ANGLIA RUSKIN UNIVERSITY

THE PROCESS OF RECOVERY FOR PEOPLE DIAGNOSED WITH PERSONALITY DISORDER: A CASE STUDY OF THE HAVEN

HEATHER CASTILLO

A thesis submitted in partial fulfilment of the requirements of Anglia Ruskin University for the degree of Doctor of Philosophy.

Submitted: September 2010

A K N O W L E D G E M E N T S

ANGLIA RUSKIN UNIVERSITY

A B S T R A C T

FACULTY OF HEALTH AND SOCIAL CARE

**THE PROCESS OF RECOVERY FOR PEOPLE
DIAGNOSED WITH PERSONALITY DISORDER:
A CASE STUDY OF THE HAVEN
By HEATHER CASTILLO
September 2010**

The study investigates the process of recovery for people diagnosed with personality disorder. This is related to the application of the new meaning of recovery from mental illness as explored by members of The Haven which, as the service setting for the study, addresses the problems of a client group that suffers significant social exclusion, known to impact on demand for health and other public services. It aims to examine efforts which attempt to reverse this social exclusion as an aspect of the recovery process. An earlier inquiry by the author yielded a new understanding of the diagnosis of personality disorder as defined by service users, and contributed to a change in the national agenda when the Department of Health responded by providing new national guidance and funding for pilot projects throughout the country. This resulted in The Haven, the service context for this current study.

As yet, internationally, there is no agreed rationale of recovery for those diagnosed with personality disorder and few researchers have sought the views of service users regarding the issue. The following study is the first internationally known research about personality disorder and recovery. A Participatory Action Research approach was chosen for this study and The Haven Research Group, comprised of the author and Haven clients, formulated proposed research questions and conducted Focus Groups and Individual Client Interviews with 66 participants, over a period of three years. The group has been concerned with the effectiveness of The Haven as a recovery tool from the perspective of service users and carers.

An examination of emerging themes, and the interplay between themes, gives insight into what participants consider to be the key steps to recovery for someone with a personality disorder diagnosis. From this thematic analysis a map is proposed of the journey of recovery for people with the diagnosis. Findings offer contributions to knowledge in terms of the service model and propose a new construct regarding recovery in personality disorder. This is defined as a journey of small steps highlighting recovering as a process, rather than recovery as a goal, leading to the emergence of the new concept of Transitional Recovery. As an alternative to the historically sequential path of rehabilitation and proposed recovery, this study offers a new, socially inclusive way of working with people who have a personality disorder diagnosis where they may choose to retain a haven while continuing to develop and progress on their chosen path in the wider world.

Key Words: Personality Disorder; Transitional Recovery; Social Inclusion

C O N T E N T S

Human existence cannot be silent nor can it be nourished by false words,
but only by true words, with which men and women transform the world.

Paulo Freire 1970

THE CONTEXT FOR THIS STUDY

Introduction

The thesis addresses the problems of a client group which suffers significant social exclusion and which has a high impact on health and other public services (Bagge et al 2004; NIMHE 2006). It aims to examine efforts which attempt to reverse this social exclusion.

The major focal points in this study are the investigation of the process of recovery for people diagnosed with personality disorder, relating this to the principles of recovery in generic mental health services, an exploration of this process in relation to The Haven as the service setting for the study, and an examination of the collaborative process of service users as co-inquirers.

This chapter describes the motivation for the research and the subject of this thesis. In Chapter One, I will highlight the importance of the prevailing attitudes to personality disorder in the 1990s and explain how this led to an earlier study which is an integral part of the context for this current research. Attitudes and policy developments over the past two decades are related to changes in mental health law.   Service developments, stemming from the earlier study, create the setting for this research, and the service context is described.

The Local Context Regarding Personality Disorder in the 1990s

Twelve years ago, as a mental health advocate working for Mind in Colchester, in North East Essex, and based at the local psychiatric acute inpatient hospital, the advocacy office was a frequent port of call for service users with this diagnosis. The themes they brought were consistent; discharge immanent even though still suicidal; being sectioned and subject to close observation; being transferred to a secure unit; at risk of losing children via child protection procedures; ending in prison; and a whole gamut of desperate

outcomes, all contributing to a compounding of symptoms and feelings of being fundamentally and irrevocably misunderstood.

The American and European psychiatric diagnostic manuals refer to personality disorders as enduring patterns of behaviour that deviate markedly from the expectations of the individual's culture, and pervasive, inflexible deficits which are stable over time (DSM IV 1994; ICD 10 1992). This gives the service user little cause for any hope at all. It is a category about which considerable doubts have been expressed and it is a diagnosis which is often hidden from patients. Lewis and Appleby (1988) reported that untreatability was a widely held belief. In their study 'The Patients Psychiatrist Dislike', a random sample of 240 psychiatrists was assigned one of six case histories. Patients who had a previous history of personality disorder were seen as difficult, annoying, manipulative, attention seeking, in control of their suicidal urges and less deserving of care. This caused Lewis and Appleby to view the diagnosis as an enduring pejorative judgement rather than a treatable clinical diagnosis.

During the 1990s a growing number of people with the personality disorder diagnosis sought advocacy support from the service in Colchester; however, our assistance in finding solutions to their problems was largely ineffective. What became clear was that the responses they received tended to exacerbate their situation, frequently resulting in worsened behaviour. In February 1997 a service user from Cambridge published a story in The Guardian called *'A Criminal Waste of Life and Time'* (Tallis 1997). This was in fact her premise, a criminal waste of five years of her life and of the services' time. When transferred to a secure hospital she said *'It was the worst day of my life……I only knew that murderers and bad people went to places like Broadmoor. I did not realise that people labelled as self-harmers were put in such places'*. This brought about an awareness of the possibility of a national situation regarding this diagnosis, rather than it being merely a local concern.

In July 1997 a consultant in public health for North Essex Health Authority published an article in the Guardian called *'Everyone's life has a price'* (Ooi 1997). His suggestion,

that money could be saved by denying hospital admission to those with personality disorder, prompted a local service user to write from hospital in Colchester stating *'I am a victim of childhood sexual and ritual abuse. I am not yet a survivor. I don't see why I should be deprived of the care and expert counselling that I most definitely need. It was, after all, not me who carried out abuse on a minor. I am just trying to cope with the aftermath'* (Allen 1997). It is also important to note that the term psychopathic disorder, used synonymously with personality disorder, became included in legislation in the 1959 Mental Health Act, with a clause in the 1983 Act requiring that those detained must be amenable to treatment to justify detention. Problems arose regarding the question of treatability and this remained a major consideration in proposed revisions of the 1983 Mental Health Act.

The National Service Framework for Mental Health (Department of Health 1999a) heralded a new ten-year plan for improved mental health services in this country. However, personality disorder was not mentioned within the document. In July 1999 the Home Office issued policy proposals for managing dangerous people with severe personality disorder suggesting removal to special units, without deterioration in clinical state, if deemed potentially dangerous to the public (Department of Health 1999b). This seemed to cause fairly widespread fear amongst those with the diagnosis. The advocacy service began to hear from anxious service users who had at some time received the diagnosis or who had at one time assaulted another, no matter how minor the offence. Notwithstanding assurances regarding the small number proposed for indeterminate detention, and their historical dangerousness, many were not calmed. *'This is doing time for no crime'………'It's the thin end of the wedge'*. The impulse to form a local research group arose from a growing and shared sense of alienation amongst those who had attracted this label.

An Earlier Study

In 1998, I embarked on a Masters Degree and decided to focus on personality disorder as my dissertation topic. Together with local service users, I formed a research group comprised of 18 people who had attracted the diagnosis. Our aim was to carry out

research about personality disorder from service users' perspectives. The group met monthly throughout the year. Attendees were not survivors engaged in a retrospective study but were service users in the midst of their difficulties, struggling for emotional equilibrium while engaged in the research endeavour. Some were inpatients and came to the group meetings from hospital wards each month, some came even though sectioned. In a client group considered inconsistent, undependable and untreatable, the commitment from participants provided a contradictory picture.

We began our investigations with a history of the diagnosis of personality disorder, beginning over 200 years ago. An examination of the historic development of the diagnosis is described in the Literature Review Chapter, next.

The Masters study was carried out under the auspices of Anglia Ruskin University, then Anglia Polytechnic University, who provided the funding which would pay the service user research interviewers and participants for their involvement. Our research approach was emancipatory. Described by Freire (1970) as a method which challenges the validity of the privileged effectively analysing the underprivileged, here the research tools would be given to the people (Castillo 2000; Ramon et al 2001).

By December 1999 the final interview was complete and, capturing the voice of the sample, the data collected from the group and the questionnaires yielded a vast quantity of perspectives including 15,000 service user words. The study consisted of 50 participants, 20 men and 30 women, aged between 18 and 74 years. At a time when early abusive experiences were not so readily linked to present condition, the findings revealed that 88% of the sample had experienced abuse. For 80% this was childhood abuse, sexual, emotional, violent, and sometimes combinations of all three, constituting brutal life experiences. Twenty percent made the discovery that they had the diagnosis indirectly, from records, reports or at social services meetings. Others appear to have been told about the diagnosis after many years; some were told by professionals only after they had asked. Seventy-two percent of respondents considered they had received bad treatment because of the label. Confirming that the diagnosis is stigmatising, they

described their experiences in being treated as a *'service leper', 'let's give her a wide berth', 'you're ignored', 'hostility', 'not mental illness', 'brought on oneself', 'people seem to be scared of the diagnosis', 'it's saying troublemaker'.* What service users said during the interviews highlighted the sense of exclusion and hopelessness connected to finding out they had been given this diagnosis, and gave some sense of the impact this information might have on an individual labouring with the desperately hard task of living with the truth of an early abusive history.

Concurring with other studies (Widiger 1998), the earlier study also highlighted that women were more likely to receive a borderline personality disorder diagnosis and men a dissocial/antisocial personality disorder diagnosis, regardless of incidences of violence, indicating a greater likelihood of a prison disposal on the basis of gender. Data analysis questioned the validity of the classification of personality disorder and the sub-categories within it. For those involved in our study, unresolved trauma had resulted in suicide attempts of such lethality that survival seemed miraculous. Anger and hatred had become dammed up behind a narrow response function. Where early life had been sexually or violently abusive, or simply consisted of an unloving and devastating non-response from care-givers, the blunt limitations of their experience had left some stripped of control and disempowered beyond comprehension.

In a climate that emphasised issues of risk and danger, and where personality disorder was considered untreatable in many quarters, part of the purpose in carrying out our earlier study had been to engender some kind of compassion and understanding in relation to this diagnosis, as illustrated by quotes from two service users in the study, stated below.

> *Isn't it about time professionals started to find out more about the realities of personality disorder and the self-destructive torment, frustration and utmost loneliness sufferers go through. Loneliness? Yes, loneliness because we are so misunderstood, humiliated, desperate and cut-off. Why, oh why, don't and won't these professionals and health authorities accept that there is such a condition and illness? It is said that personality disorder cannot be treated. I think it can, with the help of different medications, but most of all by just sitting with us and recognising and trying to understand this condition by listening.*

It is no wonder that those of us with a personality disorder diagnosis feel like second, or more like third class citizens (life's rejects). You only have to look at the definitions given in ICD 10 and DSM IV and read comments such as 'limited capacity to express feelings - disregard for social obligations - callous unconcern for others - deviant social behaviour - inconsiderate of others - incompetence - threatening or untrustworthy'. The list is endless, but one thing that these comments have in common is that they are not helpful in any way.

Linking with the National Agenda

After a period of disseminating the results of the study through journal articles and conferences, in 2002 I was contacted by the Department of Health, who had formed an expert group to create a National Personality Disorder Strategy. They were interested in our study and how they might meaningfully incorporate the views of service users within the strategy. I was invited to attend a strategy group meeting where renowned national authorities, who had been quoted as references in the study, now sat and listened to my account of the work on personality disorder that service users had carried out in North East Essex. The strategy group decided to hold a series of focus groups and it was planned that these groups would involve service users with a personality disorder diagnosis from different parts of the country, including members of our group. Their views were to have a significant impact on national strategy (Haigh 2003). On 23rd January, 2003, new National Guidance, *Personality Disorder: No Longer a Diagnosis of Exclusion* (Department of Health 2003a) was launched. We considered ourselves to be significant stakeholders in the new guidance because we believed that our service user research work in North East Essex had a bearing on the development of the national agenda in relation to personality disorder. By this time our study had been published as a book (Castillo 2003). Within this meaningful development, concerns about funding for needed developments remained a concern. However, by the middle of the year the *Personality Disorder Capabilities Framework, Breaking the Cycle of Rejection* (Department of Health 2003b) had been created with a view to addressing national training needs regarding the diagnosis. At this time the Department of Health began to talk about investment in pilot projects for service delivery and workforce training. Our local research had given clues to better service response, ranging from being listened to, understood and feeling safe, to an out-of-hours helpline, a safe house and a crisis house.

However, at a meeting of the Personality Disorder Group in Colchester in June 2003, the local service users now began to explore, in earnest, what ingredients would comprise a service that could really meet their needs, and this is what they had to say:

We need more communication – no-one talks to you.
The response is too slow.
We don't want to be told we're not ill.
We need acceptance and staff who understand.
We need a relaxed atmosphere where we are respecting one another and we have peer support.
The day hospital isn't always the right place for us, and nor is the acute ward.
Some of us need substance abuse help and they don't understand it here.
We need help in a crisis.
We need a Crisis House and crisis support.
We need help to prevent suicide attempts.
We can feel very unsupported and need help earlier.
We need mentoring/buddying
A befriending service
One to ones
Groups can be too deep for us

We need groups when we are ready:
    Talking groups
    Writing groups
    Craft groups
    Some service user led groups

We need education:
    Positive thinking
    Coping strategies
    Anger management

We need practical help:
    Advocacy
    Benefits
    Housing
    Child protection issues
    Legal/Criminal justice support

We like the idea of alternative therapies:
    Massage
    Acupuncture
    Reflexology

Don't forget gay and lesbian support

We need the right kind of therapies to be available:
> *CBT*
> *CAT*
> *DBT*
> *Counselling and psychotherapy*

We need all services to be working together:
> *Medication if we need it*
> *CPA*
> *A strong link to statutory services*

We need a secure base where we are understood and where we can help each other, where we can get help in a crisis 24/7, and where we can get and give ongoing support.

The national proposals called for eight service pilots throughout England, one for each region of the country. Our next step was to create a multi-stakeholder group which would work to compile a pilot proposal for our area. Members of our local personality disorder group joined with representatives from other local service user groups and Colchester Mind, the local Mental Health Trust, local Primary Care Trusts, Housing Providers, the Borough Council, the Accident and Emergency Department and Essex Police.

Concurrently, a local group of professionals, commissioners and service users had been meeting to discuss the setting up of a crisis house. It had been considered that such a service would particularly meet the needs of those with this diagnosis. Some of the members of the crisis house group now joined the planning of this new service.

