared understanding of what is available and where the need is, expectations can be managed at a much earlier point.

## Individual budgets

There are many challenges to being able to plan and deliver personalised services for problem drug users. The potential individual budget pilot resulting from this project may take many months. Key to achieving personalisation is the required flexibility of service and treatment options, particularly for those around whom traditional services are not geared. This flexibility in the market will not emerge without the requisite demand: there is a need to drive the market by empowering users with personal choice and budgets.

In addition to the development of EXACT and the Recovery Alliances, the Small Sparks Scheme will provide a mechanism to test the individual user appetite to manage a budget that will support their recovery journey. It will highlight particular local challenges and develop a locally contextualised evidence base of the benefits that will support the development of an individual budget pilot.



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## Public discourse

In early 2010, the RSA published a report from its Prison Learning Network (PLN).<sup>188</sup> It argued that a more open discussion on prison education is required: 'We need leadership from policymakers and practitioners in building a public conversation about prisons as a core public service that serves us all, not just the victims and perpetrators of crime.' It found that effective and appropriate participation of users in the delivery and design of prison services delivers greater efficiency and complements rehabilitation programmes aimed at building skills and increasing personal responsibility.

The PLN's report, *The Learning Prison*, suggested that fair and transparent public services are most likely to emerge through a process of wider community participation, forging local partnerships with employers and others, and enabling direct public involvement wherever possible. The same arguments can be put forward for the drugs agenda. If broad recovery communities are to be fostered, if perceived stigma is to be overcome, if recovery is to be celebrated as something that is achievable, then we need stories of success and strong leadership to make the case for greater investment and innovation in drug policy and services from recovery champions through the public-policy-practice-user hierarchy.

## Improving user-centred approaches

This project set out to re-focus user engagement from *involvement* which is often akin to tokenistic consultation, to *centredness* which empowers and enables users to have a greater role in the design, development and delivery of treatment. We began with the idea that personalisation, the pinnacle of user engagement and user-centred approaches, was the ultimate aim. We soon found that this did not do justice to the potential that existed within the individuals we met and the communities we worked in. In concentrating on how to personalise services by embedding a user-centred approach, it became apparent that this was only one component of a much wider system of recovery. This meant that the projects focus began to expand beyond the arguably narrow, albeit ambitious, personalisation agenda to the inclusive recovery agenda.

## User-centred innovation

This project is one of a new generation of projects at the RSA that extends the thought leadership largely directed by the RSA Commission on Illegal Drugs, Communities and Public Policy, into practical innovation on the ground. In many ways, this project was a learning journey for the organisation and its staff and as such we recognise the importance of reflecting on the processes, limitations and outcomes of the project in order to continue our development.

Our introduction stated that drug users have not forfeited their rights to public services and may indeed need them more than other citizens if they are to achieve their full potential. Innovations such as individual budgets need to be extended beyond adult social care to those such as drug users who need innovation to improve and drive recovery systems. In this respect, drug users should be on the leading edge of, rather than behind, the curve.

The processes involved in the journey to our end pilot ideas are as important as the end pilot ideas themselves. The processes create the necessary momentum, trust and broad partnerships required to enable recovery in a Whole Person Recovery System.

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<sup>187</sup> Kahane, A. (2004), *op. cit.*

<sup>188</sup> O'Brien, R. (2010) *The Learning Prison*, London: RSA.

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Our experience of working with users throughout the project so far has demonstrated that there is a wealth of potential, ideas, momentum and recovery capital waiting to be forged and realised in a user-centred approach. And it is only through this user-centred approach that individuals and communities will be able to cope with the broader social and economic challenges we face today.

### The experts by experience

We met more than 200 former and current drug and alcohol users (experts by experience) in Bognor Regis and Crawley over the course of the project. Some have travelled with us from day one and continue to be leading champions in their communities as they establish groups like EXACT. Others dipped in and out and while this was expected given the nature and extent of some of the difficulties these individuals faced, this did have an impact on the project.

We set out to work with as many experts by experience as possible, bringing together a representative sample from across the two project sites. In many ways we were able to achieve this. However, as with many studies in this field, we found it difficult to reach into some of the black and minority ethnic communities especially in the Crawley area. Dedicated research in collaboration with existing and trusted organisations such as Rethink BME will enable future research to develop a far greater understanding of the particular needs and opportunities within these groups. This was beyond the scope of this project to date.

It is also interesting to note that in Crawley its thirteen estates have very distinct identities and characteristics. People identify themselves in relation to those estates rather than to the town of Crawley and as our research suggests this can have an impact on the likelihood of a person accessing support networks as well as formal treatment; not simply in relation to the transport costs for example, but as a result of a network or treatment centre being situated in a different and potentially hostile estate. Research into these relationships is beyond the scope of this project but would offer an interesting insight into support and treatment access and retention.

### The experts by profession

This project began as the local commissioned landscape changed and a new provider took over the delivery of the most of the treatment system across West Sussex. As with any field, organisational change can be turbulent and so some of the established relationships and levels of new uncertainty among the service provider staff paved a difficult path for the project. This project was ultimately seeking to change the very nature of their work, from the relationships between client and professional, to the culture and practices of their organisations and substantial changes to attitudes and beliefs.

Our focus on the users ensured that we established the foundations of the user-centred approach from the early stages. On reflection, this may have been too narrow a focus and we recognise that more was needed from the early stages of the project in bringing all service provider staff along with us on the project's journey.

### Contagious recovery

Overwhelmingly the most significant factor/resource that has emerged in discussions about every stage of an individual's journey from first trying drugs and alcohol, to the development of problematic use, and then on the likelihood of sustained recovery, is other people.

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189 Best, D. and Laudet, A. (2010), *op. cit.*

190 UKDPC website, See <http://www.ukdpc.org.uk> [08.07.10]

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The importance of others cannot be overstated. Our system notes the significance of relationships with others to sustained recovery and the importance of engaging in recovery activities. Doing so places users within recovery-supportive networks. Recovery is thought to be ‘contagious’. Helping users into recovery networks will not only support them on their journey but will enable a greater understanding of network effects of recovery<sup>189</sup> which will be key to expanding the much needed evidence base for future strategies.

These networks will help to spread the stories of hope that characterise recovery, and begin to erode the damaging stigma surrounding those with or experience of drug and alcohol problems. It will also begin to address the self-stigma and shame that acts as a barrier to many people’s own recovery. The RSA welcomes the new research programme from the UK Drug Policy Commission (UKDPC) exploring stigma and drug use in greater depth and which will ‘provide a foundation on which recovery communities, professionals and policy makers can build.’<sup>190</sup>

### The reality of recovery

Imagining a drug free society is problematic and for many might even be undesirable. After all, one of the linchpins of British culture is the pub in which the UK’s favourite legal drug is consumed and enjoyed daily. So perhaps imagining a society in which the harms caused by problematic drug use are reduced substantially and in which the necessary recovery capital that can prevent the development of problematic use exists and is continually developed, is the way forward.

Recovery means different things to different people, which is why it is essentially a personalised process underpinned by core principles (as outlined in **Section 1**). Recovery incorporates harm reduction and abstinence and promotes quality of life and the importance of contributing to society. Done right, it will fundamentally expose the hidden wealth and resources of individuals and communities which are critical as public services enter an age of austerity characterised by substantial budget cuts and a reduction in conventional opportunities and support structures.

As much as they are about changing the system, user-centred approaches ultimately require service users to change their attitudes about themselves and their role in treatment and other services. It involves them taking more responsibility for their health and wellbeing (from diet to mental health to substance misuse) as well as those around them. *Recovery* embeds this in the community, encouraging supportive networks and activities that will reinforce practices and behaviours that protect against future harm. This is the challenge to us all. We must change the way we operate on a daily basis at every level; at a personal, social and community level.

### What next?

As from autumn 2010, the RSA’s Whole Person Recovery Project will see the ideas outlined above piloted in Bognor Regis and Crawley in collaboration with the Recovery Alliances. Regular updates from the pilots will be made available at [www.theRSA.org](http://www.theRSA.org). If you would like to follow their progress or find out how you can support these pilots, contact [rebecca.daddow@rsa.org.uk](mailto:rebecca.daddow@rsa.org.uk). The RSA Whole Person Recovery Project will support these initial pilots but will gradually hand over the reins to the local Recovery Alliances; they are the legacy of the project.



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## APPENDICES

It should be noted that the participants involved in our research came with a wealth of experience of drug and alcohol use, treatment and life. The stories shared with us may not reflect their most recent experiences and may be related to other areas of the country.

**Appendix A:** Findings from the user survey

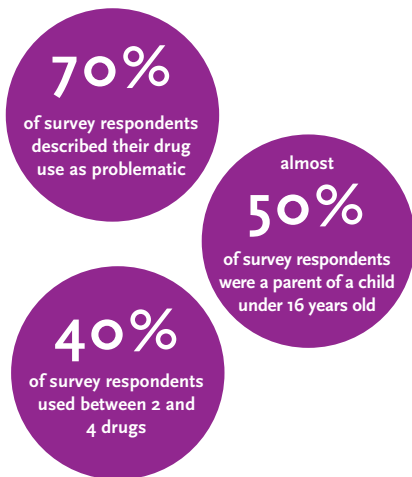
**Appendix B:** Naturalistic Narrative. The Local Workshops

**Appendix C:** Design Symposium. Route Maps to Recovery

**Appendix D:** EXACT Ethos and Bill of Rights

**Appendix E:** Recovery Alliance Membership (to date)





## APPENDIX A: Findings from the user survey

### The Hold

Who is in The Hold? Three quarters of our respondents were male. Just over a quarter were under 25 years old, 60% were aged 25-44, and one in eight were aged 45+. One in six were of non-White British ethnicity.

70% described their drug use as problematic. More than two in five also said alcohol use was a problem for them. This indicates the strength of The Hold, in that despite recognition of problematic use, users remain in the sub-system.

Just over 40% used between two and four drugs, and five percent used 15 or more different drugs. A significant proportion of users are multiply-addicted in The Hold, and move around from one drug to another. Almost half the respondents (45%) used heroin, and a quarter used prescribed methadone. Over a quarter took crack/rock, one in five used benzos, and one in five took cocaine. One in six used sleepers, and over a third used cannabis with most preferring skunk. Almost ten percent used ketamine, 13% used amphetamines, and seven percent took acid. The range and permutations of individual substance misuse indicates the need for personalised recovery treatment and support.

### The Struggle

Problematic use is illustrative of The Struggle — it can act as both a Tendency To Recover (recognising that there is a chronic problem to address, and encouraging people out of The Downer); but also as a Tendency To Relapse. How do we support recognition of problem use into Tendency To Recover?

A quarter of people were 'extremely' unhappy with their life, and a further 30% were generally unhappy. Recognition of this quality of life may support a Tendency To Recover. Those respondents whose networks were entirely made up of people who used drugs and/or alcohol were far more likely to feel extremely unhappy with life. Specifically, within the last few weeks, more than 60% experienced general anxiety, 80% slept poorly, 54% had low self-esteem, 61% felt depressed, and one third felt paranoid. One in six had suicidal thoughts, 13% had self-harmed, eight percent had taken a deliberate overdose, and six percent had attempted suicide. The vast majority of respondents wanted help with this range of issues (between 70% and 90%), although only a minority had received help on any of these issues. This help is key if Health is to drive Tendency To Recover and not self-medication and The Escape in The Hold.