The Haven was chosen as a working name for the proposal. Local service users liked the title and the name stuck because it seemed to embody everything we were trying to achieve. The proposal for The Haven was created entirely around the service users' views outlined above. Our service users flanked the proposal every step of the way. This began with their presentations at the National Institute of Mental Health Eastern Development Centre, where we made it through the second round of selections.

The service user focus groups held at national level were now transformed into a National Personality Disorder Service User Reference Group, and some of our local service users joined. This Group of 'experts by experience' worked in parallel with the National Expert Personality Disorder Group to select the successful pilot projects.

Eleven service pilots were chosen, one was selected for each region of England, apart from London which had three, and Eastern Region, where two were selected, one being The Haven. The news came in February 2004 and by the middle of the year we began to create the new local service.

During the summer of 2004 I met with Shulamit Ramon, Professor of Inter-professional and Social Studies at Anglia Ruskin University, who had been my principle supervisor for the Masters study. The funding proposal for The Haven included a research budget and discussion with Professor Ramon concerned how the earlier research study about personality disorder could be continued by building research structures into the new service. The earlier study had examined the nature of the diagnosis and the way in which it was responded to by psychiatric and other services. The Haven would provide a new service context where support and treatment could now be examined.

Service Context for the Study

The Haven aspires to be a sanctuary with a sense of safety, wholeness, caring and home which is a place of refuge and protection (Bloom 1997). It is an old Rectory in Colchester with 16 rooms and within its walls the décor is warm and inviting and the artwork is largely painted by clients. Its peaceful atmosphere spreads to the boundaries of its garden. The services offered include a therapy and group programme from Monday to Friday, 24 hour crisis phone and text lines and a Safe Centre where those in crisis may come for a few hours, at any time of the day or night, on any day of the week. There are also four bedrooms, which constitute a Crisis House, where people may find respite from outside pressures for one night or up to three weeks. The Haven has published many

leaflets and reports about its service, available on its website, and The Haven Annual Report 2009 is included here as Appendix IX.

People diagnosed with personality disorder often experience high anxiety states born of chronic hyper-arousal. Therefore, such a sanctuary should provide a relaxed, de-escalating environment where a range of options are available such as companionship, information, creative and distracting activities and groups, being able to talk to staff about difficulties and safely express emotions at any time of the day or night, life skills lessons and more structured therapy. It includes complementary therapies to help soothe the kinds of anxiety symptoms experienced physically as well as mentally. It encourages humour as a form of shared intimacy, promoting laughter, and allows playfulness that may recapture a healthy sense of being a child.

By 2006, an analysis of use of the wider service area, for the first 50 Haven clients who had been with the project for one year, showed a drop in all services measured (Table 1). Notably, psychiatric hospital in-patient admissions had dropped for the first 50 clients by 85%. Although continuing to represent a burden for GPs and the A & E Department, use had still dropped by 25% and 45% respectively. The North Essex Mental Health Trust updated this chart in 2009, suggesting that the average annual reduction in the use of their services had been maintained over a four year period (Table 2).

Calculating the reduction of the use of the wider service area, in Table 1, against health and social care figures showed that the project had saved £220,000, over and above the cost of The Haven, for the first 50 clients alone. We had now registered 110 clients, and extrapolating savings to this number showed that in excess of £480,000 could be saved, over and above the cost of running the service. The cost per week, per client, for Haven services was around £100, compared to costs ranging from £223 to £1,250 per patient per week, for personality disorder day unit or hospital therapeutic community, in other parts of the country (Chiesa et al 2002).

The Haven had, therefore, fulfilled its original promise to engage the client group in our area and to prove cost savings in the wider service area. However, concerns began to be expressed about whether the project would create a new kind of dependency. Most of the 110 clients who had registered were still with us and, although many were no longer subject to hospital admission, questions were asked about whether they could move beyond stability achieved at The Haven.

Table I

THE FIRST FIFTY HAVEN CLIENTS TO COMPLETE ONE YEAR AT THE HAVEN			
Service Area/ Intervention	**Annual Average Use Over Two Years Prior to Haven***	**Annual Service Use Since Attending The Haven**	**Percentage Reduction in Use of Service/ Intervention**
Section 136	42.5 times	18 times	-57.64%
Other Sections	11 times	4 times	-63.63%
Psychiatric In-patient Admissions	55 times	8 times	-85.45%
Use of Day Hospital	32 clients	14 clients	-56.25%
Use of Community MH Team	36 clients	14 clients	-61.11%
Use of NERIL (MH Help-line)	1,264 times	317 times	-75.92%
Use of Crisis Team	187 times	42 times	-77.54%
Criminal Justice MH Team	0	0	0
Assertive Outreach	0	0	0
Trust Eating Disorder Service	56 times	14 times	-75.00%
Psychology/Psychotherapy/Counselling	30 clients	21 clients	-30.00%
Annual Use of GP	611 times	459 times	-24.87%
Annual use of A & E	141 times	77 times	-45.39%
General Hospital Admissions	47 times	37 times	-21.27%
Police/Probation/Prison	12.5 times	2 times	-84.00%
Children's Social Services	14 clients	6 clients	-57.14%
Debt Agencies	7 clients	1 client	-85.71%
Housing/Homelessness	11 clients	2 clients	-81.81%
Substance Misuse Voluntary Agency	4 clients	1 client	-75.00%
Eating Disorder Voluntary Agency	5 clients	1 client	-80.00%
Mind Advocate	39 clients	11 clients	-71.79%

∗ Column two represents a one year average of two year's use of the wider service area prior to The Haven e.g. 42.5 detentions under Section 136 mean 85 over a two year period.

Table 2

| MENTAL HEALTH TRUST ANALYSIS OF SERVICE USE 2005 TO 2009
(Data Source: Care Base   Date 22nd June 2009) | | |
Service	Two year average before Haven	Four year average after Haven
Number of Inpatient Spells	111	*
Number of Section 136's	*	*
Number of Other Sections	*	*
Number of Attendances in Day Care Services	2364	177
Number of Attendances in Outpatient Services	370	39
Number of Attendances in CMHT Services (Community MH Team)	1196	124
Number of Attendances in CRHT Services (Crisis Resolution & Home Treatment)	168	*
Number of Attendances in CJMHT Services (Criminal Justice MH Team)	*	*
Number of Attendances in AO Services (Assertive Outreach)	71	*
Number of Attendances in Substance Misuse Services	*	*
Number of Attendances in Eating Disorder/Nutritional Advisor Services	169	*
Number of Attendances Psychology/Psychological/Counselling Services	287	*
Number of Attendances in Other Services	*	*

* Any breakdown of data where the aggregated numbers are less than 30, are not reported due to Patient Confidentiality

These questions also had a bearing on capacity at the project and the need to continue to register new clients. Therefore, in response to these concerns and as a result of emerging findings of this study, The Haven developed a new way of working called Transitional Recovery and opened a Social Inclusion Unit at the service. These developments are described later in the thesis.

Not only had The Haven been created around service users' views, they would also continue to guide its development. Early abusive experiences represent a violation of boundaries and loss of power. Being party to decisions, and in control of developments, means that someone who has lost power in the past is not subject to and dependent on authority figures in order to progress.

The Haven is not just a physical setting, but a unique aspiration to create a sanctuary which is peaceful and accepting and which belongs to its service users. With its non-

institutional aura it stands outside the norm for mental health service settings and is the antithesis of what can be the bleak prospect of an NHS environment.

Policy Context and its Link to Mental Health Law

In 2009 New Horizons has emerged as the government's plan for mental health in England over the next ten years (HM Government 2009). The focus and desired outcomes of the new government plan are discussed later is this thesis. In late 1999, and during the first decade of the new millennium, The National Service Framework for Mental Health (Department of Health 1999a) was the blueprint for mental health services in the country. Unlike New Horizons, it did not made reference to personality disorder and to complex needs.

In December 1999 a unique coalition of 26 health, disability, legal, civil rights and religious organisations published a joint statement expressing common concerns over government proposals for people diagnosed with severe personality disorder. Members of this coalition included Community Health Councils, The Church of England, The Community Psychiatric Nurses Association, The Law Society, The Mental Health Foundation, The Royal College of Psychiatrists, WISH (Women in Secure Hospitals), The United Kingdom Advocacy Network, National Mind and others. Issues highlighted included the exclusion from services of people with personality disorder; that there was no clear consensus regarding diagnosis; the difficulties inherent in risk assessment; the possibility of non-offenders being detained regardless of whether it was considered they could be treated or not; the call for more research into what could best provide treatment and care for people with personality disorder, both those in the community and those detained in penal, restrictive establishments. This coalition became the Mental Health Alliance which, today, is a coalition of 75 organisations working together to secure better mental health legislation.

In the 1983 Mental Health Act personality disorder was referred to as psychopathic disorder and the treatability clause stipulated that someone so diagnosed, who presented a risk under the terms of the Act, could not be detained unless they were considered

treatable. Proposals for an amended Act began with the replacement of the term *psychopathic disorder* with *personality disorder*. This was subsequently replaced by the term *mental disorder.* This single definition of mental disorder, as 'any disorder or disability of the mind', applies throughout the Act and abolishes references to categories of disorder. The 'treatability test' is replaced by an 'appropriate medical treatment' test characterised as meaning that medical treatment appropriate to that person's mental disorder is made available to them. In July 2007, after eight years of debate and controversy, The Mental Health Act 2007 was given Royal Assent and came into force the following year. Also, in July 2007, the Mental Health Alliance published its final report (Daw et al 2007). In this report the Alliance concluded that some significant gains had been achieved by their campaign, citing one as the inclusion of medical treatment now being stipulated as something which was to alleviate or prevent worsening of the disorder, or one or more of its symptoms or manifestations. They suggested more work on the Code of Practice to ensure that this was appropriately interpreted.

Whether god or the devil is in the details, it is the details which suggest that 'small-print', or some logical thinking around the definitions above, might bring one to the conclusion that the fundamental detail here is 'what is effective treatment?' In the 1990s, as a mental health advocate, I was very concerned with the law and the Mental Health Act. Whilst continuing to acknowledge this as an important context, during the 2000s my attention turned to the issue of treatment.

As already mentioned in page 7 of this chapter, by January 2003 new National Guidance had been created, *Personality Disorder: No Longer a Diagnosis of Exclusion* (Department of Health 2003a). From this time the climate became fertile throughout the country for the development of a number of community based, and forensic, pilot projects for the treatment of personality disorder.

Conclusion and Rationale for this Study:

In the 1990s, the grounds for the earlier study sprang from the awareness that the diagnosis of personality disorder was being treated separately and differently. There was an absence of real efforts to understand the difficulties of those who had attracted the

diagnosis or to provide services that met their needs. This chapter has highlighted the fact that the prevailing climate suggested not only that personality disorder was enduring but, additionally, that it was intractable and likely to be untreatable. The chapter has also outlined the legal context for this diagnosis which, in 2007, resulted in legislation focusing on the requirement of treatability without the substance of adequately developed and researched treatments. The chapter has described the earlier inquiry (Castillo 2003) which yielded a new understanding of the diagnosis, defined by those with a personality disorder, and contributed to a change in the national agenda when the Department of Health responded in 2003 by providing new national guidance and funding for pilot projects throughout the country. This resulted in The Haven, the service context for this current study.

The Haven is a new service which has been set up with the intention of meeting needs but, to what degree does it do so and to what extent is it successful in effecting social inclusion for clients with a personality disorder diagnosis? As yet, internationally, there is no agreed rationale of recovery for those diagnosed with personality disorder and few researchers have sought the views of service users regarding this (Stalker et al 2005). Examination of the psychotherapeutic, social and material aspects of the process of recovery is needed, from the perspective of those with a diagnosis of personality disorder. This is what the current study sets out to do.

A REVIEW OF THE LITERATURE

This review of the literature highlights the prevalence of personality disorder in the national population and its impact. It examines the meaning of personality disorder, in psychiatric terms, and how this links to the concept of recovery as cure in a biomedical model of care. Psychological perspectives regarding personality development are then considered. A range of psychological treatments and their efficacy are reviewed, and the contemporary meaning of recovery is explored.

The aim of the chapter is to reveal the limited perspectives presented by psychiatric interpretations of the disorder.   The chapter will show the more fundamental understanding of causes and the development of more effective treatments in the psychological arena. Recovery as a concept is explored, not as cure, but in relation to service user perspectives regarding its definition. The chapter positions the importance of this concept in relation to the underpinning research questions, which are the focus of this study.

The Prevalence and Impact of Personality Disorder

Coid et al (2006) estimate that four percent of people in Great Britain have a personality disorder. The British Psychological Society defines personality disorder as variations in or exaggerations of normal personality attributes, which are sometimes associated with antisocial behaviour (Alwin et al 2006). Their report suggests that many people with mental health problems also have significant personality problems which reduce the effectiveness of their treatments. The British Psychological Society suggests that a higher proportion of the population than the Coid study above, ten percent, meets the criteria for a personality disorder diagnosis and that prevalence is much higher among psychiatric patients. They highlight some studies which suggest that in excess of 80% of psychiatric out-patients and between 50% and 78% adult prisoners meet the criteria.

The National Institute for Health and Clinical Excellence has issued guidelines for the treatment and management of borderline personality disorder (NICE 2009). The

Guidelines represent suicide attempts as a defining feature of the diagnosis with some studies suggesting that suicides can be as high as ten percent (Paris 2004). They also highlight the economic impact of personality disorder. Guidelines outline a significant financial cost to the healthcare system, social services and wider society and estimated the annual cost to the NHS at approximately £61.2 million, 91% of this accounted for by inpatient care (Smith et al 1995). They also estimate that people with personality disorder in contact with primary care cost an average of £3,000 per person per year (Rendu et al 2002).

What is Personality Disorder?

The history of the diagnosis of personality disorder began over two hundred years ago (Table 3), when a French psychiatrist (Pinel 1801) spoke of *'manie sans delire'*, mania without delirium. Pritchard (1835:126) formulated the term Moral Insanity, which he defined as *'a morbid perversion of the natural feelings, affections, inclination, temper, habits, moral dispositions and natural impulses'*. Negative, judgemental and deeply moralistic language developed throughout the 19th century. Maudsley wrote *'it is not our business, and it is not in our power, to explain psychologically the origins and nature of these depraved instincts, it is sufficient to establish their existence as facts of observation'* (Maudsley1884:ix). Koch (1891) introduced the term Psychopathic Inferiority and in 1905 Kraepelin was to replace 'inferiority' with 'personality'. He defined the Psychopathic Personality as falling into seven types, excitable, unstable, eccentric, liars, swindlers, anti-social and quarrelsome.

The Mental Deficiency Act (1913) added the term Moral Defective as a legislative control for detention of those considered to fall into this category. Schneider (1923) classified ten sub-categories of personality abnormalities of all types, ranging from those who caused suffering to others to those causing suffering to themselves, including markedly depressive and insecure characters. By 1939 Henderson broadened classifications to include those prone to suicide, drug and alcohol abuse, pathological lying, hypochondria, instability and sensitivity. Borderline Personality Disorder was a concept which arose in the 1950s to describe people who were considered to be on the

borderline between neurosis and psychosis. This concept evolved into a personality disorder classified in the Diagnostic and Statistical Manual of Mental Disorders (DSM I 1952).

Table 3

HISTORICAL CONTEXT		
DATE	**DESCRIPTION**	**AUTHOR/TEXT**
1801	'Manie Sans Deleire' (Mania without delirium)	Pinel
1835	Moral Insanity	Pritchard
1857	Degenerative Deviation (Moral Imbecility)	Morel
1876	The Unborn Criminal	Lombroso
1884	'No capacity for true moral feeling'	Maudsley
1891	Psychopathic Inferiority	Koch
1905	Psychopathic Personality	Kraepelin
1913	Moral Defective - Mental Deficiency Act	Mental Deficiency Act
1923	Psychopathy - 10 sub-classifications	Schneider
1939	Three groups of Psychopaths	Henderson
1941	The Mask of Sanity	Cleckley
1950s	Borderline Personality Disorder	DSM I
1959	Psychopathic Disorder	The Mental Health Act
1980s	Severe Personality Disorder	Kernberg, Tyrer
1990s	10 sub-classifications	DSM IV & ICD 10
1999	Dangerous Severe Personality Disorder	DoH & Home Office

The first legal definition of psychopathy became contained within legislation, with criteria for detention, in the 1959 Mental Health Act. In the 1980s the term Severe Personality Disorder, defined in relation to the severity of personality disturbance, began to be used (Kernberg 1984; Tyrer 1988). This started to appear in government documents as Dangerous and Severe Personality Disorder (Department of Health 1999b) and marked the beginning of action for revisions of the Mental Health Act. The concept of Dangerous and Severe Personality Disorder (DSPD) was considered to be a more extreme form of Antisocial Personality Disorder, representing a dimension of serious risk to others.

The modern concept of personality disorder is captured in the ten sub-categories of the European diagnostic manual (ICD 10 1992) and its transatlantic counterpart DSM IV 1994, shown in Table 4. Categorising a wide range of personality abnormalities, the clinical definitions range from the most timid, to the most dangerous among us. As evidenced by its history above, the diagnosis has been characterised by lack of agreement, confusion and contested scientific legitimacy. Pilgrim (1991) described the diagnosis as having maximum stigma effect and minimum scientific value.

Table 4

DIAGNOSTIC MANUAL SUB-CATEGORISATION				
ICD 10		DSM IV		
Code	Description	Code	Description	Cluster
F60.0	*Paranoid* – excessive sensitivity, suspiciousness and hostile perceptions of others' motives and behaviour, excessive self importance and reference ≥ 3 criteria	301.00	*Paranoid* – distrust and suspiciousness of others' motives / actions as deliberately demeaning, threatening or untrustworthy (≥ 4 criteria)	A. Odd Eccentric
F60.1	*Schizoid* – social and affectional withdrawal, preference for fantasy, solitary activities and introspection. Limited capacity to express feelings and experience pleasure ≥ 3 criteria	301.20	*Schizoid* – detachment from social relationships, restricted range of expression and emotions interpersonally, reduced desire for experience (≥ 4 criteria)	
F21	*Schizotypal* – (coded under schizophrenia, schizotypal and delusional disorders)	301.22	*Schizotypal* – social and interpersonal deficits, discomfort and reduced capacity for close relationships, cognitive or perceptual distortions and behavioural eccentricities (≥ 5 criteria)	

F60.2	*Dissocial* – disregard for social obligations, callous unconcern for others, low frustration tolerance, tendency to blame others, deviant social behaviour ≥ 3 criteria	301.70	*Antisocial* – disregard for and violation of rights of others since age 15, conduct disorder before age 15 (≥ 3 criteria)	B. Dramatic Emotional
F60.30	*Emotionally unstable, impulsive type* – emotional instability, poor impulse control, inability to control anger, plan ahead or think before acting, quarrelsome ≥ 3 criteria		*(Subsumed under Borderline)*	
F60.31	*Emotionally unstable, borderline type* – disturbed self image aims and preferences, chronic emptiness, intense unstable relationships, self-destructive behaviour ≥ 3 criteria	301.83	*Borderline* – unstable interpersonal relationships, self-image, affects and impulsivity (≥ 5 criteria)	
F60.4	*Histrionic* – shallow labile affect, self-dramatisation, egocentric, inconsiderate of others, continuous need for appreciation ≥ 3 criteria	301.50	*Histrionic* – Excessive emotionality and attention seeking in various contexts (≥ 5 criteria)	
	Not specifically coded for (Can be classified under other specific personality disorders [F60.8])	301.81	*Narcissistic* – grandiose fantasy or behaviour, need for admiration, lack of empathy (≥ 5 criteria)	

F60.5	*Anankastic* – doubt, perfectionism, excessive conscientiousness, caution, stubbornness, rigidity, preoccupation with details ≥ 3 criteria	301.40	*Obsessive – compulsive* – pervasive preoccupation with orderliness, perfectionism, mental and interpersonal control at expense of flexibility, openness and efficiency (≥ 5 criteria)	C. Anxious Fearful
F60.6	*Anxious (avoidant)* – persistent feelings of tension, insecurity and inferiority. Continuous yearning to be accepted and liked, hypersensitive to rejection, restricted personal attachments, social avoidance due to exaggerated risk ≥ 3 criteria	301.82	*Avoidant* – pervasive social inhibition, feelings of inadequacy, hypersensitivity to negative evaluation (≥ 4 criteria)	
F60.7	*Dependent* – a passive reliance on others for decisions, fear of abandonment, helplessness, incompetence, passive compliance ≥ 3 criteria	301.60	*Dependent* – excessive need to be taken care of, submissive and clinging behaviour, fears of separation (≥ 5 criteria)	
F60.8	Other specific personality disorders – e.g. narcissistic, incompetence, passive compliance ≥ 3 criteria	301.9	Personality disorder not otherwise specified – e.g. passive aggressive personality disorder, depressive personality disorder	
F60.9	Personality disorder unspecified			

At the conclusion of the earlier study (Castillo 2000; Castillo 2003; Ramon et al 2001) I took part in a seminar at Anglia Ruskin University where a discourse on construct validity and personality disorder took place. Here, the views of Pilgrim (2000) concurred with findings of the earlier study. He suggested that causes are contested because there is an absence of etiological specificity. Meanings become circular. For example, someone self-harms, or displays antisocial behaviour therefore they have a personality disorder.

Because someone has a personality disorder they self-harm or display dissocial behaviour. The diagnosis is an elastic concept which may include a wide range of people and encompass a variety of presentations. DSM IV and ICD 10 definitions suggest that those with personality disorder may display certain behaviours or embody certain character traits, however, these definitions do not say why.

The next major revision of the American diagnostic manual will be DSM V. It will not appear until 2012, eighteen years after DSM IV was published. In 2000, DSM IV TR became available as a revision of DSM IV. Within it the diagnostic criteria remains largely unchanged and major amendments are confined to the descriptive text (Sperry 2003). The terminology reflects more recent developments in treatments for personality disorder and attempts to move away from the notion of untreatability. Sperry (2003) also suggests that DSM V, when it is published, is likely to make major changes regarding diagnostic criteria for Axis II disorders, and to offer a dimensional approach to the current categorical model of diagnosis for personality disorder. Difficulties in fitting people into distinctly separate clinical syndromes, and the tendency for overlapping symtomatology has, in more recent years, prompted a preference for classification of personality disorder into three clusters (Table 5) suggesting that the sub-categories may be unwieldy (Fahy 2003). Either method describes surface manifestations and fails, fundamentally, to capture the experiences of the sufferer.

Table 5

	CLUSTER CLASSIFICATION OF PERSONALITY DISORDERS
Cluster A	Personality disorders marked by odd, eccentric behaviour, including *paranoid*, *schizoid* and *schizotypal* personality disorders.
Cluster B	Personality disorders defined by dramatic, emotional behaviour, including *histrionic*, *narcissistic*, *antisocial* and *borderline* personality disorders.
Cluster C	Personality disorders characterized by anxious, fearful behaviour and include *obsessive-compulsive*, *avoidant* and *dependent* personality disorders.

Because of the current unreliability of the diagnosis, making it difficult to translate into practice, some choose to see personality disorder as a unitary syndrome (Adshed and Jacob 2009).

It is true that contested validity might, to some degree, be applied to other psychiatric diagnoses, but the classification of personality disorder, in particular, still suggests that the condition can be negatively enduring. If it were to become demedicalised, individuals could become ignored or criminalised by failing to receive any kind of support and help. However, in a medical setting what is that help likely to be?

The Medical Model and the Concept of Cure

The biomedical model of illness and health care understands concepts such as illness, remission and relapse. In psychiatry the conferring of a diagnosis has the potential to affect those concepts, instilling beliefs about the notion of cure. The psychiatric diagnostic manuals have suggested that, although most patients with schizophrenia will improve with treatment, relatively few recover to such an extent that they are back to normal. As highlighted in Chapter One, they refer to personality disorders as enduring patterns of behaviour and pervasive, inflexible deficits that are stable over time (DSM IV 1994; ICD 10 1992). Medical treatments have relied on intermittent hospitalisation and the prescribing of medication. For many with a personality disorder diagnosis being treated in primary and secondary health services, medication for depression and anxiety is very commonly prescribed and this may be the only input an individual receives. The medical model of mental illness is essentially pessimistic and offers little hope to service users. This is the case for a range of mental health problems, but particularly for personality disorder, where enduring problems are central to the diagnosis and it has traditionally been seen as untreatable, as discussed in the first chapter.

However, in relation to major mental illness, literature from 1987 to 2003 identifies a number of long-term outcome studies which show upwards of 50% recovery rates, or significant improvement over 20 year periods. Harding et al (1987) suggest recovery levels of two thirds of the people with major mental illness, such as schizophrenia, followed up over more than 30 years. In relation to personality disorder specifically, some treatments show good evidence of improved outcome. A meta-analysis of therapeutic communities, internationally, shows strong evidence for effectiveness across all 29 studies selected (Lees et al 1999). Perry et al (1999) conducted a meta-analysis of

psychotherapy, drawing on literature from 1974 to 1998. Fifteen studies were selected and the analysis concluded that psychotherapy is an effective treatment for personality disorders and may bring about progress seven times faster than no treatment. Literature reflects further successful treatments for personality disorder at therapeutic communities and other specialist treatments as described below.

Psychological Perspectives and Treatments

Although personality disorder has dubious diagnostic validity within psychiatry, it does have a living meaning within services. It also has a different meaning within the field of psychology, where discourses between personality development and personality theory have been more closely linked. The value and benefits of a psychological approach, in relation to understanding and treating personality disorder, are described below.

Bowlby (1988), in relation to attachment theory and the concept of a secure base, describes how an individual tries to maintain proximity to another clearly identified person who is perceived as being able to cope better with the world and is expected to give care, comfort and security. This encourages us to value and continue relationships. Bowlby recognised that this attachment behaviour is emphasised in childhood but also continues throughout life. A child or adult who has attachment to someone is strongly disposed to stay near and seek contact with that individual, especially in times of threat and emergency. He observed that increased risk also carries a signal; for example, threats to abandon a child as a means of control, or parental threat of suicide. He suggested that this might also result in increased arousal, not just in terms of fear, but also intense anger, especially in older children or adolescents.

The dialectical theory of self-development assumes that a sense of self develops through the perception of oneself in another person's mind. An infant builds up a viable sense of self from the repeated internalisation of the mother's processed image of the child's thoughts and feelings. This provides containment. Not only does the mother, or close caregiver, interpret the baby's physical expressions, she also gives back to the child a manageable interpretation of what is being communicated. Fonagy (1997) suggests that

an absence, or distortion, of this early mirroring experience can lead to a desperate search on the part of the child to find alternative ways of containing psychological experience. This may develop into destructive physical expression, either towards self or others. A child who has not received recognised, but modified, images of behaviour and emotional states may have trouble in differentiating reality from fantasy, and physical from psychic reality. This suggests a tendency, in later life, to cope with thoughts and feelings through physical action. Not being able to feel oneself from within, that individual is forced to find a sense of self from outside, by treating themselves as an object, or by getting others to react to them. This results in experience of self in a more authentic, if very limited, way and the need for re-enactment to augment the incomplete representation of self which has been achieved.

Herman and Van der Kolk (1987), in their work with incest victims and Vietnam veterans, discovered that trauma, especially prolonged trauma from caregivers, had a profound effect on personality development and the development of personality disorder. They concurred with Fonagy that behaviour manifestations of self-mutilation, re-victimisation, victimising others, dissociative disorders, substance abuse and eating disorders, are an effort to try to regain internal equilibrium. Van der Kolk (1996:3) has characterised this condition as *'the black hole of trauma'* and has described post traumatic stress as a failure of time to heal all wounds. For some, there is an inability to integrate the traumatic experience. He pointed out that there is a very complex interrelationship between traumas, neglect, environmental chaos and attachment patterns, and that clinicians fail to pay attention to the effects of early trauma, or to perceive the patterns of reliving, warding-off reminders or repetitive re-exposure to situations reminiscent of trauma.

In more recent years, psychological perspectives have given rise to a range of specialist treatments for personality disorder, involving both group work and individual therapy. Bateman and Tyrer (2004), in their examination of psychological treatments for personality disorder, concluded that there was encouraging evidence that some patients

were treatable, but that there was inadequate evidence to make specific recommendations for any particular therapy. A review of a range of therapies follows.

DBT:

Dialectical Behaviour Therapy (DBT) is a behaviour therapy, developed in the USA, for the treatment of borderline personality disorder (Linehan 1993). When someone begins DBT there is an expectation that they will be committed to this therapy for at least a year. The programme consists of a weekly two hour skills group and one-to-one therapy. The group aims to work together to achieve a life worth living. Dialectics involves finding the common ground between apparent opposites. In DBT this involves trying to balance positions that could be seen as contradictory, that is, accepting people as they are, but also supporting them in change. The balance between acceptance and change is a central theme in DBT. Accepting people involves understanding that severe and enduring trauma has caused emotional vulnerability and a high sensitivity to life stresses. DBT involves a technique called mindfulness, as well as other strategies which help the individual to learn to better tolerate distress and bear pain. The focus in DBT is on 'in the moment' skills, rather than dwelling on past trauma. It consists of four modules; *Mindfulness,* which is a meditation approach that involves what, in DBT terms, is called taking hold of one's mind, meaning taking control of one's mind; *Interpersonal Effectiveness Skills,* which involve relationship skills, balancing priorities, 'shoulds' and 'wants' and self-concepts in relation to respect and competence; *Emotion Regulation,* involving learning to understand emotions, reducing vulnerability to them, and decreasing emotional suffering; and *Distress Tolerance Skills,* involving distracting, self-soothing and improving the moment. The first DBT randomized control trial compared DBT to treatment as usual (Linehan et al 1991) and reported a drop in parasuicides and psychiatric inpatient stays, and better social adjustment. Feigenbaum (2007) highlights an emerging evidence base for the effectiveness of DBT revealed in four randomized controlled trials, again showing a reduction in parasuicidal behaviour, use of hospital bed days, in anger, and improvements in social functioning.