Almost half were a parent of a child under the age of 16, although only less than ten percent lived with their partner and children. A key Tendency To Recover was the desire to reconnect with family and to move into recovery for the friends and family.

Some 30% of respondents said that all of the people they knew took drugs. A quarter of people said that people in their support networks took drugs problematically. Similarly, a third said that all the people they knew used alcohol, with one in five respondents suggesting that people in their support networks used alcohol problematically. These proportions were much higher for people of no fixed address. Conversely, proportions were lower for those who were parents of under-16s, and those who were in long-term relationships (although this was truer for drugs than alcohol).

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For people with a high proportion of fellow users in their networks, this is a key driver of Tendency To Relapse. There are key differences, however, by age. Younger people (16-24) are more likely to have networks where all members take drugs. The picture is reversed with alcohol use — among 45-64 year olds, over half (53%) of respondents said that all people in their networks drank alcohol. Women were also more likely to have all people within their networks using drugs and/or alcohol. Skunk users' networks were less likely to be made up of people who all used drugs.

Almost all respondents (95%) had committed a criminal offence, and half had received a prison sentence. Almost three quarters said their sentence was related to taking drugs, and 30% said their sentence was related to taking alcohol. This contributes to users feeling part of The Scene and being Labelled, which feeds a Tendency To Relapse.

When asked what changes they would make to services, 40% said access needed to be improved (particularly times available and location), and a quarter thought staff attitudes, knowledge and experience needed to be improved. One quarter also thought the range of services available needed to be expanded. This call for improvement and personalised services will reduce the Tendency To Relapse through experience of perceived Bad Treatment.

## The Recovery

Over half the respondents had access to a computer, with most using it regularly. Of those with computer access, 80% used Facebook, although only half used an email address regularly. The vast majority (85%) had a mobile phone. Access to and participation in these communications technologies are under-utilised methods of communicating with people in treatment (text reminders from appointments; calls, emails and Facebook posts for encouragement, problem-solving and support, which could potentially contribute towards a 24-hour service). They also represent potential ways of Breaking Routines — creating (online) networks of people in recovery, channels for peer support and mentoring, and access to job search and skills development (e.g. online IT training).

Health is a potential key driver of Tendency To Recover. Two thirds of respondents said they had health problems from taking drugs, with half of these describing problems as 'major'. More than half had health problems due to alcohol, with 60% describing problems as 'major'. All but five percent of people were registered with a GP, but only 60% had a dentist.

More than two in five people lived alone and one in seven described themselves as having no fixed address. More than half said they had housing problems. Housing is a key part of recovery capital and of connecting to and supporting the transition to Rest Of My Life, as is reduced isolation and positive social networks that can support the move to and sustain recovery.

When asked who they get the most support from, 38% said friends who use drugs, 28% said friends who do not use drugs, 36% said their keyworker, 42% said their family/partner, and eight percent said NA/AA. This informal support with respect to recovery is under-utilised and represents potential sources of recovery capital. The support also needs to be mobilised in facilitating Tendency To Recover and the reinforcing connection from Decision to Recover. However, this support is accessed in very different ways and provides different forms of support and expertise at different times.

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It is important to understand on a personal basis how recovery capital is distributed and how and when it can be accessed and whether this distribution is effective, even if on first inspection it appears to cover all key components. A small number of people (six percent) stated that they had no-one to get support from and for these people, the stock of social and community recovery capital is most deficient.

When asked what kind of support they received that was important to them, 35% said someone to talk to/company, and 21% said some form of emotional support. Other forms of support included: support with their care plan (15%); practical, day to day help (often cleaning and food) (16%); and accommodation (12%). Only two percent received help in getting work or onto training, and one percent received help with improving relationships with children/family/friends. Half replied that they could access support when they needed it, with a further 29% saying they could get support at the right time sometimes. Those who were unhappy with life, and those of no fixed address were less able to access support when they needed it. These findings illustrate the diversity of recovery capital available to users, and the need to understand this in personalised terms in order to mobilise it and address significant gaps.

Older users were around 50% more likely to be able to access support when they needed it compared to users aged 25-44.

One in five people reported reading difficulties, with the same proportion having writing difficulties, and trouble with basic sums. For these people this represents gaps in their personal recovery capital, and should be addressed as part of Making A Plan.

Almost three quarters had skills or a trade that could help get employment or training, one in eight were currently employed, and only one in seven had never been employed. This potential was difficult to realise, due to lack of support, low confidence and networks, and Labelling.

Almost 40% had not been employed for many years. The majority (83%) suggested they faced significant barriers in getting (back to) work, which includes breaking out of the 'benefits trap' (allied to lack of confidence, stigmatisation, chequered employment history, health issues, criminal records, and addiction, the jump required to become financially independent appears overwhelming). Only five percent were in any kind of training, and five percent were receiving some sort of education. These factors make it hard for users to see the Rest Of My Life, and overwhelming difficulties can weaken the Decision to Recover, and hence strengthen the Tendency To Relapse.

Debt resolution and financial management needs to be a key part of Making A Plan. Almost half spent around £10 a day on drugs, with a third spending between £20-£50. Similarly, just over half spent around £10 a day on alcohol. Half said they had problems with debts, with the vast majority receiving no help with debt problems.

Over a third (35%) had received drug treatment some time before going to prison, with a quarter having received some form of alcohol treatment. Two thirds of those receiving this treatment said that it had decreased the amount of crime committed and for these people, these experiences feed The Recovery sub-system.

Two in five had never received formal treatment for their drug use. More than half who had received treatment did not finish their treatment programme as originally intended.



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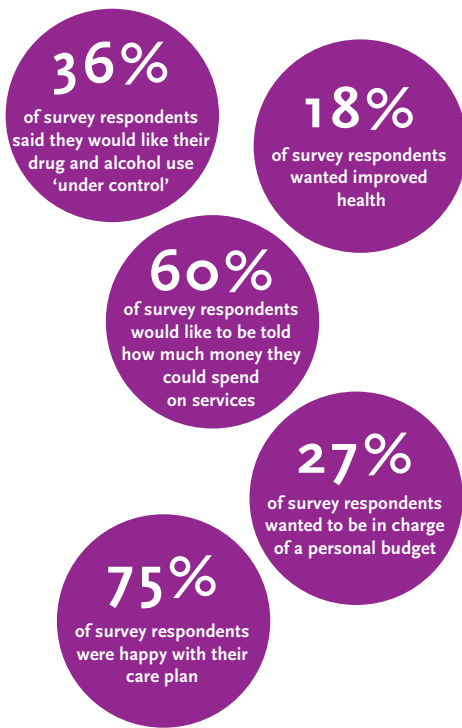
A number of reasons were given for not finishing treatment, including: started using again (22%); treatment model did not suit me (13%); not being ready to stop using (16%); and moving out of the area (13%). Treatment is a key component of The Recovery sub-system and more needs to be done to (i) bring people into treatment and (ii) increase completion rates. Unprompted, one in eight wanted a more personalised treatment model.

Of those who had received treatment, three quarters had a keyworker (or equivalent). A quarter of people saw this worker daily; half saw them weekly; and a quarter touched based with them no more than fortnightly. This is a key resource both in The Recovery sub-system, but also in supporting Tendency To Recover and in co-designing Making A Plan.

Of those having treatment, two thirds had some kind of care plan. Three in five of those with a care plan had helped to draw it up. Three quarters were happy with their care plan. The majority (60%) were positive about the level of involvement they currently had in decisions about their treatment, and just over one quarter were not happy. Heroin and crack/rock users, however, were less likely to feel involved in decisions about their treatment, as were those who were unhappy about how their life was going. Those with low basic skills (reading, writing, and maths) were also less likely to be satisfied with their involvement in treatment decisions, as were respondents who saw their substance misuse as particularly problematic. More generally, three quarters of respondents wanted more input into treatment decisions. Cannabis users, (especially those using skunk), in particular wanted more input into treatment decisions, although those with debt problems were less likely to want more involvement. Generally, this is a clear indication of the desire to personalise The Recovery sub-system, but also shows that for some, there may be too much to deal with and resolve first, before taking on more responsibility for treatment decisions.

When asked what would make the most difference to helping them achieve their goals, a third wanted better service provision, with two main goals: to address their drug and alcohol problems; and to get into education, training or employment. Respondents meant a broad range of things by better service provision. Generally, this included 'better' and more accessible staff (24%); better access to services (40%); more accessible service locations (22%); and an increased range of service and activities to support recovery (25%). When thinking about designing services that would meet their needs, respondents frequently cited improved support across a number of domains, including substance misuse, housing, family relationships, health, and financial advice. This again indicates the need to take a whole person approach in Making A Plan. However, an inspection of issues to address in individual cases reveals a very broad range of complex and inter-related problems. The skillset and knowledge of keyworkers and the coordination and ability to provide personalised support across a range of services is very challenging. It is therefore necessary to expand the sources of recovery capital and mobilise them for individual and collective support.

Half said that Friends and Family would be able to offer them support as part of a set of services and could help to deliver those services. This was particularly the case for those that had some kind of trade/skill to aid employment, education and/or training. This is both a resource in enhancing the Decision to Recover and in moving to Tendency To Recover, as well as an under-utilised resource in The Recovery sub-system. Those who had Friends and Family to (potentially) call on for support were much more likely to be happy with the way their life was going.



The majority (60%) would like to be told how much money they could spend on services and be responsible (to some degree) for choosing who provides services and support. This was particularly true for skunk users, for those less happy about how their life was going, and those of no fixed address. It was less true of those in long-term relationships. This is another indication of the desire to personalise and take greater control in The Recovery sub-system. However, one in ten were unsure if they wanted this information and responsibility, and 30% did not — personalisation does not mean individual budgets per se.

Just over a quarter (27%) wanted to be in charge of a personal budget. A further ten per cent wanted joint control of a budget with combinations of them and a trusted friend, treatment providers, West Sussex Council helping to make decisions. Two in five felt a service/treatment provider should be responsible for allocating money. Among the reasons given for this answer were that respondents felt that such responsibility would be too much pressure, they would be concerned about getting decisions wrong, and a belief that decisions should be left to professionals. Support through different components of recovery capital is needed to help users realise the personalisation they desire.

Young people were around twice less likely to feel involved in decisions about their treatment than older people, who were slightly less likely to want input into treatment decisions.

When asked where they saw themselves in five years, a third felt they would be in some form of employment, education or training. A quarter hoped that they would have improved relationships with their children/family/friends. Almost a quarter hoped to improve their housing situation over this time. For these respondents, users can see the Rest Of My Life, but cannot reach this hub in the system for lack of recovery capital, Decision to Recover and Tendency To Recover, despite drivers such as Friends and Family.