CAT:

Cognitive Analytic Therapy (CAT) is an integrative approach, used in the treatment of borderline personality disorder, utilising cognitive behaviour and psychodynamic therapy (Ryle 1997). Here the therapeutic value of the psychodynamic concepts of transference and counter-transference are recognised. The internalisation of depriving and abusive caregivers results in a narrow or distorted range of what Ryle calls reciprocal roles. Examples of pair sets might include *Abuser/Abused*, *Neglecting/Deprived*, *Controlling/Rebellious* or *Rejected/Rejecting*. CAT therapists establish which aspect of the personality is maintaining dissociation and which particular contrasting self-state, or reciprocal role, the client uses to respond. Initial mapping of self-states is carried out collaboratively between therapist and client. The number of sessions may extend from 16 to 24 and a good outcome would be the internalisation of the therapeutic relationship, enabling the client thereafter to become their own therapist. Denman (2001) highlighted that there was a growing, but still far from adequate, evidence base for the effectiveness of CAT. She suggested that there is a lack of randomized controlled trials validating CAT and that supporters of RCT methodology tend to be less convinced by uncontrolled trials. Kerr (2006) highlights the educational effect of the CAT model on professionals and teams which was found to improve their containment of splitting and anxiety about clients. The therapeutic alliance was also found to reduce readmission rates during the course of therapy. The focus of this CAT study, therefore, differed in that it highlighted the systemic implications of working with personality disorder,

Schema Therapy:

Schema Therapy (Young et al 2003) combines elements of cognitive behavioural, emotion focused, attachment and psychodynamic approaches. Its aim is to help clients get their core needs met in an adaptive manner by working with early maladaptive schemas, developed in childhood, when core needs were not met. Three schema driven coping styles are proposed; *schema surrender,* such as feeling and acting inadequate; *schema avoidance,* by suppressing feelings and avoiding situations which might evoke them; *schema overcompensation,* by striving or overworking in an attempt to counteract feelings of inadequacy. Young et al believe that many people with personality disorder

have schemas which make traditional Cognitive Behaviour Therapy (CBT) approaches unsuitable. Existing schemas might include self-sacrifice or approval seeking, feelings of abandonment and mistrust or shame, and an underdeveloped sense of self coupled with an unawareness of emotions and cognitions. This suggests that the addressing of such schemas should be the first step in therapy. Schema Therapy is the newest therapy for borderline personality disorder which, like DBT and CAT, combines elements of other psychotherapies and approaches. It was found to be highly effective in the first randomized controlled trial (Moran 2007). This randomized trial compared Schema Therapy with transference-focused therapy. Forty-six percent of Schema Therapy patients made significant progress compared to 26% percent of those engaged in transference focused therapy. They also showed greater increases in quality of life.

Mentalization:

Mentalization therapy techniques (Allen et al 2006) have been developed, for the treatment of borderline personality disorder, which address the capacity to interpret the actions of ourselves and others on the basis of our own internal mental state. The capacity to interpret is developed in relation to our attachment experiences in early life. Acknowledging the fundamental vulnerability of someone with personality disorder, the model is based on Bowlby's attachment theory, proposing that disrupted attachment relationships will result in a reduced capacity to mentalize. Fonagy and Bateman (2008) suggest that, during therapy, the vulnerability of clients means that they can easily be thrown into 'pretend mode'. They alert therapists to the importance of helping clients not to become over identified by taking on the therapist's perspective, as if it where part of themselves, but rather to focus on mental functions. This concerns addressing concreteness of thought and facilitating alternative perspectives. Fonagy and Bateman also highlight the disruptive tendency to create unacceptable experiences with others by externalising the abuser. Such projective identification can create emotionally unbearable conditions for a client. This needs to be addressed by a joint understanding of the therapist/client relationship that avoids over identification and supports the client in learning to process roles and experiences. In a study carried out by Bateman and Fonagy (2008), 41 patients were engaged in a trial which compared mentalization-based

treatment with treatment as usual. Findings showed that patients with 18 months of treatment, including partial hospitalisation followed by mentalization-based group therapy, remained better than those receiving treatment as usual, but that general social functioning remained impaired. Follow up after five years showed that improvement in symptomatology was maintained.

Gans and Grohol (2010) cite the above therapies, Dialectical Behaviour Therapy (DBT), Transference-Focused Therapy, Schema-Focused Therapy, and Mentalization-Focused Therapy as adapted psychotherapies which all address the underlying deficits in the ability of patients to manage emotions and relate to others, and which are proving successful for those who have long standing problems stemming from childhood experiences. They suggest that recent trials do not show a consensus about whether any of these approaches proves most effective but note that DBT is the most widely taught.

Stepps:

The Stepps Group Programme (Systems Training for Emotional Predictability and Problem Solving: Black et al 2004) combines Cognitive Behaviour Therapy (CBT) and Schema Therapy approaches and is considered to be adjunctive to other therapy someone is currently receiving. Here two group leaders are CBT trained, a one-to-one reinforcer is available and a reinforcement team exists. The group programme consists of 20 day sessions of two hours each, homework between sessions, one-to-one reinforcement from clinicians and an evening reinforcement team which can consist of family, carers and friends. The programme includes a redefinition of borderline personality disorder to Emotional Intensity Disorder; management strategies such as distraction and relaxation techniques; cognitive strategies which challenge unhelpful schemas; and behavioural strategies concerning problem solving, abuse avoidance, lifestyle issues and goal setting. Members of the group have to be ready for therapy in terms of meeting certain criteria. They must be able to tolerate groups, have motivation, recognise there is a problem, be relatively un-chaotic and be free of severe problems that may interfere, such as substance misuse. The programme originated in the USA (Blum et al 2008) and has proven success for 53 clients in the six areas of Sussex where the programme has been established, with

a further 25 still progressing in groups. On six month follow-up in Sussex success was shown in dealing with the effects of trauma and in self-development, with a reduction in hospital bed usage and positive feedback from clinicians and service users (Harvey 2009).

Therapeutic Communities:

The Therapeutic Community model is a whole service model rather than a specific treatment. It involves a group of clients, sometimes referred to as residents, who have considerable involvement in running the community. There is recognition that service users are sometimes better able to assist each other than health professionals. The ability to flatten the hierarchy, by delegating decision-making, is still combined with firm leadership while residents assume autonomy and responsibility for their own behaviour. Therapeutic communities are not just based on responsibility but also citizenship and empowerment (Campling 2001). Some therapeutic communities work only with psychodynamic groups while others include individual psychotherapy. All encourage the interest of members in learning about themselves and others, developing a culture of enquiry which constitutes a living, learning environment. Differing in structure from each other, therapeutic communities have a unifying philosophy that community can be used to contain its members while undergoing therapy. Haigh (1999) explains the five universal qualities which constitute a therapeutic environment; *Attachment,* a culture of belonging; *Containment,* a culture of safety; *Communication,* a culture of openness; *Involvement,* a culture of participation and citizenship; and *Agency,* a culture of empowerment. Campling and Haigh (1999) extol the values of the therapeutic community model as a method of moving away from social control towards the development of therapeutic relationships and open minded thinking.

Menzies et al (1993) highlighted the economic importance of providing effective services for a client group that often consumes considerable amounts of psychiatric, social, probation and prison services in an unproductive way. Follow-up studies for 24 patients at the Henderson Hospital therapeutic community showed a saving of £12,700 per person, per year, meaning the cost of specialist treatment could be recouped in less than

two years. The international review of studies about therapeutic communities, carried out by Lees et al (1999), included 181 therapeutic communities in 38 countries. One hundred and thirteen of these therapeutic communities involved outcome studies, 52 of which were controlled and ten of which were randomized controlled trails. Twenty-nine acceptable studies emerged from a rigorous sifting process and strong evidence for effectiveness was shown across all 29 studies. Findings highlighted the effectiveness of the therapeutic community model in the treatment of personality disorder, particularly severe personality disorder. Haigh and Lees (2008) examine the growing fusion of therapeutic communities which encompass more people with addiction issues. They describe this as a blend of the historical development of therapeutic communities in Britain for those with personality disorder and the American model arising from groups working with alcohol and drug problems. Whilst embodying many traditional therapeutic community principles, the fusion is characterised as offering more innovation, providing specific groups and therapeutic interventions, encompassing a recovery ethos and a willingness to respond to a call for evidence of effectiveness.

The various approaches described above suggest that, contrary to the psychiatric model, recovery may be possible. The National Institute for Health and Clinical Excellence, in addition to the new guidelines for borderline personality disorder (NICE 2009), has also issued guidelines for antisocial personality disorder (NICE 2010). The guidelines for antisocial personality disorder suggest that the evidence base for successful psychological treatments is limited (Duggan et al 2007) and that much more emphasis has been placed on psychological interventions for borderline personality disorder. Many treatments are mentioned in the borderline personality disorder guidelines, ranging from complimentary and arts therapies to psychodynamic approaches, and they include all therapies mentioned above. Although the guidelines make brief mention that people with the diagnosis should be involved in planning personality disorder services, and that autonomy, choice, optimism and trust should be fostered, there is little more in the document that suggests a recovery ethos.

The Haven, as one of the National Community-based Personality Disorder Projects, provides a service that encompasses some of the psychological approaches discussed above. During the course of our study, the National Evaluation for the 11 community-based personality disorder services took place (Crawford 2007; Price et al 2009). The evaluation spanned only the first two years the pilots were in operation. In the evaluation there was some agreement regarding the principles that should underpin service delivery, such as consistency, boundaries and open communication. Similarly there was consensus about some key aspects of service delivery such as the provision of psychological and social support, providing opportunities for peer support, the fact that services needed to provide long term interventions and that dedicated personality disorder services were welcomed. However, the evaluation showed a lack of consensus on important issues such as outreach, the role of medication, and the fact that only the two user led projects, out of the 11 pilots, were providing out-of-hours crisis services. Although it was acknowledged that the pilot services had achieved a great deal in a short timescale, with expressions of satisfaction from service users, conclusions of the evaluation called for further evidence. I believe the National Evaluation was only able to provide a snap shot of activities in the limited timescale for their study and was not able to focus on outcomes or the concept of recovery.

What is Recovery?

Nehls (2000) suggests that, although some advances have been made, psychological approaches developed in treating personality disorder are not consistent with the concept of recovery as a vision constructed by the client, and that a new vision of treatment, based on recovery, will require a fundamental shift in control from professionals to the person who is recovering. Therefore, it has been important in this study to examine the underpinning values, in the field of mental health, in relation to the possibility of recovery, and to identify the important factors in recovery for those diagnosed with personality disorder.

A History of Recovery:

Roberts and Wolfson (2006) place the origins of recovery-oriented care, in this country, in the 18th Century when William Tuke, a Quaker, developed a spiritual and family-like retreat in York. Here physical restraint was replaced by moral, psychological and work-oriented treatments in a safe and peaceful environment. In the 19th Century, John Percival wrote 'A Patient's Account of his Psychosis, 1830 to 1832', known as Percival's Narrative:

In the year 1830, I was unfortunately deprived of the use of reason ...The Almighty allowed my mind to become a ruin under sickness – delusions of a religious nature, and treatment contrary to nature. My soul survived that ruin (Percival 1961:3).

This autobiographical account of mistreatment, and what actually helped, became an important forerunner of personal accounts about what is meaningful to recovery. This was followed, in more recent times, by the writings of people in the USA and UK. In the late 1980s a former service user with a diagnosis of schizophrenia first began to write about recovery as a new vision in mental health, encompassing hope and the challenge of living (Deegan 1988). In 1988, Judi Chamberlin wrote about her experiences in a landmark book called 'On Our Own'. She made a compelling case for patient controlled services as an important alternative to public and private hospitals, which she believed had destroyed the confidence of so many. Other hope-inspiring accounts followed (Coleman 1999; Leete 1989; Reeves 1999; Unzicker 1989) accumulating a foundation of personal experiences relating to a recovery approach. These accounts concerned coping with symptoms, not being defined by illness, and regaining a satisfactory sense of personal identity.

Professional Rhetoric and International Developments:

By the late 1990's, The National Institute for Mental Health in England (NIMHE) introduced the concept of Mental Health Recovery as a central tenet of government policy and established the post of NIMHE Fellow for Recovery in 2000. In January 2005 NIMHE published a *Guiding Statement on Mental Health Recovery* which characterised recovery as the practice of values and the 'how' of service delivery and put service users

at the heart of mental health recovery. Slade et al (2008) consider that this policy consensus became mirrored in professional rhetoric. In this country the concept of recovery was adopted by clinical psychology (British Psychological Society Division of Clinical Psychology 2000), mental health nursing (Department of Health 2006), occupational therapy (College of Occupational Therapists 2006) and psychiatry (Care Services Improvement Partnership, Royal College of Psychiatrists, and Social Care Institute for Excellence 2007). In the USA the term was adopted by the most internationally influential body in psychiatry (American Psychiatric Association 2005).

Ohio and other U.S. States developed system performance indicators in relation to recovery (Brower 2003; Hogan 2001; Onken 2004; Roth et al 2000). Ohio eight-year longitudinal studies have shown that high concentration of service input has not necessarily lessened symptoms, and that consumers consider themselves disempowered within the system. Therefore, core values of the Ohio initiative are that the concept of recovery should drive service provision and that, together, providers with consumers and their families should share responsibility for generating hope and determining services and supports. Outcome measures have balanced issues of access, quality and satisfaction with the practicalities of cost. Onken's study, based at Columbia University, New York, spanned nine U.S. States. One of the primary findings of this study, considered integral to the process of recovery, was that mental health services must recognise and allow for self agency while supporting such efforts, and that the individual should be seen as a whole person beyond labelled identity. In 2000, concepts and policies related to recovery increased significantly in Australia (Slade et al 2008). Australia was not just influenced by recovery literature from the USA and Canada but also from New Zealand which, in 1998, became the first country to adopt a recovery ethos in mental health.

However, concurrent with this new vision the existing psychiatric context still prevails, including diagnosis, prescribing and hospitalisation. Hospitals may save lives, but Topor (2004) believes that the recovery context is simply not there in psychiatry and that the essence of the personal is destroyed within it. Topor relates a story about a secure ward outside Stockholm. After pressure from the psychology department agreement was

reached that the ward should be left unlocked. Somewhat to his disappointment no-one absconded for several weeks. One patient on the ward was a young Swedish girl who had been subject to both schizophrenia and personality disorder diagnoses at different times. Her demeanour was slow and lifeless but one day she looked up and smiled at him and made a dash for the door. He describes running and running through the streets of the village trying to catch up with her. She jumped into a train and he followed. When he reached her carriage he sat down and they began to engage in conversation and he discovered they had a mutual passion for art. They spent several hours in the city, looking through art galleries and at exhibitions, stopping for coffee to discuss what they had seen. Eventually he asked her if she thought they should return to the ward and she agreed, yes, it was okay to return now. Once back on the ward she returned to her slow and downcast demeanour. He tried to explain to staff how very changed she had been in a different context. However, the staff remained disbelieving.