More negatively, one in six feared they might be dead, a quarter suggested they would still be using drugs and alcohol, and seven percent felt they would probably be in prison. One in ten found it impossible to offer any opinion as to where they might be in five years and could not look beyond the here and now. This indicates a strong Tendency to Relapse and/or difficulty in escaping The Hold, and no clear way of reaching The Recovery sub-system and connecting to Rest Of My Life.

When asked where they would like to be in five years, 70% said in employment, education or training — in terms of aspirations, users can connect with Rest Of My Life. Over a third (36%) said that they would like their drug and alcohol use 'under control', compared to 23% who said they would have wanted to stop their drug/alcohol use (in addition, one percent said they would like to be 'in recovery' and two percent said 'in treatment'). The differences in personal outcomes reflect the need for personalised approaches and an acceptance of the diversity of goals users have. The findings may also indicate that 'recovery' is not yet a 'live concept' for many users (they are unaware of it and do not use its language, particularly for those not in treatment).

Over half wanted to have improved relationships with their children/family/friends, which can support Tendency To Recover through acting for the Friends and Family. Respondents also wanted improved health (18%), finances (13%), and housing (58%). This indicates the need for a personalised, whole-person approach, if recovery is to be maintained.

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## APPENDIX B: *Local Workshops*

### Naturalistic Narratives: The voices of the experts by experience

#### SUMMARY OF KEY POINTS FROM ALL WORKSHOPS

- Almost all participants think treatment services should be staffed by recovered drug and alcohol users.
- For most participants, GP's were the first point of contact when seeking help and most felt that they were unprepared, unformed and unsympathetic to their needs.
- Homelessness is one of the main drivers of problematic use as well as one of the most significant barriers to recovery and is a major issue in both Bognor Regis and Crawley.
- Many of the participants would choose to continue using substances if the addictive qualities and other problematic factors could be removed.
- Participants feel that, in general, the public have little understanding of drug and alcohol use and users, which often reinforced their desire to use substances, stopped them from seeking help and influenced the likelihood of relapse.
- Participants have a wealth of knowledge about the variety of substances available and the physical and mental effects that they bring about. Many were aware of the potential dangers involved in using them before even trying them and had witnessed others suffering as a result of their use; but circumstances related to their environment and friends and family meant that the immediate return negated the potential risks.
- Participants felt that experimentation with alcohol and drugs amongst younger people cannot be seen as directly leading to problematic use in later years but should be seen as experimentation. There are far more people who experiment with drugs that do not go onto use problematically, than do.
- Participants felt that aftercare was particularly poor in both areas and contributed to the high levels of relapse.
- The younger participants suggested that having a job would stop them from using substances daily but felt there was nothing on offer in their area. They also felt that they had little chance of getting anything given their lack of experience and criminal records.

### Background & Methodology

The workshops were designed to compliment and enrich the quantitative data gained through the user survey which interviewed 152 individuals across the two sites of the project; Bognor Regis and Crawley. Bringing together 29 participants, the three workshops provided an ideal space for the participants to provide a naturalistic account of their substance using experiences and to explore in more detail the influences that strengthened and weakened their substance using behaviour.

The workshops were held in the two sites of the project: Bognor Regis and Crawley. Our ambition had been to hold two workshops at each site and while we were able to do this in Crawley, adverse weather conditions meant that we were only able to hold one shorter workshop in Bognor Regis within the timeframes.

Participants at the Crawley workshops were a mix of experts by experience (i.e. former and current drug and alcohol users) and experts by profession. The experts by profession were briefed before the arrival of the experts by experience to ensure they understood their role as impartial observers.



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The participants at the Bognor Regis workshop were only experts by experience. In total there were 8 experts by profession and 21 experts by experience. In this document 'participant' refers to the expert by experience only.

#### **EXPERTS BY EXPERIENCE**

- 18 Male 3 Female
- 9 participants identified themselves as having or had problems with or using alcohol
- 6 participants identified themselves as having or had problems with or using drugs
- 6 participants identified themselves as having or had problems with or using both drugs and alcohol
- 17 participants have or have had problems with housing or homelessness

The workshops were semi-structured with participant responses guiding the sequence of questions and set of associated prompts offered by the facilitators.

The first section of the day drew out the particular experiences of the participants. Participants were invited to share their stories which covered a full spectrum of areas from family situations, their first experience of drug or alcohol use, significant events, experience of treatment services, influence of friends and family, to detailed accounts of the physical sensations of consuming particular substances. While one facilitator provided prompts and questions, the second facilitator wrote each point onto a post-it note capturing each element separately and in the language used by the participant to be revisited in the second section. All participants were invited to ask each other questions or to contribute to the discussion in whatever way they felt most comfortable. The experts by profession were not present for section one.

This section was followed by a break during which time the facilitators laid out the many post-it notes that had accumulated.

During the second section participants were asked to examine the post-it notes and to group/cluster those with similar points, topics or themes. The participants worked together to form these clusters, asking facilitators for clarification and assistance intermittently when required.

Once the clustering had been completed, the participants were asked to name each cluster. The third section of the workshop engaged the participants in an exercise designed to help visualise the linkages between these named clusters. The participants were each given one of the cluster names and asked to think about which other cluster they most strongly linked to and why. String was then used to demonstrate these links and provided a visual web, or influence map.

Once the web had been constructed participants were asked to think about which links they would like to strengthen or weaken to meet their end goal.

The final section of the workshop invited reflections from the participants on the day, the discussions and any other issues that they might wish to address.

The workshops were audio recorded. Participants were remunerated for their time.

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## Crawley Workshops, 10th & 11th December 2009

### Key themes (Section One)

The participants were drawn from the local area and also included four individuals at the YMCA Horsham. There was a distinct difference in age in the first workshop with the four individuals from the YMCA aged between 17-20 years and the two individuals from Crawley Open House above 50 years old. The second workshop had a much wider spread of ages from 25–55 years.

In the first section of the workshop, participants were asked to discuss their experiences. The following provides a brief overview of the most prominent themes.

#### 1. Psychopharmacological effects

The changes in perceptions, behaviour, mood, thinking and sensations brought about by the consumption of drugs and / or alcohol were reoccurring factors in the discussions and were the primary reason for using them. The underlying reasons for seeking these changes however, were personal to each individual.

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*“I’m a better person on drugs. Without them I wouldn’t be sitting here right now; I’d get angry, I don’t talk at all. I’m just no fun to be around unless I’ve either taken something or drunk something.”*

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#### IN THEIR WORDS

The younger participants were extremely knowledgeable about the types of drugs (legal and illegal) available and the specific effects that they had on their bodies, minds and behaviours. In their words:

- Magic mushrooms: depends on how many you take
- 2CB: like mushrooms but with pills
- Pills: everyone knows, lovey dovey effect
- K: ketamine. If you take in small amounts you feel light and floaty. If you take too much then you’ll zone out, it’s called k-hole
- Speed: that’s quite dirty, just a rush. Huge down
- Coke: it’s evil. It’s just so moorish. Bad comedown as well
- GHB: date rape drug. Mix it with juice not alcohol cos it’ll make you like you’ve drunk 2 litres of vodka. You’ll think you’re acting sober but you’re not
- Meow Meow (mephadrone)
- Acid: it’s nuts mate. It’s weird.
- Cannabis: just gets you stoned. You relax. It’s the best stuff they’ve got.

Responses from some participants reflected on their levels of self-esteem and suggested that the substances were a crutch to them. One respondent for example, felt that drugs made them a better person to be around, changing their fundamental nature from quiet and angry to talkative and quiet.

For some participants the experiences on the substances were fun and helped them to encounter feelings they wouldn’t otherwise.

*“Drugs are amazing. They take you to another dimension that you’ve never been to.”*

For most participants using substances was a way of blocking out feelings or memories, offering them the chance to forget for a time.

*“Whatever bad thing that happens, you do things to forget. Some people can without it [drink], some people can’t.”*

For some participants with extensive experience of problematic drug use, they described how drug taking quickly progressed from an enjoyable experience to one which managed their symptoms; their drug taking became self-medication for the negative physical and mental effects that their substance use had brought about.

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*“At first it [heroin] wraps you up in cotton wool... but after a month, maybe 6 weeks, then that hit, all it does is bring you back to normal. You get so ill that you’re using it as medication.”*

And again participants described it as a way of treating emotional distress and to erase, temporarily, memories and feelings they would otherwise be confronted with.

*“A lot of people drink to self-medicate; drinks a symptom of what’s going on — you can have such powerful emotions. It’s so easy to take these chemicals to take it all away again.”*

One of the most surprising outcomes of the two workshops was the fact that a participant in each workshop described how they used amphetamines to lose weight. Both participants reported that they had been bullied as a result of their weight and so took speed to help them lose weight.

## **2. Understanding one’s own limits**

All participants were very aware of how substances affect them, often through trial and error. Participants were able to list the effects of a number of substances as detailed in the **box opposite**, and described how they would seek out particular substances for their particular effects.

For some participants, the simple fact of a drug being available meant that they were likely to use it and would then learn from that first experience.

*“If it’s there I’d give it a try — not everything, there’s a limit. I tried crack once... I wouldn’t do crack again.”*

*“Mixing alcohol and ketamine ain’t good — it gives you a bad stomach. It puts you in a hole, mate. I enjoyed myself!”*

*“With cocaine, or cannabis or ecstasy or anything like that, it’s all in there [in your head] but heroin is absolutely physical.”*

One participant who had drunk heavily for years told us how he would always fall asleep when drinking and how one day he had his eyebrows shaved off when he had fallen asleep in a pub. He did not necessarily seek sleep through drinking but knew that this would be the effect.

*“[Alcohol] just sends me to sleep.”*

Participants had their own limits in terms of what they would take or drink. This is something that we have seen repeatedly in our research; there is a hierarchy of substances and substance users among the using and non-using populations with those drugs seen as most addictive and problematic receiving the most negativity.

*“I wouldn’t do crack, heroin or crystal meth.”*

*“If there’s one drug that no-one should take its heroin — I’ve seen 4 people O.D.”*

*“I wouldn’t use hard drugs — my body couldn’t take it.”*

Interestingly, the younger participants who reported polydrug use were very negative towards alcohol mainly as they felt they had more control over their actions and behaviour when using drugs.



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### **3. Feeling like society has nothing to offer them**

The younger participants repeatedly referred to their drug taking as a kind of response to the society around them, the lack of employment opportunities, their experiences in life so far and the stigma they experience from others around them. These participants seemed to suggest that they have only two options for example, joining the army or drugs.

*“I wanted to join the army but they wouldn’t let me cos of my asthma. That ain’t fair. So what am I gonna do then? I’ll just take drugs.”*

Another participant felt more generally that there was little on offer for them and that their attempts to ‘get the best out of life’ had just been chucked back in their face.

*“I take the drugs as well cos what does this place offer me? I try to get the best out of life and it gets chucked straight back in my face. I try and give up drugs and it’s just not happening — someone just has to do something to wind me up enough and I just do it again.”*

There was no indication of what these attempts had been and in many ways this is irrelevant as the participants’ responses suggested that they felt victimised, not only because of their lifestyle choices, but for simply being young or dressing in a particular fashion.

*“Its constant aggro. We get pointed out...the way we dress, you know. I guarantee if we were sat on a train and we both didn’t have tickets, they’d come up to me. It’s discrimination... so I’m just going to do more drugs. Get away from them and the civilisation that we live in cos I just think it’s a load of pants really.”*

*“Being young I sometimes feel inadequate.”*

### **4. Experience of treatment services and GP’s**

The participants of the second Crawley Workshop had a greater level of experience of treatment services than the first and so much of the discussion was focussed on this area. Within this the main points were:

#### **Practitioners**

Participants shared with us a number of negative experiences they had had when seeking help through their GP. This has been a common feature in our research with reports that they were rude and had been extremely prejudiced against them once they had found that they needed help with substance misuse; that the GP had dismissed the physical and emotional effects of the substances; that the GP simply had a lack of knowledge about what treatment was available and how the participant could access this.

*“We get judged all the time, wherever you go you get judged. GPs especially — they’re like it’s all self-inflicted so just get on with it.”*

*“They just say a rattles not going to kill you so get on with it... but I’ve never experienced something so painful in all my life and to put it into perspective I had a car crash and broke my back in 2 places and spent 4 months in hospital and that was less traumatic than trying to come off the heroin.”*

*“He told me to pull myself together!”*

The participants suggested that this was due to a variety of factors including prejudice towards problem drug users, and lack of knowledge or training. One participant was told for example, that they were too young to have an addiction and was turned away.

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*“When you go to Addaction or KCA and you try to explain these things you do get the impression that the person on the other side of the desk has only ever read it out of a book. And that is so patronising because they’re saying you shouldn’t be feeling like that and you’re like, hang on — you haven’t got a clue.”*

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*“When I first went to the doctors they were like, you’re too young, you don’t really have an addiction. And I just kept getting turned away. It was only when I started using needles and went to Social Services for help.”*

For many of the participants, these reactions were frightening and deterred them from seeking further help in many cases until their substance use became even more problematic. GPs were often the only medical practitioner that many of the participants had come into contact with and so these reactions shattered the trust they held in the medical profession, putting treatment services at a much greater disadvantage once the participant reached them.

In part this could explain the negative experiences the participants described with the practitioners within the treatment services. However many of these criticisms were centred on the apparent lack of knowledge held by the practitioner which most participants felt they had learned from a book rather than learned through experience.

*“There needs to be more understanding about addicts, what they need, what helps them prevent relapse and that when they do relapse, it doesn’t mean they’re going to be on it for good.”*

Nearly all participants agreed that they would prefer to have practitioners within the treatment services who had firsthand experience of substance use and who were more able to empathise with and understand the physical and emotional experiences that they were going through. Participants suggested that practitioners with this experience could spot when they were lying, challenge them using lived experience and offer them a source of hope by showing them that people can recover from drug and alcohol addiction and dependence.

*“Compared to someone who knows; someone who is just reading it out of a book is a completely different kettle of fish... it’s the understanding — you can tell they know how you feel.”*

*“Ideally, the people that work in Addaction should be a recovered drug addict.”*

*“if someone could have sat and told you what it felt like to have a dirty hit, to feel like you’re dying, to feel like your head is exploding, everything hurts... it would have given me awareness to be more careful.”*

### **Access and availability**

In addition to these challenges, participants were also very critical of the availability of treatment and the length of time they had to wait to receive help once they had asked for it. For many participants, making the decision to ask for help was a huge step and so being told that they would have to wait for weeks or months before receiving treatment was devastating. For one participant it meant that they ended up in prison because they had to continue feeding their habit, when faster access to treatment would have prevented it.

*“I decided I wanted to give it up but I wasn’t getting any help so I was out there committing crime and ended up locked up.”*

Another participant simply felt that the length of time and the processes they had to go through was too difficult and so detoxed themselves. This participant repeatedly relapsed following their homemade detox which could have potentially been avoided with formal treatment.

*“I tried going to a service a few times but it was so hard to get a script that I just ended up doing it myself.”*

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## 5. Making the decision to make a change

The workshop participants were at very different points in their substance using experience. Two participants were polydrug users who did not consider their drug use problematic and with little desire to stop using in the immediate future or indeed, at all. However, one of these participants did believe that having a job would reduce the amount of drugs they did to weekend rather than daily use.

*“I do actually want to find a job. I just can’t be bothered to be honest and there’s just crap work out there. But I’m not going to give up to have a job... But if I had a job it would be different. I wouldn’t go out every day, I’d probably only get fucked at the weekend. But like, because I haven’t got a job at the moment, there’s nothing better to do, there’s nowhere for us to go or to do.”*

The participants who identified themselves as problematic drinkers were different in their approach to the future, and had or were seeking treatment. Most of these participants felt that their addiction was an illness that they had to battle everyday and that it was important to hold onto a faith that things will get better in order to stay sober each day.

*“Addiction is an illness and it potentially kills. I sometimes don’t feel like giving up, I don’t see the point. But it comes down to faith; faith that life will get better. Things like getting trust and respect, little things like that.”*

*“I’ll give up by looking at people and thinking that ain’t me. I don’t want to end up like that.”*

Other participants had a long history of getting clean and then relapsing; even when they had made the decision to get clean, something happened in their life that they felt unable to cope with and made them seek the escape offered by substances.

*“The first time I got off it, I actually just got in my head — that is it, and I done it and stayed off it for a year. But then something happened with my children and I went straight back down that road again.”*

## 6. Homelessness and housing problems

10 out of the 12 workshop participants were or had previously experienced housing problems and/or homelessness. Participants felt that this contributed to almost all other areas of their substance using; reinforcing their desire to use, to use more than they may have wanted, and in increasing the likelihood of relapse.

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*“I can’t give a 100% guarantee that I won’t drink again because I’m an alcoholic. The only guarantee I can give you is that I’m not drinking today.”*

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## Identifying the main spaces and the links (Section Two)

As described in the methodology above, the participants were asked to group the notes taken in the first section into clusters. The Crawley workshops identified 18 different but interrelated cluster groups, briefly explored and illustrated below.

### The Downer connected to Making a Plan, No Light, The Buzz, The Hold, Treatment, Getting clean

Participants described the downer as the after-effects of taking particular substances, but mostly as hitting rock bottom; when **the hold of the fix** had become so strong that eventually the **balancing act** that they have been living by breaks down until there is no hope, **no light**.

*“I have my plan but then I need more of the fix because it has a hold of me that means I’m creating more of a downer, and then eventually I lose the plan and hit rock bottom.”*

*“Over the years I have lost at least 10 people that have died under the age of 30 from overdoses.”*

Participants across the two Crawley workshops agreed that it was at the point where there is **no light** that most seek **treatment**.

### The Hold connected to Breaking the Routine, The Fix, Making a Plan

The participants felt that the most prominent feature in the web was **the hold** and would be the most significant part to remove. Participants felt that without the addictive elements of substance use, they could continue using without the problematic elements as described by **the downer** and **no light**.

*“I’d rather have the experience but without the addictive bit...I wish I could try everything but just once.”*

*“Unless you get that fix, then you feel like you’re going to die.”*

*“You start by dabbling in it... then you need to use more and more to get the same buzz. But you never get the same buzz again.”*

*“The amount of times I’ve come off it [heroin] and said right, I’m not going to do it again. And then someone will offer you a little bit and you think that won’t hurt and then the next day you think, I’ll have a bit more, that won’t hurt. And then before you know it you’re absolutely in trouble.”*

The links between **the fix**, **the hold** and **making a plan** were clearly discussed in relation to funding the substance use.

*“If you’re really ill, I call it kamikaze style. You’ll just run into a shop, take something and then run out and if you get caught, you get caught and if you don’t then you’re alright.”*

*“I’ve never actually robbed people or mugged people... I do understand how some people get like that.”*

*“I’ve shoplifted and borrowed money knowing that I’m not going to be able to pay it back.”*

*“I was spending like £100 a day; I don’t know where it was coming from. And it was getting worse and worse and worse. And I was spending my months wages cos you’d get £1500 and you’d just go bang, and pay off your tick bill and then you’d just run up your tick again.”*



## The Environment (the scene) connected to Friends and Family, Getting Started, the Escape, Being Labelled, The Rest of My Life

The circumstances in which individuals live, grow up, work, and use substances were considered extremely significant to all other clusters but most specifically in relation to:

- **friends and family.** Participants more often than not described how friends and family were influential in their **getting started**; first trying drugs and/ or alcohol. For those participants who identified themselves as alcoholics, they particularly noted how drinking had started out as a social event, drinking with friends in pubs.

*“Friends and family: they’re the ones that started me out.”*

*“I started drinking socially but as I got more into the addiction, I stayed at home so people wouldn’t know how much I was drinking.”*

*“My parents were dealers... so for me drugs was a normality.”*

*“I smelt my dad’s breath from the day I was born. Alcohol was in my life.”*

For some participants events involving friends and family influenced the start or advancement of drug taking.

*“I was in a violent relationship when I started.”*

*“I had a marriage breakdown and got so desperate that I basically wanted to end my life. And then heroin came along and I used it and thought ah, this is going to help me out and before I knew it I was in trouble.”*

*“Some women that are in some relationships — the man tends to try and get them back on the gear so they stay with them and they’ve got a hold over them... That’s how it was with me.”*

*“My wife knew about it then and I actually got her into it for a brief period of time but I was just letting her have joints of it, top-loading it so she wasn’t getting much.”*

*“It’s the people, you can’t get away from the people.”*

- **the escape.** Participants felt that if the environment was better and people felt better about it then they wouldn’t feel the need to seek **the fix** or **the buzz** in order to **escape**. Participants felt that one of the main ways to improve the environment was to get rid of **being labelled**.

*“You change the way you feel by getting the buzz.”*

*“When I ended up on the streets I started using a lot more heavily than when I had somewhere to live. If you’re on the streets and it gets dark at 4 o’clock, what do you do? The only way to get any sleep, any rest at all, is to get absolutely out of your face.”*

*“If you were completely, 100% happy with where you are then the martian would never leave his planet would he? You all do different things to make your life better whether that’s playing golf, drinking coffee, smoking cigars, buy a nice fast car. It’s all stuff that makes you happy. And your wife — you chose your wife because she’s the one that makes you happy. What if someone turned around and said that it was illegal to be with your wife?”*

*“With heroin, it’s not for boredom. Because of the circles we live in, we all know the effects it can have and how addictive it can be so it’s not a thing with boredom. It’s that you get so low, that you think it’s the only way out.”*

- **the fix.** Most participants felt that the scene in which they found themselves while using drugs was one of the most difficult but important links to break.

*“When I got clean it wasn’t the drugs I missed, it was the environment. I missed skulking about, the seediness of it. You’re always on the go. So I reckon the scene would be the one to break.”*

*“They always say you should disconnect but it’s the hardest thing to do.”*

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*“I opened up to someone I didn’t know very well and it allowed something to click like a wake-up call.”*

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*“The doctor’s tone of voice changed — they were determined to get the truth. And they did eventually.”*

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## **Bognor Regis Workshop, January 2009**

As a result of the weather conditions we were only able to hold one shorter workshop in Bognor Regis which brought together only experts by experience.