Conversely, one approach in this country, with proven success for in-patient settings, is the Tidal Model (Barker and Buchanan-Barker 2005). This approach emerged as one of genuine collaboration between service users and mental health nurses. The model embraces the concept of recovery as something which can begin to be addressed when someone is at their lowest ebb or most distressed. It focuses on the continuous, inherent process of change and seeks to support individuals in finding the meaning in their experiences by valuing the importance of each individual's voice and story. It emphasises that personal language should be respected rather than silenced or colonised through the power of diagnostic categories. In their evaluation of the use of this model in acute in-patient wards in Birmingham and Newcastle, Gordon et al (2005) found a decrease of in-patient stays, decreases in violent and untoward incidents and a drop in self-harm, over a follow-up period of one year.

Recovery-oriented approaches in this country also include developments in the county of Devon. In 2003, the Wellness Recovery Action Plan, WRAP, developed by service users in the USA (Copeland 2001), was introduced to Devon. At its first small meeting in Exeter this recovery initiative became a group of peers where people were seen as just

people, rather than professionals or service users. The group was eventually launched as Recovery Devon and, since 2007, a top-down commitment, to this bottom-up development, has resulted in the values and practical application of recovery principles being aspired to by commissioners and managers throughout mental health services in Devon. These values include a redefinition of what recovery means to those with severe mental health problems and open the possibility of recovery to all (Roberts and Wolfson 2004).

A user-led initiative in this country, for people with bi-polar disorder, is the Recovery In-Sight Service, a new social enterprise, which offers training, self-help and peer support, research, and advisory services on practice and service development in the area of recovery. The team comprises mental health service users, and people who care for service users, who have lived experience of mental health issues and believe they are aware of what is needed to recover and to offer appropriate quality services to those who are in recovery (Straughan 2006). The Recovery In-Sight Centre was chosen by the Hertfordshire Federation of Small Businesses Awards 2010 as the best new business.

Such initiatives described above exist against a backdrop of less recovery-oriented services and this has caused McGowan (2010) to question the concept of the 'expert by experience' as an NHS myth. He suggests that this is often of little or no use, resulting in tokenistic service user involvement, inviting fragmented and non-productive contributions, rather than fundamental involvement.

Defining Recovery:

Ramon et al (2007) highlight that psychiatric services combine aspects of care and control, whereas recovery oriented services shift responsibility to the individual service user. They suggest that governments who are preoccupied with risk management and reducing public funding may cause services users to fear that, if they are not 'recovering', services will no longer be available to them. Recovery as a clinical concept, measured in out-come studies as an approximation of cure, may be considered an imposition upon people struggling with serious and painful conditions as an unrealistic expectation and a

burden to get well. Wallcraft (2005) considers that concerns, fears and objections to recovery will best be overcome by ensuring that it is a philosophy for life that becomes owned and defined by service users and survivors, and that this ownership must be respected by politicians, planners and service providers.

The word recovery has a range of meanings, suggesting that conceptual clarity is necessary. Slade et al (2008) identify two classes of meanings. First is the traditional concept of recovery as cure. This locates the concept within an illness framework. Second is the personal definition of recovery, which has emerged from service user narratives. These accounts emphasise the understanding of recovery as something other than the absence of mental illness. Anthony (1993:16) proposes that the process of recovery can still take place in the presence of symptoms and disability, and defines recovery as …

…a deeply personal, unique process of changing one's attitudes, values, feelings, goals, skills and roles. It is a way of living a satisfying, hopeful, and contributing life even with limitations caused by illness. Recovery involves the development of new meaning and purpose in one's life as one grows beyond the catastrophic effects of mental illness.

Repper and Perkins (2003) suggest that recovery is not necessarily cure and is not about getting rid of all problems but rather looking for the individual beyond problems and illness. Recovery may be a matter of finding abilities, possibilities, interests and dreams. It requires hope and opportunity. It is about building a future and recovering social roles and relationships that give meaning and value to life. Repper and Perkins see recovery as a process rather than a goal. Therefore recovery might best be defined as The Journey of Recovery.

There may be a risk in conceiving of recovery as a simple act of faith. However, recovery cannot be achieved without faith and hope (Roberts and Wolfson 2004). There is an assumption, in recovery oriented care, that professionals and clients will pursue client-oriented goals together, but decisions about what services are delivered are usually controlled by providers. Roberts and Wolfson suggest that, in contrast with a patient struggling for cure, recovery depends much more on collaboration than on treatment.

However, the skills, knowledge and commitment that professionals can bring to the recovery process, while valuing and learning from the client, are stressed. They emphasise the need to develop research methods that will incorporate subjective accounts of recovery, from service users, in order to better inform professionals and suggest that professionals will find little guidance about what might help recovery from a randomized controlled trial.

A Summary of the Literature and the Focus of this Research

This chapter has shown the national prevalence of the diagnosis of personality disorder and its costliness. It has highlighted the lack of scientific validity the diagnosis holds and how this has mitigated against helpful responses for those who have received it.

The chapter has also discussed what recovery means and how the essence of the personal can be destroyed within psychiatric services because the recovery context, as defined by service users, has rarely existed within it. It has been shown that recovery is a unique journey, personal to the individual who has embarked on it. Even if successful treatments are developed and introduced to a service, this chapter has questioned the degree to which this encompasses a new vision of treatment, based on recovery, and constructed by service users. It is service users who have suggested that recovery can still take place in the presence of symptoms. The chapter has highlighted that, in this thesis, recovery is not defined as cure, which suggests outside agency, it has been interpreted as learning to understand and manage difficulties better and learning to take control of one's life and to change one's own destiny, making life more satisfying.

The following chapter outlines the research questions developed from an understanding that there was a need to define recovery for people with personality disorder in personal terms and a need to discover and define the factors that are important in the journey of recovery for service users at The Haven. The research methods which have been used to find the answers to these questions are also described, as is the participatory nature of the study which has incorporated the shift in control necessary to discover what is important to those who are recovering.

M E T H O D O L O G Y

Introduction

This research sets out to explore and understand, from the service user perspective, the process of recovery for people diagnosed with personality disorder, using The Haven as a case study. The aim of the study is to find answers to the following questions:

- How do those with a personality disorder diagnosis define recovery?
- What factors are important in taking control over one's life for those diagnosed with personality disorder?
- Does The Haven, as a project, contribute to this process, and if so how?

This chapter describes, debates and justifies the methodological approach to the research and its methods and design. This involves an examination of underpinning values and a discussion and selection from research paradigms, which has led to making decisions at a methodological level that encompass ontological and epistemological concerns.

Research Paradigms

There is interconnectedness between ontology, the nature of reality and being; epistemology, the theory of knowledge and the relationship between the enquirer and knowledge; and methodology, the way in which we come to know the world (Oliver 2004). Following, is a consideration of the positivist and anti-positivist paradigms as potential approaches to gaining knowledge.

Positivism has a long and complex history, with overlapping elements. This makes it challenging not to oversimplify the concept (Kolakowski 1995). It is the dominant paradigm and is, therefore, worthy of discussion and consideration in the study of knowledge. Essentially positivism defines what deserves the name of knowledge. Its central tenets include the phenomenalist view that, in the pursuit of scientific awareness, we should record only directly observed phenomena, and that opinions are untrustworthy (Kolakowski 1995). The rule of nominalism considers that abstract concepts do not

constitute knowledge. This rejects abstract reasoning and considers value judgements to be part of a metaphysical domain beyond the concrete realism of the visible world.

In the history of ideas, during the 14th and 15th centuries the spiritual forces that constituted a medieval world view began to wane and a paradigmic shift occurred away from religion and mysticism towards realism and material cause and effect. Two main traditions began to contribute to the evolution of scientific thought, namely Aristotelian and Galilean which suggested that knowledge could be measurable, subject to deductive processes, predictable and understandable in a finalistic way (von Wright 1995). Unity of scientific method for acquiring knowledge was considered to exist in all spheres of experience, including both the laws of nature and of human nature (Kolakowski 1995; Popper 1980).

Positivism has subsequently contributed to great developments in science and technology, and this philosophy of human inquiry and knowledge held sway throughout the 19th and 20th centuries, and maintains a dominant influence in the sciences today.

Anti-positivistic ideas began to gain prominence at the end of the 19th century. Here, thinkers rejected the methodological monism of positivism as the single ideal for the rational understanding of reality (Hammersley 1989). The philosophy of hermeneutics began to be concerned with human behaviour rather than with physical phenomena, and ascribed potential meaning to the phenomena (Rowan and Reason 1981). Human beings were considered to have self-determinism and the ability to give meaning to their experience. The philosophy of hermeneutics opened the door to an interpretive approach, with an emphasis upon description and the representation of reality through the eyes of participants. It is concerned with emerging concepts rather than immutable facts. It focuses on exploration of meanings of experience and their interpretation. It is developmental rather than finalistic.

The German historian-philosopher Droysden (1858) said that the aim of the natural sciences is to explain, while the aim of history is to understand. Empathic understanding

is a way of defining experience, which includes contexts, aims, purposes and deeper significances and meanings. Therefore, hermeneutics is concerned with reality viewed through the eyes of participants in relation to meaning, behaviour and context in its full complexity, capturing the uniqueness of human existence (Henwood and Pidgeon 1994).

Gray (2004) suggests that the theory of hermeneutics considers social reality too complex to be understood through the process of observation and that the researcher needs to interpret in order to reach deeper levels of knowledge. Interpretive, phenomenological analysis is a process of double hermeneutics, where the researcher tries to make sense of the participant making sense of their world (Smith 2003).

A positivistic approach has been rejected as a suitable philosophical standpoint from which to effectively conduct this research. It is my opinion that the topic of this study requires a consideration of the subjective and inter-subjective meaning, given by service users, carers and professionals, to recovery as playing a central part in enabling or disabling recovery from personality disorder. In the humanities there are alternatives to positivism which have a less reductionist approach to human consciousness. A non-positivistic, hermeneutic philosophical approach to this study has been selected as a way to explore, holistically, reality through the eyes of participants, encompassing context and empathic understanding, and interpreting the deeper meanings in their lives.

The Participative Dimension

Freire (1970) first posed that the study of a problematic or oppressive reality should not be carried out by experts but by those experiencing the oppression.

It is only the oppressed who, by freeing themselves, can free their oppressors. The latter, as an oppressive class, can free neither others nor themselves. It is therefore essential that the oppressed wage the struggle to resolve the contradiction in which they are caught. (Freire 1970:10)

This process of mutual learning is achieved through a creative dialogue between researcher and participant, or co-researchers. What Freire describes as dialogics

necessitates both reflection and action in radical interaction which seeks meaning and change.

Human existence cannot be silent nor can it be nourished by false words, but only by true words, with which men and women transform the world. To exist humanly is to name the world, to change it. Once named, the world in its turn reappears to the namers as a problem and requires of them a new naming. Human beings are not built in silence, but in word, in work, in action-reflection. (Freire 1970:34)

Participatory Action Research (PAR) is a way of carrying out research which is designed and carried out by all participants, including the initiating researcher. It focuses on concerns highlighted by the reflections of those involved (Winter and Munn-Giddings 2001). Stanton (1989) highlights the fact that most research serves those in power, such as governments or managers. Gorman (1999) considers that researching those who comprise stigmatised groups is a form of oppression. Therefore, a core issue in PAR is empowerment and its goal is democratic as well as collaborative. It challenges inequality and establishes the right of people to actively participate in processes that affect their lives. Oliver (1996) also emphasises empowerment and reciprocity as fundamental to an emancipatory research approach. Some researchers advocate that, wherever possible, service users should become researchers, with control over the selection of issues to be researched, data collection, analysis and dissemination (Evans and Fisher 1999).

The link between research and action is seen as a characteristic feature of a PAR approach. Investigation, reflection, learning, and taking action are considered by some researchers as an interrelated whole, rather than separate or distinct from each other (Payne 2003; Stanton 1989; Winter and Munn-Giddings 2001). Aymer (2001) similarly describes the cycle of action and reflection as the participatory encounter and the moment of realisation, or changed consciousness. Although such a cycle may help to make sense of one's life, and to transform perspectives on past experiences and influence action in future situations, I believe the action in the PAR cycle can be made explicit. Action research occurs in repetitive cycles of planning, action, observation, reflection and revised planning (Kemmis and Taggart 1988). Plans and the action stemming from them

carried out in a concrete way in the world, complete the cyclical process described in a PAR approach. Habermas examined the idea of communicative space as a boundary crisis between systems and the world (Wicks and Reason 2009). Action research can support the creation of communication networks that open a discourse in communicative space which strengthens collective empowerment, not just in terms of understanding the world but also in changing it.

Reason (1995) describes a new paradigm in action research which represents Co-operative Experiential Inquiry. As in the PAR approach, he characterises this as a way of carrying out research where all those involved in the inquiry contribute to the creative thinking that shapes the research, the methods selected, the data collection and the task of making sense of the information found. The distinction between researcher and participant is less defined and all who participate in the co-operative inquiry become co-researchers who simultaneously create a co-existence of types of consciousness. Participatory action research and co-operative inquiry can be viewed as closely related, collaborative approaches to inquiry. Both concern carrying out research 'with' people rather than 'on' people. Reason (1994) distinguishes the difference between PAR and co-operative inquiry as follows:

The PAR strategy of developing knowledge through empowering dialogue initially between animator and a community of people appears to be most appropriate when the inquiry involves a relatively large number of people who are initially disempowered. PAR also draws our attention to the political issues concerning ownership of knowledge and the need to create communities of people who are capable of continuing the PAR process………Co-operative Inquiry is a strategy more likely to be successful with a group of people who experience themselves as relatively empowered and who wish to explore and develop their practice together. (Reason 1994:335)

Heron and Reason (1997) make claims for PAR as a paradigm. Characterising the concept of a paradigm as a worldview, they suggest the need for a shift to a participatory worldview in response to the legacy of ecological problems and human alienation currently experienced by man as a co-inhabitant of our planet. Kuhn (1972) observes that scientific research travels through settled periods of accepted scientific norms punctuated

by turbulent times, when competing paradigms may emerge, resulting in the embracing of a new paradigm. Heron and Reason claim that a participatory worldview allows us to see that we are part of the whole and places us back into relationship with the living world.

A participatory action research approach has been selected for this study because this recasts the roles of researcher and participant. It provides a vehicle where both the initiating researcher and all those participating can come to see the problem in a radically different way, which may give rise to innovative action for change. In this study there are a relatively large number of co-inquirers who have a variety of roles and different power in relation to the endeavour. Most are members of a stigmatised group who have attracted a diagnosis of personality disorder and they are not likely to see themselves as the kind of relatively empowered practitioners who would benefit from a co-operative inquiry approach. Participants are all involved in some way in the cyclical spiraling process of change which begins with dialogue about the problem, collectively generated solutions for change, putting those changes into action, and reflections and evaluations of those changes from which lessons can be learned and more changes generated. Therefore, it has been important to capture the cycles of reflection and development that have arisen from the research and how the participants have seen themselves in relation to this dialogic and participatory action research process.