### **Key themes (Section One)**

The participants of this workshop all had experience of treatment services; some were in recovery, some still in treatment and others had relapsed. So while the participants shared their stories about how they got started, the majority of the discussion concentrated on the periods around entering treatment, from the *realisation* of their problem to seeking help, treatment and what followed that treatment. The main themes from this discussion were:

#### **1. The importance of someone listening**

Many of the participants were able to describe the first time that someone listened to them and their stories and revealed the significance of this simple factor to their recovery.

*“I opened up to someone I didn’t know very well and it allowed something to click like a wake-up call.”*

*“The doctor’s tone of voice changed — they were determined to get the truth. And they did eventually.”*

*“Just someone asking the question ‘what’s wrong?’”*

*“I started making things up just to go to the doctor. I felt better as soon as I got there.”*

For the participants who had experienced this, they considered it the first step in their recovery.

#### **2. The inconsistencies**

Many of the workshop participants had lived in other areas and experienced more than one service. Most had experienced services in the local area but each had a different experience and in most cases highlighted the lack of joined up working across the services in the locality, for example one participant was given conflicting information at one service than at the next.

*“I was being given completely opposite advice at Ravenscourt to what I got at Sands.”*

Another participant described how they had bonded with a group during the early stages of their treatment and had formed a supportive network with them but this had been broken when they were separated from the rest of the group and sent to a different treatment service for the next stage. This had a hugely negative impact on their treatment and removed the supportive network that had been a significant encouragement in their recovery.

*“I didn’t get the funding when everyone else did and went onto secondary but I had to go to Sands.”*



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One of the most surprising outcomes of the discussion was being told how some participants had had to drink more heavily in order to reach a certain level on the breathalyzer that was required to get into the service. So while the treatment service was meant to help the individual, they were in fact worsening their drinking behaviour.

*“I was drinking vodka on the bus so I could get into rehab.”*

*“It took me 4 months to get in and they told me I had to be over a certain level.”*

*“It was unbelievable the amount I was drinking just to get in.”*

One participant had been housed in a predominantly male treatment service which she felt was inappropriate and made her very uncomfortable. This participant felt that the service was geared towards the male majority with little consideration of how women might approach or respond to the treatment.

*“It should have been a male place — the girls were not looked after at all.”*

### **3. The importance of aftercare and support in aftercare**

All the participants at this workshop had some experience of being in treatment services and had a wealth of knowledge about what was available to them once they had completed the treatment offered. The participants were very critical about the lack of aftercare available especially in relation to housing where they felt abandoned by the services into a ‘ghetto’ that was renowned for the prevalence of drug and alcohol use. This further reinforced their feelings of being separated from and judged by the wider community as well as putting them at a greater risk of temptation and relapse.

*“They get people well and then they move them to a ghetto.”*

*“They got me a flat and said ‘you’re ok now’ but they just stuck me there.”*

The participants felt that the poor level of aftercare was indicative of how committed the services were to their prolonged recovery rather than ticking boxes and meeting targets for the number of people getting through the service. Many participants described a feeling of being abandoned.

*“Once they get you through the process — they got me a flat in Littlehampton that was renowned for drinking. There was no support.”*

Some of the participants had been informally offering outreach and support to other local people, providing a level of support, befriending and advice that many felt was not available elsewhere. This was very striking and participants pointed to these individuals as examples of the types of individuals they would like to see as practitioners within the services.

Most of the participants were keenly aware of the importance of having supportive networks around them especially in the first stages of recovery. They knew that without them they would struggle not to reach for a drink or other substance.

*“If you were sitting alone would you be able to say that you wouldn’t have a drink?”*

*“No.”*

## Identifying the main spaces and the links (Section Two)

Once the participants had grouped the post-it notes from section one, the facilitator took them through the names that the other workshops had used for their clusters. While the participants appreciated these names they felt it more appropriate to use different terms. The links between the clusters are briefly explored and illustrated below.

### Growing up / normality linked to friends and family, the high and reasons / break from reality

Participants felt that the network of circumstances in which people find themselves is one of the most difficult to break. For most participants substance use was part of growing up and considered normal in their family and friend circles. For others it was normal in their current situation especially amongst those who were homeless.

*“Street life is a killer.”*

*“Friends, brothers, family kept going ‘have you tried this?’”*

The high for most participants was a way to break from reality. The homeless participants couldn't see an alternative to substance use while they continued to be homeless; it was a way of coping with their situation, the cold and to fit in with the other homeless people.

*“It makes heat to keep me warm on the streets.”*

For some of the participants, drinking became necessary to function in everyday life.

*“I'd have to have a drink to do the housework.”*

*“It became medication to keep your head and body straight.”*

### Friends and family linked to realisation, services and treatment, aftercare

While the association between friends and family and growing up / normality was predominantly negative, the participants also discussed the more positive role that their friends and family had had in helping them to realise the need to change and to seek help.

*“If it wasn't for my mother, I wouldn't be here.”*

*“My kids were totally disgusted with me.”*

Most participants agreed that friends and family should have a greater role to play in supporting individuals through treatment and in recovery. It should be noted however, that some participants had poor relationships with their families and so they felt that this would never be an option for them personally.

### Aftercare linked to friends and family and services and treatment

As mentioned earlier, the participants were keenly aware of the importance of supportive friends and family for those in recovery. Participants felt that aftercare should not be seen as something separate to *services and treatment* but an extension of it.

*“Early recovery for a lot of people is ‘it's just for today.’”*

*“Being alone in early recovery is absolutely disastrous.”*

*“People feel like they're in limbo — not sure where you belong.”*

*“Women's choices are even more limited.”*

Participants believed that **friends and family** offered some of the best opportunities for increasing the support available in recovery and most of the participants were already supporting one another.



The following statements draw together the cluster groups from all the workshops and a description is given for each to illustrate what the groups were attempting to detail.

### **Getting Started / Getting into it**

The participants told us about how they started using drugs / alcohol, when they started and in many cases how experimentation led to problematic use.

### **The Hold**

The Hold describes the experience and feelings linked to being dependent on a drug. The participants described how it felt to be physically addicted as well as some of the effects that 'the hold' can have on the mind and body.

### **The Buzz**

The Buzz describes the experience of taking particular drugs sometimes described as a rush, the feeling they sought by taking a drug or drinking.

### **The Desire**

When the participants talked about 'the desire' they were referring to the need for the user to make the decision for themselves to get clean. The desire to get clean or sober.

### **The Scene / The Environment / Growing up — Normality**

This refers to the environment in which the individuals live, work, take drugs, drinks, as well as their general circumstances and how they impact on their drug taking behaviour.

### **The Fix / The High**

The Fix is the actual substance used by the individual.

### **Friends and Family**

The participants repeatedly referred to their friends and family throughout the discussion, in relation to their first experience of taking drugs or drinking, getting into, through and out of treatment and in relation to their drug taking behaviour.

### **Making a plan**

Day to day management of substance use can be troublesome. The participants repeatedly told us about a variety of coping strategies that they had employed to deal with a variety of issues, most of which simply rested on knowing their own boundaries.

### **Breaking the routine**

This refers to the processes needed for someone to decide to stop using drugs or alcohol and how someone might get clean, often linked to treatment.

### **Getting clean**

This refers to not using substances, to be drug and alcohol free.

### **Treatment / Services and Treatment**

This primarily focussed on the group member's experiences of existing services. Unsurprisingly, this received a large amount of attention and feedback.

### **No Light**

This referred to the end point for many, when the experiences and lifestyles had reached the lowest point and there seemed little hope. Many participants described this as the point at which people might seek help, be forced to seek help, or die.

### **Being labelled**

Many of the participants felt they were judged negatively in a variety of circumstances ranging from family, to doctors and strangers on the street. Being labelled was also talked about in terms of stigmatisation.

### **The Balancing Act**

The participants described how they coped day to day while using. This included getting more money to pay for the drug, hiding it from friends and family or employers, reducing the potential harm.

### **The Escape/ Reasons, breaking from reality**

The participants used the term 'escape' as a way of describing the reason for using substances.

### **The Baggage**

This was used to describe past experiences that may have had an influence on their using behaviours and can resurface at various points of a recovery journey.

### **Rest of my life**

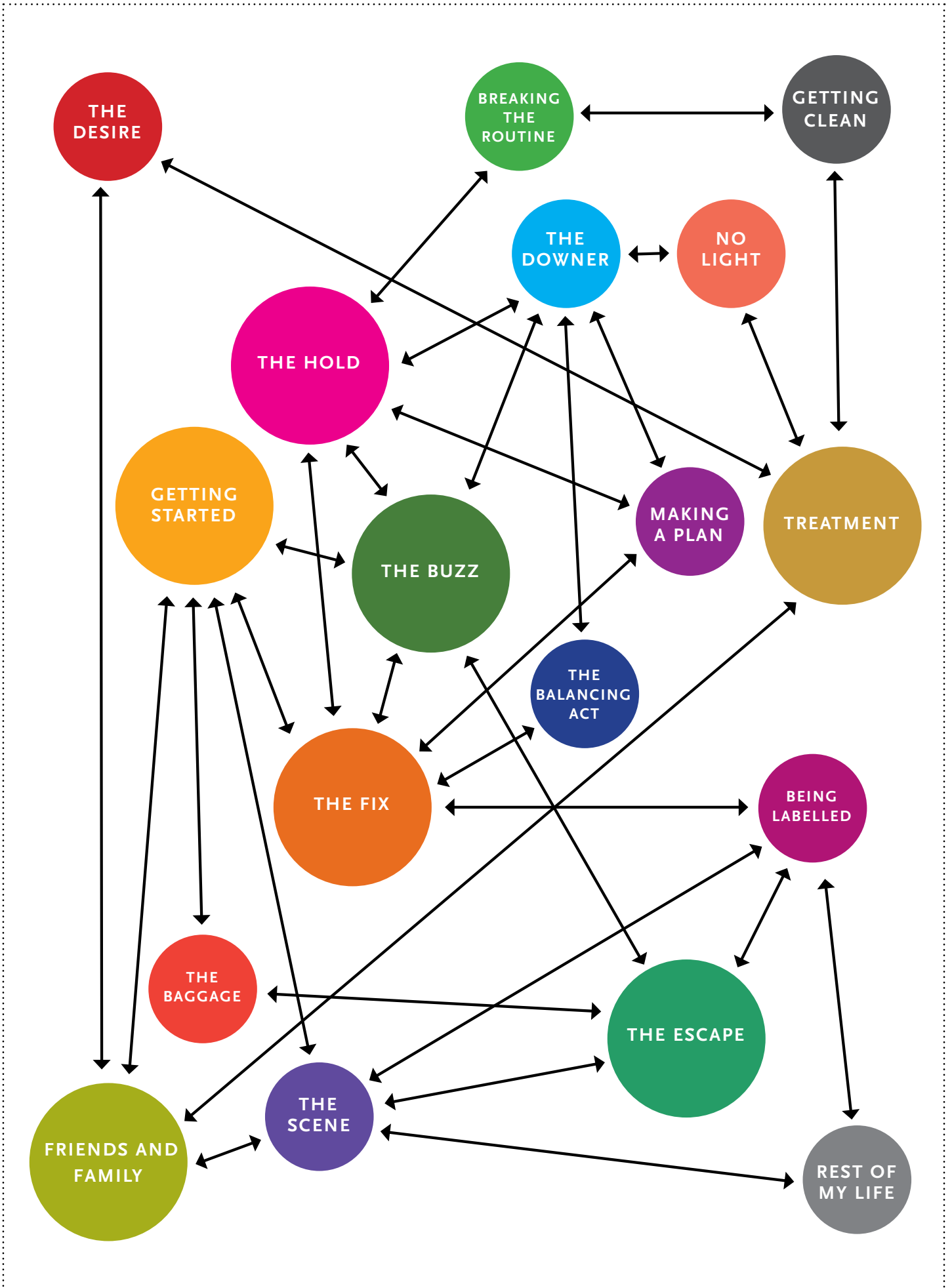
The participants were asked to think about where they would like to be in 5 years, where they saw themselves and all the factors that might impact on their future.