Methods

In this section quantitative, qualitative and mixed-methods approaches to conducting the research are examined and considered.

Quantitative Approach

Essentially numerical and objectively observable, quantitative research is concerned with frequency, averages and percentages, and can be analysed by statistical methods (Fuller and Petch 1995). Central to answering questions and hypotheses is the examination of relationships between and among variables. The quantitative approach excludes rich veins of knowledge, understanding and potential for change (Bannister et al 1994).

Rowan and Reason (1981) criticise this method as lacking in social context, alienating and disempowering, detached and dehumanising. However, because quantitative data is in a numerical form it can be more easily presented graphically, and can be used to compare tendencies in populations and between groups.

Quantitative approaches espouse many of the principles of positivism, which the researcher has already rejected as a theoretical paradigm for the study. Foucault (1972) suggests that this method has reduced things to single systems of differences. Such scientific approaches are a major contributor to the descriptions of personality disorder in the Diagnostic and Statistical Manual of Mental Disorders, DSM IV, and its European counterpart, ICD 10, which focus on surface manifestations and fundamentally fail to capture the experience of the sufferer. However, in a study such as this, which is rich in subjective experience, the statistics provided by quantitative approaches should not be ruled out as they may strengthen the research data by describing the context and outcomes in numerical terms.

Qualitative Approach

This approach is interpretive study of a particular issue or problem (Parker 1994). Qualitative research is part of a debate rather than a fixed truth. It is an attempt to capture the reality that lies within and is linguistically based, often using verbal data, which highlights depth and meaning rather than reducing it to numerical scores. It involves building rapport and credibility with participants and the employment of methods that are humanistic and interactive.

The qualitative approach begins with participants' views, which are then interpreted by the researcher and can encompass interaction and a complexity of perspectives. This research has based its design on qualitative methods for data collection. The approach was chosen because I believed it would provide the most effective method for collecting data which can be described and interpreted, and it has accommodated the emancipatory style of participatory action research.

Mixed Methods

Robson (1997) suggests that taking a multi-methods approach, involving the collection of both qualitative and quantitative data is likely to antagonise both sides of the ideological divide. However, Henwood and Pidgeon (1994) believe that the study of psychological and social realities is rarely followed up by the exclusive use of either method and that qualitative and quantitative methods should not be viewed simplistically, as stemming from contradictory paradigms. This would deny the possibility of strengthening and enriching research by principled use of a blend of methods. Creswell (2003) advocates pragmatism about what will produce the best understanding of a problem. This allows researchers the freedom to select from both quantitative and qualitative approaches to choose techniques that best fit the needs and progress of a study, as long as there is a unifying rationale or framework.

A mixed methods approach is relatively new in social and humanistic research and its evolution in psychology can be identified when Campbell and Fiske (1959) used multiple methods to study the validity of psychological traits. Mixed methods were also employed by using a triangulation of different quantitative and qualitative data sources (Jick 1979) and further refinements regarding reasons and procedures for mixing methods emerged (Tashakkori and Teddlie 1998).

Such an approach might employ both survey-type questions and open-ended questions. Here the inner world of participants is explored while the numerical data from the survey might serve to profile the sample. This type of hybrid approach requires that researchers are familiar with both qualitative and quantitative approaches and are very clear about how they are being used in the study.

I engaged in the use of a triangulation of qualitative and quantitative research methods for data collection in the earlier study described in the Context Chapter (Castillo 2003). Using mixed methods enriched what was essentially a qualitative study, contextualising results with descriptive statistics. It also aided in profiling the sample into helpful dimensions, augmenting knowledge of the issue. However, this current research is not a

mixed methods study. It is a qualitative, rather than a mixed methods study, because it seeks to map the process of recovery in personality disorder by a fundamental exploration of participants' experiences and reality. The use of quantitative background data collected by The Haven for its funders, the Department of Health, has been used in the study simply to enhance and describe the context in numerical terms.

Research Design and Methods of Data Collection

An examination of philosophical paradigms has resulted in a theoretical approach which is interpretive, hermeneutic, participatory and emancipatory. Qualitative methods, employing a participatory action research approach, were selected for the study. This section aims to describe the vehicles used in a participatory action research endeavour. It will show how the study has relied on the participation of *Experts by Experience* in the form of a large number of people with a personality disorder diagnosis, and a smaller number of carers and family members who are involved in the day to day living of some of our clients.

The methods of data collection included focus groups and individual interviews which are described below. The methods of data collection and analysis are also represented in a Timeline in Appendix I. Before looking at these methods the function and actions of the Research Group are explained.

The Research Group

The Research Group was a prime mover in this process. The group was formed in June 2004 and met until September 2009. Appendix II is a Research Group Diary, which constitutes a précis of the minutes of 35 Research Group meetings occurring during that time. I was a member of the Research Group and, with the group's agreement, and encouragement, part of my role in the process was to carry out work to compile this thesis. The Research Diary reveals the participatory nature of the study in detail. The group essentially consisted of ten core members, me and nine Haven clients.

The intention to create a group was made known to clients by advertising with posters and mailings. The membership of the group was by self-selection. During the early stages of the group The Haven had just opened and the first eight clients had been registered at the service. The initial concern of members, at the first meeting of the group, was that *recovery* was not a term they would have chosen. They set out to define recovery in their own terms. Recovery implies returning to a previous state of being, whereas members were seeking to create a new future, the future they wanted, and maybe to become reborn, not to go back to all that was wrong in the first place (Research Diary p2). Our concept of the length of the study was modest at the outset. We aimed to look at if, how and why The Haven was successful over its first two years and we expected to apply for ethical permission to conduct the research within a few short months. At the first meeting members also began to look at the sorts of questions the research should ask, and what the nature and quality of the support at the service should be (Research Diary p3).

By October 2004 the service had registered 50 clients. It was now decided that ethical permission for the study and formal data collection were some way off and the idea of Service Evaluation Groups (SEGs) was agreed. The service evaluation groups were planned as forums where participants could, as a group, become familiar with the process of responding to research questions. This would give us the opportunity to begin to collect more informal data, in addition to other background data and minutes. It would also allow us to pilot potential research questions (Research Diary p5). The construction of research questions remained a major focus at the group and the first questions were agreed at the December meeting (Research Diary p6).

By January 2005 a stable membership of the group had formed and the date for the first service evaluation group (SEG) was set for February 2005, just days after we were due to move to our permanent premises and open all parts of the service (Research Diary p6). A wider selection of clients was invited to the first SEG by posters and mailings. With the permission of attendees, it was agreed that the SEGs should be taped to enable full transcripts of what was said to be made available. At the Research Group meeting in

March 2005, members felt that the SEG had been a great success, with constructive criticism and a highlighting of improvements to be implemented. The honesty and laughter were appreciated and it was agreed that SEGs should be held every three months until formal data collection began. At the March meeting it was also agreed that question four was repetitive in relation to question five, which asked about coping strategies. The original question four asked: 'Are you learning new skills which are helping you to understand and cope better?' and it was agreed to amend this to: 'Are you learning any new skills that are helping you to understand yourself better?' (Research Diary p7). Supervisors had also suggested that participants should have pseudonyms, enabling us to distinguish between respondents and to see development over time (Research Diary p7). This necessitated re-listening to the first SEG tape and inserting chosen pseudonyms into the transcript. From this time statements at all research events were preceded by the participant stating their pseudonym.

At the April meeting of the Research Group, after a discussion about barriers to recovery, the group decided to add a question about whether or not recovery is frightening (Research Diary p7-8). Thirteen clients attended the second SEG in May 2005 and, at the July Research Group meeting it was agreed that questions for future SEGs should remain the same because this would provide a consistent yardstick. However, one more change was suggested and agreed. This was the addition of a final question about what else The Haven could do to support people in their recovery (Research Diary p8). From this time SEG questions remained as they are shown in Appendix III. Until ethical permission for the study was requested and granted, and formal data collection was begun, four more SEGs were held until May 2006. This was a total of six SEGs taking place at three-monthly intervals. The Research Group also considered that, after completion of the focus groups (described below), the SEGs should resume at regular intervals and two more were held before the end of the study, in August and November 2007.

Research supervisors considered that the facilitation of focus groups, and the conducting of individual interviews (described below), should be carried out by a service user participant rather than by me, because I was also Chief Executive at The Haven. Reasons

for this decision are discussed further in the Ethical Issues section of this chapter. Therefore, the Research Group was tasked with selecting one of its members to be the service user researcher, who would facilitate focus groups and carry out individual interviews, in the more formal phase of data collection. This highlighted a possible dilemma in that more than one service user may have wanted to take up this role. The group may not have reached agreement about who should do this and may have wished to select someone that they felt comfortable with but about whom I had reservations, in terms of intellectual grasp and ability to draw out themes. One member wished to take up the role and, fortunately, we all felt she met the various necessary criteria. She had previous research experience, was educated and warm, and the unanimous decision of the group suggested that she was someone to be trusted both academically and emotionally (Research Diary p11-12).

The group was essentially concerned with the effectiveness of The Haven as a recovery tool from the perspective of service users and carers. Members aspired to embrace a critical consciousness regarding their condition and progress by entering into a creative dialogue with each other. This began to create a network of understanding in the Research Group, amongst SEG attendees and within The Haven community as a whole where transcripts were made widely available with attendees' permission. Each person seemed to see their involvement in a different way ranging from the disinterested, the interested on-looker, the keen participant in the service evaluation process and focus groups, to a committed co-researcher with major involvement in the collaborative process of mapping the journey of recovery in personality disorder. Each client was free to participate in the way that they wished.

Data Collection Methods
<u>*Client Focus Groups*</u> can be used as a form of group discussion in dialogical research which reveals, both to the researcher and the participants, hidden aspects of problematic life experiences (Padilla 1993). Elaboration of identity, negotiation of realities and collective methods of meaning-making are constructed within social contexts and in an empowering way (Wilkinson 1999). Zeller (1993) considers that a major risk in this

method is that participants may respond, within the pressure of a group situation, in ways that lack fidelity to their actual experiences and opinions. The research agenda and questions can achieve a mitigation of such risks by repetitively addressing themes from different perspectives. Problems can also arise in relation to one or more respondents dominating the discussion. Boundaries and guidelines, made clearly known to participants from the outset, and the facilitator's vigilance in addressing such issues during discussion, are likely to minimise such occurrences. It is also important to note that Focus Groups, as a method of data collection, are often carried out with people who do not know each other. However, at The Haven over time trust had developed between many participants and this also mitigated some of the difficulties a focus group might otherwise present.

The intention of the Research Group was to use the SEG questions in Appendix III as focus group questions. However, research supervisors suggested refinements regarding wording and sequence. At the Research Group meeting in April 2006, members felt it was important to retain current questions but to be open to small adjustments (Research Diary p11). At the June meeting members agreed the final draft of focus group questions compiled from the suggestions of academic supervisors. A more logical order was achieved, questions were less leading and opportunities had been added to explore the impact of The Haven as a therapeutic community. This agreement regarding amendments came with the exception of question six which concerned disliking oneself less. Suggested revision was about liking oneself more. The group considered that the double-negative phrasing of the original question was more conducive to eliciting valid answers from people with personality disorder (Research Diary p13). With me acting as go-between this process represented an interesting dialogue between client participants, who conceived of the questions, and academic supervisors, who added their research expertise for final question formulation. The Research Group's refusal to change question six represented their empowered position regarding what they felt was right and the fact that this was their research. This became question seven in the client focus group questions, which now became finalised and are included as Appendix IV.

Focus groups seemed a natural progression from the service evaluation groups (SEGs), which had yielded so much information in the previous year and a quarter. The focus group method also proved to be a dynamic form of data collection where one participant's thoughts and ideas might spark and elicit responses from others. Here the sharing and understanding arising from the interpersonal dialogue and dynamics reflects an important aspect of the PAR approach. Maintaining a three-monthly rhythm, the timetable (Appendix I) reflects a seamless change from the last service evaluation group in May 2006, to the first Client Focus Group in August 2006. Four client focus groups were held, at three-monthly intervals, the fourth taking place in May 2007. Each focus group was one and a half hours long and clients were invited by advertising, with posters and mailings, and attendance was by self-selection. The same client facilitator, selected by the research group, attended each focus group, as did I in the capacity of an observer. I believe the group felt differently about my attendance as an observer, rather than a facilitator. Participants felt able to disagree and be critical, despite my presence, as shown in the findings. The focus groups were similar in flavour to the SEGs, with use of pseudonyms and transcribed tapes, but attendance was limited to a maximum of 12 in order to ensure significant time and space for all participants.

Some continuity of attendance for participants was maintained at focus groups to aid mapping of experiences and progress over time. Participants came for a variety of reasons ranging from curiosity to the sense of empowerment achieved in articulating views and listening to the views of others. Because some attended all or most focus groups, this provided an opportunity to reflect on progress over time. Those who had also attended the SEGs provided additional mapping over a two and three-quarter year period.

Individual Client Interviews were not a method originally considered for data collection. This method proposed separating interactions from others because the dialogue would occur between interviewer and individual interviewee. This did not seem consistent with the paradigm which had been adopted for the study. The Research Group, the SEGs, focus groups and other groups at The Haven invited a multitude of interpersonal

dynamics to occur. Participatory and collaborative research begins and ends in shared activities and understanding, captured in the dialogue of groups, as the main method of revealing all participants to themselves (Padilla 1993). However, one supervisor suggested that individual interviews with some participants might provide additional dimensions of data possibly more easily disclosed in a private setting. Winter and Munn-Giddings (2001) suggest that one-to-one interviewing may cause difficulties in trying to avoid leading the dialogue, especially if the interviewer is of a higher status. However, in this study a participant researcher carried out the interviews. Whittaker (2009) compares the effective use of focus groups for accessing shared public knowledge, compared to the fruitful setting of individual interviews for highlighting more personal and biographical data. He also suggests that interviews can be used, in conjunction with focus groups, to access sensitive information that might not arise in a group setting. Denzin (2009) proposes that research is a social act through which the actors construct data. Here the interpretive process means that people, whether collectively or singly, define the situations and events they encounter. Creswell (2003) also suggests that individual questionnaires or interviews can be legitimate in a PAR approach to generate information that could not be ascertained in another way. This was considered by the Research Group and it was decided that it would be an additional, valuable dimension of data collection which should be encompassed (Research Diary p11). Some clients found attendance at an individual interview easier than responding in a group situation and this provided additional participants that would not otherwise have been included.

The Research Group constructed a Client Interview Questionnaire that contained an interview schedule which mirrored the client focus group questions. Because it was considered that there would be more time and space during individual interviews, an additional question about comparison with other services was added. Two questions about The Haven as a community were also added, one of which was also included in the focus group questions. It was agreed that the wording and the sequence of the interview schedule would be consistent with the changes suggested by supervisors for the client focus group questions. Preceding the interview schedule were a series of tick box

questions which would help to profile the sample. The client interview questionnaire is shown as Appendix V.