### **The Downer / Consequences**

This was used to describe the negative aspects of drug use, not only the feelings experienced when the drugs wore off but the associated physical effects of substance misuse.



Fig 13. The influence map



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## APPENDIX C: *Design Symposium.* *Route Maps to Recovery*

January 2010

### **Background and Methodology**

The Symposium was a full day event held at the RSA House on 18th January 2010. The event provided a forum in which to present the combined quantitative and qualitative research gained through the user survey which interviewed 152 individuals across the two sites of the project, Bognor Regis and Crawley, and from the deliberative workshops which captured the naturalistic narratives of 21 experts by experience, to a diverse group of stakeholders.

The Symposium brought together 80 delegates from a variety of disciplines including experts by experience, senior policy makers, academics, local community members, local councillors, mental health professionals, substance misuse practitioners, homelessness practitioners, RSA Fellows, and employment advisors.

### **The Symposium had two main aims:**

1. To use delegate policy/research/practice expertise to build on the existing user-generated influence map to populate it as fully as possible, to identify where current activity is situated, whether it is effective and what needs to change in order to deliver more personalised services.
2. To create, develop and present to a Dragons Den a series of innovative ideas for the *ideal* personalised route through drug and alcohol services based on the research and group discussions.

The event's programme was structured into four distinct components. Delegates were split into eight groups to work on these components throughout the day. Each group included the experts by experience that had helped to develop the influence map and ensured that the user centred approach was maintained in the discussions.

### **Enriching the systems map**

Delegates were asked to use their area of expertise to identify on the user generated influence map where current activity is situated, effective and what needs to change in order to deliver more personalised services.

### **Concept innovation groups**

Using the enriched influence map each group was asked to develop the *ideal* intervention / set of interventions / system for personalised, user-centred drug and alcohol services that they would later pitch to the Dragons Den.

### **Ritual dissent**

Ritual dissent is a method designed to test and enhance the proposal/ pitch/ innovation/ idea that was developed in the previous session by subjecting them to ritualised dissent (challenge) and assent (positive alternatives). This was a forced listening technique, not a dialogue or discourse. The basic approach involves a spokesperson/s presenting their group's ideas to a different group who receive them in silence.

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The spokesperson then turns their chair, so that their back is to the audience and listens in silence while the group either attack (dissent) or provide alternative proposals (assent). The ritualisation of not facing the audience de-personalises the process and the group setting (others will be subject to the same process) means that the attack or alternative are not personal, but supportive. Listening in silence without eye contact, increases listening.

Delegates tested their pitch with two other groups before returning to their original group to revise and strengthen their pitch.

### **Dragons Den**

Due to time constraints two Dragons Den sessions ran in parallel with four groups presenting their pitch in each. Each group chose a spokesperson to present their 3 minute pitch to the Dragons as well as to an audience which was made up of the three other groups. Following all pitches the Dragons gave their feedback and chose which idea they would invest in.

In listening to each pitch, the Dragons were asked to consider two questions:

1. To what extent is the idea personalised and geared towards what users need and want?
2. Which idea is the most powerful in supporting people in recovery?

The Dragons were drawn from a group of experts by experience and senior roles within the substance misuse field:

**William Butler**, Chief Operating Officer, Addaction

**Viv Evans OBE**, Chief Executive, Adfam

**Dr Chris Ford**, Substance Misuse Management in General Practice Clinical Lead

**Vince Peck**, Arun EXACT

**David Royce**, Chief Executive, CRI

**Pamela Spalding**, Home Office, Drug Strategy Unit

**Chris Thompson**, Horsham YMCA



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## Identifying the gaps and issues to be resolved

The eight breakout groups were asked to use the user-generated influence map as a guide and identify where the gaps in current activity or provision existed or where it might need to change to deliver more personalised services. As we expected, the gaps across all groups were similar and are briefly outlined here.

### Stigma & re-integration

**GAP:** *Lack of community engagement and of information about substance misuse, problems and services.*

Many individuals with substance misuse problems or backgrounds find themselves negatively labelled by other members of the community, employers, GP's, and staff within services and other agencies. For many this can act as a barrier to accessing treatment, completing treatment and to sustained recovery. For those who have successfully completed treatment, this stigma can act as a continuing barrier to their successful re-integration into a community.

CRB checks were highlighted as a particular barrier to those wishing to enter the substance misuse field as a volunteer or practitioner and can limit positive natural approaches from being used.

It was generally agreed that there was little done to combat this stigma and there was an immediate need to improve community engagement and improve the information available to the general public about substance misuse, services and those with substance problems.

### Tension between experts by experience and experts by profession

**GAP:** *Lack of understanding and information about personalisation and what that means to those involved; the treatment service staff and the service users.*

Traditional power relationships are being unsettled as user centred and personalised approaches become more central to the design and delivery of services. Currently experts by profession dominate the relationships within most treatment services. Services users can often feel powerless in these relationships and can be reluctant to voice their complaints, fearing that it would have repercussions on their access to treatment.

This is often a result of poor understanding of these new approaches and what they mean to the various roles within services.

### Lack of integration between services and advice

**GAP:** *Lack of joined up working across services and joined up commissioning, leading to a lack of consistency and through-care.*

The current commissioning structure can mean that services are often set up in competition to one another and this has negatively affected individuals as they try to navigate through their recovery. It can also mean that there is a distinct lack of joined up working and so individuals can fall between the gaps as they move from one service to another, eroding the motivation that many can feel in the initial stages of recovery. This is particularly apparent when an individual leaves prison; they require immediate care but services rarely collaborate to ensure these individuals are picked up on release.

This structure also means that there is often a lack of consistency in advice and care plans leading to confusion and in many cases a break down in trust.

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## Dual diagnosis

**GAP:** *There is no single service to help individuals with mental health and substance misuse problems.*

Often mental health issues and substance misuse issues go hand in hand. There is a wealth of anecdotal evidence highlighting how individuals' issues in both areas, are passed from one practitioner to another as they claim that mental health must be treated before the substance misuse or vice versa. This points to the lack of joined up services.

It was also suggested that mental health professionals often had a poor understanding of substance misuse problems and often saw the associated problems as self-inflicted.

## Lack of contact with care co-ordinators / key-workers

**GAP:** *Appointments with key-workers are too short and infrequent. Inexperienced staff.*

Most agreed that the amount of time in meetings available to speak to care co-ordinators and / or key-workers was insufficient. An hour a week did not provide adequate opportunity to treat a person 'holistically' and to meet their range of needs. It can take time to develop trusting relationships and to fully appreciate the underlying problems to substance misuse and associated life problems.

## Family & friends involvement in treatment

**GAP:** *Lack of widespread support for families and friends of substance misusers. Lack of information available for friends and family about substance misuse and services.*

It was acknowledged that involving friends and family in treatment can be complicated not least because they can sometimes be one of the main drivers in drug or alcohol use. But many felt strongly that under the right conditions families can often be an integral part to the process of recovery.

It was also acknowledged that services are geared towards treating the individual user without considering the support needed to those closest to them, the friends and family who will have been affected by the substance misuse.

The West Sussex Family & Friends Project was seen as an example of best practice in providing support and information.

## Personalised treatment

**GAP:** *Services not geared toward offering personalised treatment.*

Current services offer a prescribed menu of options and a specific route through. This can make service users feel as though they must 'jump through hoops' and have little choice in their own recovery.

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## Access & opening times

**GAP:** *Lack of immediate treatment for those in need (long wait). Lack of services outside of 9am–5pm, Monday–Friday. Lack of assertive outreach.*

Accessing services can often take far too long, from the point of asking for help to the point of receiving it. Services should be able to offer some degree of immediate treatment. Most services only offer limited opening times, usually Monday to Friday, 9am–5pm. This means that there is no support at the most critical and risky time i.e. at weekends and in the evenings.

## Treatment services

**GAP:** *Lack of aftercare. Lack of meaningful activity. Lack of assertive outreach*

At the moment services provide little in the way of meaningful activity that can help build individual's skills, confidence and self-esteem and could lead to better recovery outcomes such as employment. It was generally felt that there needed to be more pathways out of treatment rather than simply falling off the edge once a care plan had been completed.

This was closely linked to a lack of assertive outreach which could offer support to those in recovery in their own communities.

## Housing

**Gap:** *Lack of housing for those in recovery. Propensity to ghettoise those in recovery in particular areas. Lack of evidence to answer whether those in recovery should be housed together.*

Most felt that there was a lack of housing for those in recovery who might find it difficult or risky to return to their original environments. It was noted that there is some good provision but that it needs to be expanded enormously to meet the need.

## Hope is missing

**Gap:** *Lack of stories of hope and recovery.*

Experts by experience repeatedly explained how individuals with substance misuse problems need to feel and believe that things can improve and that this needs to be continually reinforced. Too much emphasis is placed on the idea of rock bottom or 'no light' which only then leads to treatment or death.

There are some good examples of this happening in parts of the UK such as the Recovery Walk in Liverpool in 2009 and in Glasgow in 2010, supported by the Recovery Academy.



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## The Pitches

The following pages are a written version of the eight 3 minute pitches made to the Dragons Den. Some pitches provide more detail in regards to operational issues such as premises and staffing, while others are more conceptual and propose an approach and way of working.

### C.L.U.B. Citizens Lifechange User Bureau

**Keywords:** EMPLOYMENT, USER-CENTRED, USER-STAFFED, BUDDY, BROKER, NETWORK, SOCIAL ENTERPRISE

C.L.U.B. would be a life changing network that is user centred and user staffed and ensures easy access to recovery pathways for all. It would provide a buddy and guidance system which ultimately aims to improve people's sustainable role in society.

It would be a social enterprise funded by new types of social bonds and so would maintain a degree of independence. A C.L.U.B. can be set up in any area by local individuals; so if you want one then you have to participate in creating it with support and guidance from appropriate structures. This follows an enterprise approach. Information about C.L.U.B would be distributed through doctor's surgeries, hospitals, treatment services and other local hotspots to promote the benefits of the Bureau.

C.L.U.B. would collaborate and act as a broker to other specialised agencies; it would not be set up to compete with them but to provide the missing core of the user centred approach throughout the whole pathway from start to finish. It would fundamentally benefit the user group through empathetic involvement in the multiple steps of recovery and paradoxically, it would actually increase the value of other existing services.

As a broker, C.L.U.B. would be a very well informed network about everything that was available and would be able to provide a variety of choices with no commitment to any one service, which would mean that individuals would maintain their links with C.L.U.B. over a long period on a voluntary basis as they liked it, not because they were caught in that particular system.

Importantly, C.L.U.B. would follow the individual through their journey and would not abandon them in the middle ground which can often happen. It would be able to provide fast-response back-up to anyone at any stage of their pathway, where through shock, surprise or an unexpected event, they need further support.

This would be sustained through the intrinsic buddy principle which acts as a kind of social relationship much like an extended family, and provides a network of people that the user would get to know through involvement in the process, that they could call on. This support would not necessarily be highly specialised and technical, but would provide somebody the user could relate to and have some confidence in. This would be similar to the AA / NA set up but would be more free choice and focussed on natural empathy rather than a strict set of rules.

Ultimately, C.L.U.B. would help to improve people's sustainable role in society for example helping them into employment. Through its network, C.L.U.B. would contribute to the general culture, reducing the stigma often attached to those with experience of something like substance misuse and can act as a barrier to employment. The organisation itself would model that as a microcosm.

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## The FORGE

**Keywords:** MULTI-AGENCY, SOCIAL ENTERPRISE, VOLUNTEERING, COMMUNITY ENGAGEMENT, 24/7, OUTREACH

The FORGE would be a multi-agency centre that offers all types of services such as drug and alcohol treatment advice, housing, mental health, education, benefits, health issues such as sexual health, needle exchange, legal advice, outreach, and most importantly, fun. This fun would be fundamental to the holistic approach and provide out of the box treatment such as art, music, laughter.

The FORGE would be a social enterprise and therefore independent, commissioned by the local authority. This service would become an increasingly indispensable service as personal budgets become more widespread.

The FORGE would be staffed primarily by experts by experience; those with experience of substance misuse. The structure of the organisation would provide a clear pathway for all through from service user to specialist leading to employment in their career of choice or into education:

**Service User** → **Volunteer** (stable current/former users) →  
**Support Staff / Peer Mentors** (former drug / alcohol users) →  
**Specialist** (abstinent, ideally former drug / alcohol users)

All services users would have the opportunity to develop their skills and training, not necessarily in the substance misuse field but they could aim to be specialists in housing or benefits advice, or any of field of their choice.

All governance, policies, and procedures would be designed and developed by experts by experience and the overall ethos, or soul of the centre, would be user led. Any specialists without personal experience of substance misuse working at the centre would work within that framework and governance structure.

The FORGE would develop relationships with all existing treatment services as well as other service providers, community groups, education centres, local institutions i.e. prisons, courts, police, probation, employment groups, social services etc.

Wider community engagement would also be essential given that the centre would be an extraordinary, open drug and alcohol service, which could bring with it problems in the community. The FORGE would seek to address these issues through an early widespread consultation process at all levels through stakeholder workshops, encouraging the wider community to feel as though they have a stake in the centre and encouraging greater understanding and a more balanced dialogue: after all, drug and alcohol problems do not exist in a vacuum.

This approach would be further complimented by a volunteering programme which would allow the centre's volunteers to choose projects within the community that would make tangible positive impacts and help to win over the hearts and minds of the wider community and start to address the stigma that most former and current substance users experience.

The FORGE would be based on the old hub and spoke model with six main centres in the six main localities of West Sussex and smaller outreach, satellite units across the rest of the county. The hours of service would extend far beyond the 9-5pm model of current provision and especially into the weekend. It would offer a 24/7 phone line and provide outreach through its peer mentors and satellite posts.

Everyone would get what they need.

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## **Whole systems approach to recovery and reintegration**

*A system to fit me, not me fitting the system*

**Keywords:** WHOLE SYSTEM, JOINT COMMISSIONING, CASE MANAGEMENT, PERSONALISED CARE PACKAGE, USER INVOLVEMENT, LOCALISM

At the moment there are informal and formal mechanisms for service user involvement and feedback. Based on this we know that service users currently enjoy some aspects of treatment but feel that other aspects need to be improved and changed. This process will formalise these mechanisms and utilise them and take advantage of them a lot more than we currently do.

This forms part of the strategic integration we propose, eliminating the silo working and separate strategies that deal with compartments of the individuals' needs i.e. housing, benefits, and alcohol. This proposal brings these strategies together so that the individual can be seen as a whole person not as their needs in isolation.

It can often be difficult for commissioners to talk to one another in the current structure but increasingly this will become crucial as the government moves towards localism where local areas make local decisions rather than simply follow broad government dictates, and within the LAA's, authorities are expected to look at what the local needs are.

Strategic integration will enable greater joint commissioning which benefit not only in economical terms but will also be beneficial for the end user. This is already happening across other areas like housing and treatment and has proven to be a much cheaper way of commissioning services and better able to cater to individual needs but has involved and relies on substantial culture change.

The ethos of personalisation is that the end user is the commissioner rather than the classic traditional commissioner and we are now shifting to a place where the end user is deciding how they are going to spend their individual budgets or their virtual budgets and we need to acknowledge that culturally.

In terms of operation, this proposal is based on a case management approach where individuals have one Keyworker who assesses their needs at every level: social needs, health needs, drug and alcohol needs, financial needs and other economic needs.

The Keyworker would act as a broker and would either physically or virtually enable the individuals to manage the system, moving away from the current system where the individual has a Keyworker at the drug treatment centre, a Keyworker at their mental health service, a social worker, someone at the benefits office, and even a hostel Keyworker. This often means that one person can have 5 different assessments, care plans or treatment plans with little co-ordination between them.

These personalised care packages would:

- Produce economic benefits as they are essentially cheaper although an initial injection of money may be needed.
- Produce a higher quality of service as they are personalised and the individual has greater involvement in choosing what they are.
- Increase retention as they are higher quality and tailored to the individuals particular needs.
- Reduce crime bringing about wider community benefits.
- Be value for money.
- Mark a culture change where the end user becomes empowered to become the commissioner rather than the authorities.



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## **IT STARTS HERE** *Recovery for all*

**Keywords:** WRAP AROUND, CO-OPERATIVE, PEER MENTORS, RECOVERY, LOCAL COMMUNITY MEMBERS

For many people services such as AA & NA meet their needs well. But for others who are less comfortable with the idea of attending these groups, there are few alternatives offered. This proposal suggests how that gap might be filled by providing a service in parallel but one that caters to diverse communities and does not rely on a commitment to a Christian recovery model.

The service would be aimed at those people who have some trepidation of going to speak to a professional in an organisation or service but could talk to people who have gone through it, who have had personal experience. The service would be the first step for many in accessing help and would be a gateway to the other specialist services they might need right up to the rest of their lives.

This new service would wrap around an existing drug agency in order to use their facilities, but offering additional services between 6am–9am and 6pm–9pm. The additional services would be peer support led with groups or workshops offered around harm minimisation, self assertiveness, sexual health, and drug awareness etc.

The service would be based on a co-operative model with a paid coordinator and management committee of peers and would seek to involve local community members in providing training sessions. The committee would be made up of people at different parts of their recovery and recovery from a range of different issues.

Once trained, the peer mentors would be able to initiate their own group so that the service could offer a range of support groups and discussions around life skills, housing, and criminal justice for example. This would allow service users to choose from a variety of groups with the possibility of shaping future groups.

The service would not stop anyone from attending groups if they relapsed or were still using substances (outside the service) as it would aim to provide a route for individuals enabling them to go through the service without any responsibility to go through the service and ‘pass’.

The service would promote recovery for everybody; encouraging service users to stay with the project and to help other people to come into treatment and address the issues they might have concerns about.

### **Complimentary, interactive and peer led service agency**

**Keywords:** PEER LED, ADVOCACY, BUDDY, EMPLOYMENT, SIGNPOSTING, EMPOWER, 24 HOUR HELPLINE

This service would be peer led, peer owned and peer controlled and would be complimentary to informing standards of other services, to care pathways and a variety of different protocols. The service would have a static base with satellite outreach in the different locations which would ensure the service remained flexible.

The service would have two main aspects: advocacy and buddying linking into the assertive outreach world of services, tier 2 open access, helping to signpost people, and supporting them into the fellowships and other options for user support.

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It would seek to meet those who are not yet engaged in treatment to those who have gone through treatment and might need continued support. It would also link into existing structured day care and other prescribing services and needle exchanges.

The hope is that the service would eventually expand its remit to include other issues such as overdose prevention, hepatitis awareness and peer education support.

The service would offer a 24 hour helpline. The buddying aspect of the service would have a particular place of value between tier 2 and tier 3 services, where issues of retention are often around having available support, having people who understand the challenges faced, and need fast responses to issues at the time that they arise. This is a period of enormous change for most so this service would offer people a relationship with a like-minded person at this very crucial point who could for example, help them think through all the available options and what it might mean to leave a service.

The service would provide signposting to different available options, provide information for those who need to make a choice, empower those involved and provide ongoing support.

This service would offer two-way benefits. Not only would it benefit the person receiving the support, the advocate or buddy would receive training, skills development, confidence building and would learn about how to develop these relationships. This would be an important stepping stone in line with the DWP policy to support long term unemployed towards employment.

Over time, the service would provide an evidence base for the effectiveness of peer led support and could support additional campaigns in the future around housing issues and homelessness.

### **Substance misuse centre**

**Keyword:** LISTENING, LOCAL OUTREACH, 24/7, HOMELESS SHELTER, PEER SUPPORT, RURAL

This service understands that substance misuse and the associated issues do not only occur between 9am–5pm, Monday–Friday, when existing services are usually open. This service offers 24 hour, 7 days a week open access; offering a personalised response to whoever should walk through the door.

The service would have a central location with local hubs across West Sussex and offer a one stop shop for information and a drop in point for anyone in need of a cup of tea, some toast or someone to listen to them. Listening would be an important element of this service ensuring that people did not feel like they were being rushed out of an office, and that they had time to talk through their issues with someone who could signpost them to specialist services if needed and to help them navigate through the processes as they try to deal with their problems.

The service would help to develop closer working relationships between experts by experience and experts by profession.

The service would seek local sponsorship and would seek to tap into funding streams aimed at promoting crime reduction and positive social outcomes. It would work closely with existing local outreach teams and would seek to build evidence about peak times to inform the need for 24/7 access or just 24/7 communication. Any transport to rural areas would be covered through advertisements.

The service would also seek to provide shelter for the homeless.

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## Outreach service in personalised recovery environments

**Keywords:** COMMUNITY, OUTREACH, RECOVERY ENVIRONMENT, ECONOMICAL

There are a number of individuals such as substance using parents, who find it difficult to access a centre based service for a variety of reasons.

We know that it is vital that individuals are in an environment that makes recovery possible for them and this service not only allows the individual to choose that environment but offers the opportunity to tap into the support within that environment as part of their treatment and work with the community and other ex-users.