It was anticipated that interviews were likely to be approximately one hour long, which proved to be the case, and it was decided that they should be taped and transcribed. Twenty interviews were considered to be the number we should conduct in relation to other data collection occurring in the study. It is not always appreciated that vast amounts of data can be produced from qualitative studies (Pope et al 2000). We were aware that SEGs (service evaluation groups) each produced in excess of 30 pages of transcripts and it was anticipated that focus groups would give a similar yield. Individual interviews might generate 20 to 30 pages each and interviewing more than 20 participants individually was likely to bring the study beyond saturation point. It was judged that 20 would encompass a range of clients from the service and they were conducted between August 2006 and July 2007. Some participants attended focus groups as well as individual interviews and results reflect whether different dimensions of information arose in an alternative setting. Other participants for interviews were suggested by the Research Group (Research Diary p14). Some of the clients suggested by the group had found it more difficult to participate in SEGs and in focus group activities and readily agreed to be interviewed on an individual basis, because they considered it would be a more palatable setting in which to disclose sensitive information.

Carer Focus Groups were also planned during the course of data collection. The involvement of carers and family members was discussed during the study at the Research Group meeting in January 2006 (Research Diary p10). Supervisors also considered that carers and family members were logical partners in this inquiry because of their close association with the day to day living of clients. It was decided that two carer focus groups would be held and the Research Group drafted their ideas for the questionnaire (Research Diary p10). Proposed interview questions were circulated to eight carers and concerns were expressed by them about question four: 'Do you experience personal difficulties regarding the person you support?' (Research Diary p12)

The Research Group reworded the question to make it less personalised and research supervisors made further suggestions about the wording: 'Research shows that carers often experience difficulties in caring. Do you think this statement is correct and, if so, in what way do you think the role affects carers?' (Research Diary p13) This resulted in a more generalised question about the burden of the caring role, which was acceptable to potential participants. The carer focus group questions are shown as Appendix VI.

It was important to reflect on the burden of personality disorder from a relative or carer's perspective, and if and how The Haven impacted on this. An examination of carers' perspectives about recovery were also considered as a point of comparison with service users' views, and to ascertain to what degree hope was present. The carer focus groups invited up to ten participants by mailings via all Haven clients and attendance was by self-selection, with prior agreement of the client concerned. Carer focus groups were one and half hours long, and were also taped and transcribed. Someone who was a carer for a Haven client was selected as facilitator for the carer focus groups. This choice was approved by the Research Group and again it was suggested that this person met both empathic and intellectual criteria (Research Diary p13). She facilitated both carer focus groups, which were held in March and August 2007 and I also attended as an observer. Again, my role of observer did not appear to inhibit participants in relation to their willingness to disagree or express criticisms.

Numerical and Other Informal Data was also collected. Since its inception, a broad range of numerical data has been recorded and statistically presented at The Haven, for all clients. This data was collected for monitoring purposes for the Department of Health and local Commissioners, and had also been required as part of the National Evaluation of the 11 Personality Disorder Pilot Projects. At The Haven this data encompassed 166 clients by the end of the study and included number registered, gender, age, ethnicity, reason for referral, and outcomes about the use of the wider service area before and after registering at The Haven. Some of this information has been used as background data to enrich the study by augmenting the analysis of themes numerically.

All service users at The Haven are invited to participate in the user-led Haven Community Advisory Group Meetings and Community Discussions. Here the dialogue is augmented and continues on a day to day, month to month basis. All meetings are minuted and relevant contents have also been used as background data to illustrate themes.

The data streams described above represent a rich amount of information which was analysed, in consultation with the Research Group, to construct a mapping of the recovery journey in personality disorder.

Sampling

In quantitative research sample size is used to strengthen the claims made for the generalisability of results (Parker 1994). The sample size should be as statistically representative as possible in relation to the general population. Matched groups may be compared to examine variables in, for example, age, location, social class, socio economic status, or treatment models (Edwards and Talbot 1994). Objective selection of participants is considered to be best achieved by random sampling where each has an equal chance of being selected. Concerns about representativeness and generalisability to the overall population underpin the process (Fuller and Petch 1995).

In qualitative studies, the aim is to provide an in-depth examination of meaning and its diversity. An improved understanding of complex human issues is more important than the generalisability of results. Parker (1994) considers that a qualitative researcher should state very clearly why a particular selection of participants was made, and highlights the moral responsibility placed on the researcher in relation to convenience and volunteer sampling, which involves a selection of the most accessible and willing. He also highlights that the types of people who choose to take part in a study may be different; for example, brighter or friendlier. Although self-selected samples are justifiable in qualitative research, additional strategies are possible, such as purposive or judgmental sampling (Marshall 1996). Here researchers actively select what is considered to be the most productive sample in terms of specific experiences. Age,

gender or social class may also be important for a particular study. Consideration can also be given to negative case analysis (Henwood and Pidgeon 1994); that is, in order to address the self-selected nature of some of the sample, and questions regarding trustworthiness in the use of purposive or judgmental sampling, the selection of some participants for interview who disagree and who might have a disconfirming potential may be of value in assuring that any assumptions are sufficiently challenged. By making sure not to include only those people who will say good things, the aim is to capture a diversity of potential opinions.

Marshall (1996) considers that, in qualitative studies, samples are usually theory driven to a greater or lesser degree. Theoretical sampling involves building interpretive theories from emerging data then selecting a new sample to examine and expand on the theory. This is a grounded theory approach (Glaser and Strauss 1968) but can be used in any qualitative study involving interpretation. Overlap may occur between these categories of sampling and it is important to recognise that qualitative studies are essentially naturalistic (Marshall 1996). They involve the study of real people in natural settings and sampling needs to take account of this context.

The potential sample population at The Haven consisted of all those who had registered at the project, which totalled 166 by the end of the study. All service users are included in the quantitative data collected at the project and, at the time of registration, they are asked to provide information for numerical data to be used anonymously for research purposes. None have refused to provide the data. This has contributed to a range of analytical vehicles and has offered background data to the study.

The overall number of participants involved in the formal data collection of the study was 60 clients and six carers. Self-selection from The Haven population sample was effected by posters and mailings about the research, and the ready availability of information sheets and consent forms at the service. This opened up attendance at focus groups and individual interviews to all registered clients. Therefore, convenience sampling was expressed as self-selection and volunteering in attendance at various research meetings

and interviews. The Research Group addressed this issue by also considering a degree of purposive and theoretical sampling. Here, consideration was given to age, gender, domiciliary situation, marital status, parenthood, education and presenting problems (Research Diary pp12, 14, 16-17). Two clients who had left The Haven in unsatisfactory circumstances, due to unacceptable behaviour issues, were also interviewed individually, in order to test and challenge theories. Others were invited because of their comprehensive use of various parts of the service or because of marked positive change in terms of coping strategies. Tables 13, 14 and 15, page 76 in the Findings Chapter, show representative percentages of client research participants compared to overall Haven population, for age, gender and ethnicity. Table 6 below shows the length of time each client participant had been a client at The Haven.

Table 6

Length of Time at The Haven	
Timescale	Number of Clients
Under 6 months	3
6 months to 1 year	4
1 year to 2 years	12
2 years to 3 years	17
3 years to 3½ years	24
Total	**60**

Table 7 below shows how many research events each client participant attended. The highest number, attending one event, reflects those who only attended an individual interview.

Table 7

Attendance at Research Events	
Event	Number of Clients
1 event	24
2 events	20
3 events	5
4 events	1
5 events	2
6 events	3
7 events	1
8 events	2
10 events	1
11 events	1
Total	**60**

Table 8 below shows the length of time each client participant was involved in the study. The highest number, involved in the study for one month, reflects those who only attended an individual interview.

Table 8

Time involved in the study	
Timescale	**Number of Clients**
1 month	24
Up to 3 months	13
Up to 6 months	5
1 to 2 years	12
2 to 2¾ years	6
Total	**60**

Data Analysis

The data collection process had spanned two and three-quarter years. By March 2007 we had already amassed approximately 600 pages of verbatim transcripts (Research Diary p14). By the end of data collection, in November 2007, this amounted to 770 pages. Data analysis took one and a half years. During the data collection phase of the study, challenges to the timescale had occurred from the outset, in terms of the sheer volume of work involved in setting up a new service (Research Diary p4-5). Staffing difficulties had also caused delays and the cancellation of Research Group meetings for several months in 2006. I questioned the possibility of being able to continue the study. Members of the Research Group were determined it should continue and staff offered extra service support to enable this to happen (Research Diary p11). During the data analysis phase, after all we had experienced prior to this time, a mere broken wrist did not seem at all to be a significant barrier to continuing the analysis (Research Diary p27). Within the context of my time-limited study schedule, the year and a half taken to analyse the data was mainly attributable to its great volume and to the testing of methods by which the findings could be effectively evaluated.

Words have a quality of undeniability: *'Words, which are by far the most common form of qualitative data, are a specialty of humans'* (Robson 1997:370). Compared to the abstraction of numbers in quantitative studies, narrative accounts and other collections of

words are rich and full. However, if qualitative data is to be persuasive to policy-making audiences, the findings must prove themselves worthy of attention in terms of trustworthiness (Lincoln and Guba 1985). The data analysis needed to yield sufficiently detailed descriptions to allow judgments about transferability to be made by the audience. Detailed attention also needed to be given to systematic analysis, and analytic tools were required comparable to those that existed for quantitative data. Tesch (1990) identifies 26 different kinds of approach to qualitative analysis and suggests that, although this covers a large range of prospective tools, in practice there are similarities in procedures. Braun and Clarke (2006) acknowledge that Thematic Analysis of qualitative studies is broadly used but suggest that there is an absence of agreement and theory which adequately outlines this methodological approach. They argue that thematic analysis, while often seen as joined to such theoretical frameworks as grounded theory, or narrative analysis, should be considered a method in its own right.

In analysing this research, thematic analysis was chosen as a systematic way of relating a large quantity of data by coding, descriptively and interpretively, and by searching for themes. Here, data from focus groups and interviews could be classified and related, into themes, ideas and theories. Data from service evaluation groups, community discussions, and advisory meetings further augmented the study, by being similarly coded and analysed for related themes.

Thematic analysis is a method of identifying, analysing and reporting patterns within data that is rich in detail, and it searches for certain themes across an entire data set (Braun and Clarke 2006). It is concerned with the way individuals make meaning of their lives and the way in which the broader social context affects those meanings. All theoretical frameworks carry a number of assumptions about the data and a good thematic analysis makes this transparent. Braun and Clarke (2006) outline a phased approach to thematic analysis. Whittaker (2009) presents this six-stage approach in a graphic and palatable way, as follows:

1. *Becoming familiar with the data* necessitates an immersion in the material involving repeated reading in order to search for patterns and meaning. This can be time consuming and it may be tempting to skip over this stage, but this is not advisable as it is the bedrock of the analysis. A familiarity with our data already existed. Transcripts had been circulated, read and re-read. I had been present at every focus group. Our participant researcher, who had facilitated research events, had been present at every focus group and interview. At the Research Group meeting in March 2007, the group had already begun to list ideas for themes emerging from the data (Research Diary p15-16). During December 2007 I read through all data again, manually marking some of the major themes with coloured pens (Research Diary p18). Here, I began to mark areas for coding, which would develop throughout the entire analysis. This required very detailed reading of individual interviews and focus groups together with service evaluation group transcripts and minutes of client meetings at The Haven.

2. *Creating initial codes* began after the familiarisation with the data produced a list of ideas about what was relevant in the research material. In this phase the initial coding of the data was organised into groups that could be related to themes. Fuller and Petch (1995) suggest that confronting a pile of raw data can be a daunting prospect, and that analysis with the help of a computer software package for social sciences can greatly aid the process. Robson (1997) also suggests that the ease with which a computer package can help to relate large quantities of data make it near to essential. The quantity of data in our study benefited from the use of the Nvivo[7] computer software package. With the use of Nvivo[7] I coded the transcripts into 14 categories, or nodes (Research Diary p18-19). This coding of data differed from the analysis of themes, which was broader. For example, the Research Group had produced a list of initial ideas about themes relating to recovery, in the March Research Group meeting, which began with the need to feel safe. However, as transcripts were more closely examined, related sub-categories emerged which included, for example, the importance of being welcomed, of kindness and being listened to.

3. *Searching for themes* begins when all the data has been initially coded and compiled into a list. These themes were worked on by assigning transcripts to different Research Group members at our Research Group meeting in January 2008 (Research Diary p19-20). From January to August 2008 we worked on the 14 transcripts (Research Diary p20-25). During this time, with the use of Nvivo[7], I also constructed 60 additional nodes by creating individual transcripts for each client participant (Research Diary p23). This was done with the idea of including some individual case studies in the research report. Unified themes began to emerge during the Research Group's work on the analysis as we refocused at the broader level of themes and began to analyse the codes and to consider how they might combine into a unified theme. Here, for example, we began to see that issues of safety and the importance of matters such as being listened to seemed to constitute a broad primary category about safety and trust.

4. *Reviewing themes* occurs once a set of initially qualifying themes has been devised. Themes are refined by discarding those with insufficient data to support them, or if the data is too diverse. Two themes might form one, and other themes may need to be broken down into more than one. If the thematic map works then the researcher should move on to the next phase, if not, further review and refining of codes should occur. By this time, as well as the electronically themed nodes, we had an additional pile of handwritten analyses of these transcripts, which had been produced by the efforts of the Research Group. These related the aspects of the various nodes to each other and suggested broader themes. The 60 individual node transcripts also showed clear patterns of improvement for individual clients over time (Research Diary p23).

However, at our Research Group meeting, in August 2008, I spoke to members about my growing realisation that we had missed out a step in our analysis and that I felt a further refining of data was needed. At the beginning of the data analysis I had considered organising responses to each research question, numerically into themes. This step had been omitted, not just because 66 participants were involved, but also because many clients had answered the same question more than once. Some had answered questions multiple times at different research events. The SEG questions had also changed in

sequence over time and had become refined into focus group questions. The individual interview questionnaire contained additional questions. The carer focus group questions also included differences. In terms of timescale, this represented a great deal of complex work (Research Diary p24).

The Research Group agreed that it was very important to see the breakdown of responses to questions, in terms of their themes and also their incidences. Three months was the target set for me to conduct this breakdown of findings from the individual research questions. I felt it was important to stress to the Research Group that their work on the thematic analysis had not been wasted. In fact, it was crucial that all parts of the findings and analyses eventually worked in unison to produce themes that would fit together in a way that would tell a story about our data (Research Diary p24). Thirty-four research events had occurred during the course of the study. As shown in the tables on pages 59 and 60, 32 research events involved Haven clients; that is, eight service evaluations groups, four focus groups, and 20 individual interviews, held over a period of two and three quarter years, between February 2005 and November 2007. The duration of participant involvement of the 60 clients involved in the study ranged from one month to two and three quarter years. The additional two focus groups were those held for family members and carers, during 2007. Six family members or carers were involved. Three attended both focus groups. Two attended only the first focus group and one attended only the second. From September 2008 to January 2009 transcripts of the findings from the research questions were distributed to members of the Research Group for comment (Research Diary p25-26). By the end of January 2009 the analysis of findings from the questions was complete. Research supervisors considered these findings were too lengthy to incorporate into the research report. Therefore, they have been included as Appendix VII: Findings from Clients Questions, and Appendix VIII: Findings from Family and Carer Questions. Removing the findings from the questions into the appendices, enabled us to focus on the primary research topic of recovery for people with personality disorder. The next stage of the analysis, described below, represented a meta-analysis of all the data collected during the study.