By offering a community based outreach, this service would be a place where ex-service users, families, friends with similar experiences, or experts by profession, could come together in their local environment where they felt safe, and offer them a choice of a range of services that better suit their needs.

The service would be an economical option, removing on-costs associated with having a building and instead, investing in the staff ensuring that it is rooted in the community that it's trying to serve.

## Large scale personal budgets pilot

**Keywords:** PERSONAL BUDGET, INFRASTRUCTURE, USER CENTRED, ALIGNED BUDGETS, CULTURAL SHIFT

This pitch proposes a large scale pilot of personal budgets in order to bring about a shift in infrastructure, culture and environment that would better support the changes proposed in previous pitches.

The premise of this pitch is that by shifting more responsibility to the service user, the infrastructure would *have* to shift and change would flow from there, enabling a user centred approach to the creation and delivery of services and putting more choice and control into the hands of the people who use those services.

A basic minimum of service would be guaranteed to ensure those individuals who might not be in a condition to choose or did not want that responsibility, could continue to receive a core of services.

These core services and personal budgets would be drawn from a large central pot made possible by aligning budgets held in a variety of areas that touch on all the possible needs of problem drug users including housing, employment and benefits. This pooling of resources would allow the money to follow the user rather than the other way around.

These changes would allow individuals access to services when they needed them rather than facing the delays so prevalent in the current system and answers the question about who determines the appropriateness and relevance of services to the individuals seeking help.



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## Reflections

The Symposium aimed primarily to bring together a range of stakeholders from within and outside the substance misuse field to work together to design interventions, services or systems that would better meet the needs presented in the research materials i.e. the survey findings and the influence diagram.

Eighty delegates attended the event including:

- 20 former and current drug and alcohol users
- 13 Policy including Home Office, DWP, NOMS, and Department of Health
- 12 Academics, researchers and designers
- 35 Service Providers including GPs, drug and alcohol treatment services, DAATs, homeless shelters, and mental health practitioners

## Securing the user-voice

From the outset our ambition was that the voice of the expert by experience remained at the fore, and that the language used throughout the event reflected the language used by those who had informed the research to date and had been used in the events materials.

Following the event we sought feedback from delegates so that we might learn from this event. A delegate with a wealth of knowledge in the recovery field pointed out the difference between service users and service user/ recovery advocates which is often overlooked by those new to the field. The former group are often invited to events and can become despondent when they are confronted by service providers using jargon, promoting their own services and discussing the politics involved. Service User/ Recovery Advocates have usually received training or have gained experience in speaking at these events and are often more able to articulate their point with confidence and challenge the professionals/ service providers on a level playing field.

The experts by experience at the Symposium had been invited as a result of their involvement in earlier stages of the project and while they made up 25% of the delegation, once they were divided across the eight workshops, some (though only a minority) felt that their involvement was reduced to tokenism. So while we were able to ensure that the research materials placed the user voice at its heart, the groups discussions were skewed more towards those confident to voice their opinions, often the service providers and other treatment practitioners.

While the majority of feedback from the experts by experience was extremely positive, we would learn from this and in future we would plan events differently with experts by experience leading each group following in-depth training prior to the main event, and working alongside the facilitator.

## The pitches

Eight distinct pitches were successfully made to the Dragons Den at the end of the event and although they were similar in many ways, they demonstrated that interventions, services and systems can be co-designed and uphold a user centred approach.

The similarities between the pitches highlight the general consensus about the critical gaps within the existing system that need to be addressed. Most notably these include:

### OPENING HOURS

Drug use problems are not 9-5 and do not only occur Monday to Friday. Often the most risky times are evenings and weekends and yet there is little to no support available in local areas at these times.

Longer opening hours and 24 hour communication options need to be offered to ensure ongoing support and help prevent relapses during the most critical times.

### EASY AND FAST ACCESS TO TREATMENT

It can take a lot for somebody to make the decision to ask for help and yet once they do they can be met with disdain from their GPs and with long waiting times to access specialist treatment. This damages trust, erodes motivation and can make it so much harder for individuals to believe that things will get better.

Additionally, some individuals simply cannot access the services which are often in central locations. There is a distinct lack of assertive outreach that a) meets people in their local communities and b) can support them through their journey even before the point of formally asking for help.

### THE HUMAN TOUCH

Everyone wants to feel as though they matter, that they are being listened to and that somebody understands them. Service staff need to offer a more human response to those who seek help with their substance misuse problems and not simply consider them as a list of symptoms or issues that need to be treated. This means that service users need more contact with key-workers or care-co-ordinators who have a greater understanding or personal experience of all the issues involved, and means they are treated as a whole person.

### COMMUNITY ENGAGEMENT

The stigma associated with substance misuse acts as a barrier to individuals asking for help, accessing treatment, completing treatment, re-integrating into their communities, finding employment and sustaining recovery. It can act to suppress creativity in the sector and to transparent investment from a variety of sources. Problem drug use touches all parts of a community and so recovery from it must involve all parts of a community not least to ensure that those in recovery are better able to sustain their recovery and feel supported in it.

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The Dragons were impressed with the ideas presented to them offering their support particularly to C.L.U.B and The Forge in room one, and The Substance Misuse Centre and the Outreach in personalised environment in room two.

It was our hope that as most of the Dragons were drawn from senior posts within existing treatment services, they would be able to take some of the ideas back to their own organisations and inform their own thinking about how better to embed user centred approaches to the design and delivery of their services.

## Conclusion

Overall, the Symposium was a success. Eight ideas were developed, providing a test and informing our learning about how best to apply a user centred approach in the design of drug and alcohol services.

The next stage of the project will provide a test and inform our learning about how to apply this approach to the delivery of drug and alcohol services.



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## APPENDIX D: *EXACT. Ethos and Bill of Rights*

### EXACT Ethos

Exact is the new service user project for people who have been affected by drugs and alcohol in West Sussex.

By 'service user' we mean anyone who is, has, or may in the future, access drug and alcohol services. If you are in contact with one, in any way, we'd like to hear from you.

Service user involvement is basically about making sure that the voices of the people who use services have the opportunity to voice their opinions about the services they receive and the chance to make real, sustainable change to those services.

The people using drug and alcohol services in West Sussex are the experts in the services they receive. They know what works well and what doesn't, and they know what improvements need to be made.

That's why the voices of service users need to be heard and why they should be able to influence the support they receive.

That's why, if you are using a drug and alcohol service within West Sussex, you should get involved. You are the expert.



## EXACT Bill of Rights

A statement of the principle that all have the right to recover from addiction to alcohol and drugs.

1. We have the right to be viewed as capable of changing, growing and becoming positively connected with our community, no matter what we did in the past because of our addiction.
2. We have the right — as do our families and friends — to know about the many pathways to recovery, the nature of addiction and the barriers to long-term recovery — all conveyed in ways that we can understand.
3. We have the right, whether seeking recovery in the community, at a GP's, a treatment centre, or whilst in prison, to set our own goals, working with a personalised care plan that we have designed based on accurate and understandable information about our health status, including a comprehensive, holistic assessment.
4. We have the right to select services that build on our strengths, armed with full information about the experience, and the credentials of the people providing services and the effectiveness of the services and programmes from which we are seeking help.
5. We have the right to be served by organisations or health and social care providers that view recovery positively, meet the highest public health and safety standards, provide rapid access to services, treat us respectfully, understand that our motivation is related to successfully accessing our strengths and will work with us and our families to find a pathway to recovery.
6. We have the right to be considered as more than a statistic, stereotype, risk score, diagnosis, label or pathology unit — free from the social stigma that characterises us as weak or morally flawed. If we relapse and begin treatment again, we should be treated with dignity and respect that welcomes our continued efforts to achieve long-term recovery.
7. We have the right to a health and social care system that recognises the strengths and needs of people with addiction and coordinates its efforts to provide recovery-based care that honours and respects our cultural beliefs.
8. We have the right to be represented by informed policymakers who remove barriers to educational, housing and employment opportunities once we are no longer misusing alcohol and/or drugs and are on the road to recovery.
9. We have the right to respectful, non-discriminatory care from doctors and other health care providers and to receive services on the same basis as people do for any other chronic illness.
10. We have the right to treatment and recovery support in the criminal justice system and to regain our place and rights in society once we have served our sentence.
11. We have the right to speak out publicly about our recovery to let others know that long-term recovery is a reality.



## APPENDIX E : Recovery Alliance Membership (to date)

BOGNOR REGIS RECOVERY ALLIANCE	
<b>Roger Beach</b>	Locality Manager, Addaction
<b>Jane Brown</b>	Projects Manager, Drug & Alcohol Action Team, West Sussex County Council
<b>Glen Carpenter</b>	Vice Chair, Arun Exact
<b>Emma Drew</b>	Action in Rural Sussex
<b>Emma Fawell</b>	Joint Commissioning Manager, Drug & Alcohol Action Team, West Sussex County Council
<b>Vicky Fenwick</b>	Harm Reduction Programme Manager, NHS West Sussex
<b>Chris Green</b>	Project Manager, The Sands Project, Stonepillow
<b>Brian Morgan</b>	Service User Project Co-ordinator, Drug & Alcohol Action Team, West Sussex County Council
<b>Carley O'Hara</b>	Chair, Arun Exact
<b>Claire Page</b>	CRI Project Manager, Clock Walk Project
<b>Alison Rummey</b>	Commissioning Manager, Substance Misuse (Young People), West Sussex County Council
<b>Mike Sartin</b>	Client Services Manager, Stonepillow
<b>Amanda Shephard</b>	Team Leader, Impact Workability
<b>Maxine Thomas</b>	Service Manager, Impact Workability
<b>Reverend Andrew Wadsworth</b>	Vice Chairman of Trustees, Stonepillow

CRAWLEY RECOVERY ALLIANCE	
<b>Edlira Alku</b>	Advice Centre Manager, Central Sussex CAB, Crawley Advice Centre
<b>Jane Brown</b>	Projects Manager, Drug & Alcohol Action Team, West Sussex County Council
<b>Lisa Burrell</b>	CEO, The ARK Horsham
<b>Steve Byhurst</b>	Advice and Information Coordinator, West Sussex Wellbeing Initiatives
<b>Claire Cole</b>	Crawley Exact
<b>Chris Cordell</b>	Service Manager, Addaction
<b>Kate Drake</b>	CRI Services Manager, West Sussex and Hampshire
<b>Emma Drew</b>	Action in Rural Sussex
<b>Simon Martin</b>	Locality Manager, Addaction
<b>Brian Morgan</b>	Service User Project Co-ordinator, Drug & Alcohol Action Team, West Sussex County Council
<b>Malcolm Nicholas</b>	Senior Health Coordinator, Crawley Open House
<b>Amanda Shephard</b>	Team Leader, Impact Workability
<b>Sam Tearle</b>	Joint Commissioning Manager, Drug & Alcohol Action Team, West Sussex County Council
<b>Dr Geraint Thomas</b>	Director, Crawley Health Centre
<b>Geraint Thomas</b>	Labour Councillor for Northgate, Crawley Borough Council





Affluence

Growing up /  
Normality  
(Norm)

Services  
&  
treatment