5. *Defining and naming themes* required a further analysis of the data within them. A write-up of each theme needed to occur, outlining what it was about, what was of interest and why and how it fitted into the overall story. Now it was possible to continue the thematic analysis with further coding carried out on all transcripts. A variety of nodes was compiled and compared as a verification of data within transcripts. This offered opportunities for reflection, enabling a rich analysis of themes against some of the numerical incidences of their occurrence. At the Research Group meeting in March 2009 I presented the analysis of the first two themes to members and we spoke about the third proposed theme. A further discussion occurred about later themes (Research Diary p27-28). At the May meeting I circulated the transcript for the first four themes and an in-depth discussion occurred about later themes and how the first four related to them (Research Diary p28). By June 2009 the first draft of the thematic analysis had been sent to the 66 research respondents. I had presented themes in the journey of recovery for personality disorder graphically, as a Maslow-type pyramid, and the Research Group liked this because they felt it represented growth and progress (Research Diary p29).

6. *Producing the report* should tell the complex story of the data in a way which convinces the reader of its value and the thoroughness of the analysis. Therefore, the report needed to provide more than just data. It needed to be convincing and compelling in a way that used narrative to illustrate our story. The findings are presented in the next chapter, first as a series of tables providing background data, then as a profiling of the sample against the overall Haven population, and as an outlining of some of domiciliary and life circumstances of participants and, finally, consideration is given to each theme in the journey of recovery for personality disorder. As already mentioned, the findings from the research questions are included as Appendices VII and VIII. Within these findings efforts were made to include quotations from all participants, ensuring their voices were uniformly heard. A higher incidence of the inclusion of quotations from some participants reflects the greater number of research events they attended. In the Findings Chapter quotations have often been chosen because they illustrate a point in an eloquent and compelling way. Quotations have been liberally included in this chapter because I felt it was important that the story was told, as far as possible, in participants' words. The

Findings Chapter is, therefore, necessarily long. This meant that, although we had planned to include some case studies in the research report, there was insufficient space to do so. However, data from Newsletters and Reports at the service became available during the study. These amply illustrated progress and achievements made by many participants. They have been included in the Findings Chapter, mainly in the Achievements section.

To ensure that the service user voice continued to be heard, the Discussion Chapter continues to use participant quotations, though to a lesser degree. Again, although a number of participants may have said something similar, quotations have been selected because of their expressiveness. One theme that only I worked on concerned organisational learning and change. Although I analysed this data against Haven records, to ensure fidelity of timescale regarding organisational changes, the Research Group continued to comment on emerging data and the results as they were written up. This chapter also incorporates data extracts and has been included as a separate and penultimate chapter in the thesis.

Ethical Issues

In any research study it is important to set the boundaries between ethical and unethical research. This is both a methodological and a moral issue because it concerns our treatment of people (Parker 1994). There are ethical issues, for participants and researchers, throughout the process, from planning, through outcomes and beyond (Tindall 1994).

Creswell (2003) stresses a primary ethical issue as the importance of ensuring that the research findings will be of benefit to people. Participants should also not be misled about the true nature of the study (Robson 1997). Tindall (1994) discusses the importance of equalising the power relationship and democratising the process. She suggests this may be aided by promoting ownership of the research, and ensuring participants receive copies of interviews and transcripts, in order to generate shared understanding and an opportunity to view data objectively. Tindall (1994) also stresses

accountability in the research process which begins with the purpose of the study. What function does it serve and who is it for? Qualitative researchers make visible people's lives and can bring about social change. She questions who is to change, who decides the direction and who is authorised to recognise whether change has taken place. Who is the expert? Accountability, in all its facets, is an integral ethical issue, but it is often overlooked (Burman 1994).

This research meets the criteria for ethical permission from the University Ethics Committee and was given approval in August 2006 (ARU 2006). Participants were asked in advance if they would like to take part in the study. They were provided with a comprehensive and comprehensible information sheet and signed a consent form to give informed consent. The form included a tear-off slip which enabled them to withdraw from the research at any stage, should they wish. Confidentiality was protected by the use of pseudonyms and further assured by making certain that other identity indicators were amended in transcripts. Copies of verbatim transcripts were sent to all participants, giving them the opportunity to correct or further amend their contribution, should they wish, which some did. A service user researcher was trained and supported to facilitate focus groups and to carry out individual interviews. A carer was trained and supported to facilitate carer focus groups. This was to ensure that participants were not unduly influenced in their responses, by being questioned by me, because I held the dual roles of initiating researcher and Haven Chief Executive. However, I was present throughout all focus groups, as an observer. As already discussed, this did not appear to have been inhibiting in terms of affecting the openness of responses from participants, nor in influencing their willingness to disagree or express criticisms, and who seemed to react well to the presence of the Chief Executive, seeing it as an acknowledgement of the importance and value of their responses (Research Diary p11-12). From an ethical perspective it is, however, important to note that I was present. Facilitators were valued by receiving payment for conducting focus groups or individual interviews. Participants were also valued by being paid for the time they devoted to any attendance at a SEG, focus group or individual interview. Immediate support was provided should any participant become unduly distressed by attendance at a focus group or interview. This

happened at research events on two occasions. First, a participant whose child had been taken into care became distressed when a discussion occurred about hopes and dreams of having children. Second, another participant became distressed while trying to define recovery as it seemed impossible to attain. Both participants received immediate support from Haven staff and the second returned to the focus group to continue the discussion.

In addressing ethical issues regarding power and power-sharing, Tindall (1994) suggests that consciousness-raising in research often involves a one-way movement towards the researcher's understanding. However, in emancipatory research, when change occurs the role of the researcher as agent for change is less central and powerful than the group as a whole (Beresford and Wallcraft 1997; Ramon et al 2003; Winter and Munn-Giddings 2001). The Research Diary throughout, Appendix II, reflects the collaborative nature of the study, from the discussion of concepts; the creation of research questions; the scheduling and carrying out of data collection; to the data analysis.

Freire uses the concept of conscientization, critical consciousness, as a way of posing questions that affect the cultural realities which shape our lives (Leistyna 2004). The Research Group, with the use of The Haven as a community, aspired to embrace this critical consciousness and to capture a more ethical and egalitarian notion of change which valued the expert by experience at all stages of the study.

Validity

Validity in quantitative research is concerned with generalisability. It asks questions about generalising results to wider populations and other settings (Schofield 1995). It is based on the logic of probability as a scientific way to generalise findings to diverse populations and times. Schofield (1995) considers that the classic view of validity is of little help to qualitative researchers.

Guba and Lincoln (1985) suggest that human behaviour is related to context and that the value of data depends on trustworthiness, which will convince an audience that findings are worth taking into account. In qualitative research the criteria for trustworthiness are

reliability, transferability, dependability and confirmability. Table 9 shows a comparison between quantitative and qualitative research concepts and terms.

Table 9

COMPARISON BETWEEN QUANTITATIVE AND QUALITATIVE CONCEPTS		
PRINCIPLE	**QUANTITATIVE RESEARCH (Validity)**	**QUALITATIVE RESEARCH (Trustworthiness)**
Truth Value	Internal Validity	Credibility
Applicability	External Validity	Transferability
Consistency	Reliability	Dependability
Neutrality	Objectivity	Confirmability

Credibility

A prolonged time spent in the field helps to develop an in-depth understanding of the phenomena being researched and enhances credibility (Gray 2004). This researcher and the Research Group were involved with the project for over five years. Persistent observation helped to identify what was relevant and to recognise when participants were responding with a lack of fidelity in relation to their actual values and behaviours. This involved the building of trust, developing rapport and building relationships in order to obtain a wide scope of accurate data.

Triangulation of data collection methods was employed including the Research Group, service evaluation groups, and minutes from the client advisory group and other community discussions, service reports and newsletters, and the transcripts from focus groups and individual interviews. This resulted in information from a variety of sources, collected in a variety of ways, thus strengthening credibility further.

Credibility is also achieved by ensuring that the researcher consults participants regarding the accuracy of the constructs which are emerging (Koch 2006). The use of member checking by taking transcripts, reports and themes back to participants verified whether or not they considered them to be accurate. Additionally, our emancipatory approach to

this study aimed to break down the traditional distinction between the role of researcher and the role of participant. The fact that service users were co-researchers, involved in the creation of research questions, gathering data, reviewing transcripts and critically reflecting at all stages of the study, meant that there were opportunities for negotiated reality which aspired to credibility from the outset.

Transferability

Transferability refers to the degree to which the results of qualitative research can be transferred to other contexts or environments. This may be achieved by employing sampling strategies, such as purpose sampling, that substitute for the random nature of sampling in large quantitative studies aimed at generlisability. Clearly describing the context for a study, and providing thick descriptions that richly illustrate the data, will provide a research consumer with sufficient information to judge whether or not the findings can be applied to other settings.

The use of some purposive and theoretical sampling has strengthened transferability in this study by ensuring the most productive sample in terms of obtaining the broadest range of information based on relevance, and in testing emerging ideas.

Using rich, thick description to convey the findings has also enhanced transferability because it aims to increase reader empathy and understanding (Gray 2004). By use of such descriptions, aided by the use of systematic thematic analysis (Braun and Clarke 2006), this study has added external validity, in terms of transferability, by contributing a deeper understanding of recovery in personality disorder.

Dependability

Researcher reflexivity creates dependability by offering an open and honest dialogue with readers (Gray 2004). The research process in this study and reflection about it, in terms the Research Group, has been made transparent.

Koch (2006) suggests that dependability is achieved by ensuring the reader is able to audit the events and decision trail of researchers. This is also known as transparency. All details of decision making, in the Research Group minutes (Appendix II Research Diary), are made explicit, together with the temporal dimension of data collection and analysis.

Confirmability

Use of an external auditor to review the entire project, throughout the process of the research, contributes to confirmability (Gray 2004). In this research, three external supervisors have provided a range of different approaches which has offered a diversity of perspectives. Shulamit Ramon, Professor of Inter-professional and Social Studies at Anglia Ruskin University, has acted as principle supervisor, and was also the principle supervisor for my earlier study (Castillo 2003). She has brought inspiration, a wealth of research experience in involving service users as co-researchers, and international perspectives regarding recovery. Dr. Nicola Morant, senior lecturer from the Psychology Department at Anglia Ruskin University and former researcher at the Henderson Hospital, also acted as a supervisor for my earlier study. She has brought great attention to detail concerning research design, the review of literature, and the trustworthiness of research findings, insisting on evidence every step of the way. Dr. Stewart Piper, Senior Lecturer in the Faculty of Health and Social Care at Anglia Ruskin University joined the supervisory team half way through this research. He has urged cohesiveness in the study and again brought an insistence on transparency and trustworthiness.

I believe that trustworthiness has been achieved by establishing credibility, transferability, dependability and confirmability in ways which indicate that different sources of data resonate with one another (Sandelowski 1994).

Conclusion

The choice of methodology claims the philosophical ground that guides the research and accurately reflects the interpretive methods within the chosen philosophy. Koch (1996) suggests that the rigor in any methodology basically lies in the soundness of philosophical perspective. Before the researcher began the topic already existed.

Hermeneutics allows what already exists to move forward and it concerns presenting interpretations in a way that draws the reader into a compelling dimension, where the topic becomes alive.

An important interpretive emphasis, in this research, has been the relationship between power and knowledge, and the injustice that occurs when the creation of knowledge is removed from the hands of ordinary people and given to select groups. This process is not simply about justice but is ontological and epistemological, as well as political. At the last two meetings of the Research Group, in August and September 2009, members expressed what it had meant to them to be part of this study (Research Diary p29-31). The following words, from our participant research facilitator, reflect not just her sense of confidence, purpose and privilege regarding her involvement, but also speak of the opportunities that have emerged because of her involvement, and the satisfaction she has felt regarding the influencing of professionals by giving talks about the study.

> *Dee: Being involved in the Research Group has led to so much for me, including now doing research for other universities. It's increased my confidence, sense of purpose and I have also been paid. The overall feeling of influencing the minds of professionals with the results our research has yielded. Also, the privilege of getting the vote of confidence from everyone to do the interviews and facilitate the focus groups, to be trusted was a privilege. This has led to other things and when I give input at talks and meetings it gets a really good response and I'm told, 'we don't get this in other lectures'.*

In summary, the methodological approach chosen for this study is non-positivistic and hermeneutic and involved an interpretive analysis which was a process of double hermeneutics whereby I attempted to make sense of the participants making sense of their world. Qualitative methods, employing a participatory action research (PAR) approach were selected. PAR was the most logical approach, not just in terms of its empancipatory precepts, but simply because it emerged as the most effective way to gain knowledge in this situation. As a comparative outsider, in terms of not having received this diagnosis, how could I hope to fundamentally understand the issues better than those to which this diagnosis had been given? How could the questions, for the study, be better conceived

by me, or the interpretations of the data be more validly construed by me alone, rather than informed by those who were engaged in this journey? The methodology selected for this study has supported an interpretive examination of inner and outer realities in relation to what it means for someone with a personality disorder diagnosis to be engaged in a journey of recovery. In employing this methodological approach and methods of data collection and analysis, the following chapter shows the findings that have been yielded.

FINDINGS

This chapter describes the findings of the study. It begins with numerical background data. An explanation about the findings emerging from client and carer questions is also given. The final section of the chapter represents the themes which emerged from an analysis of all the data collected during the study and it is a mapping of the process of recovery in personality disorder.

Background Information and Demographics

Since the Haven opened, in July 2004, a range of data regarding all clients has been recorded and statistically presented. This data has been collected for monitoring purposes for the Department of Health and for local Commissioners, and has also been required as part of the National Evaluation for the Personality Disorder Pilot Projects.

This data encompasses numbers registered, sources of and reasons for referral, gender, age and ethnicity. Some of this data has been compared, numerically, with the research sample. Additional information about the life circumstances of the research sample has been included, as have findings regarding the research sample's reduction in use of psychiatric services during the course of the study. Sixty Haven clients were involved in this research study and Table 10 illustrates the overall Haven population and how many were using mental health services at the time they registered at The Haven.

Table 10

Haven Clients	
Clients	**Number**
Total number of clients registered by the end of the study	166
Engaged with Mental Health Services at time of registration	144
Current number of clients registered at the end of the study	116

Table 11 shows the source of referral for each client who was registered at The Haven at the time data collection for the study was completed.

Table 11

Source of Referral	
Source	**Number**
Self	45
Hospital/Psychiatrist	41
Community Mental Health Team	33
GP	9
Other	8
Family and friends	7
Mind	7
Crisis Resolution and Home Treatment Team	5
Criminal Justice Mental Health Team	3
Housing providers	3
Assertive Outreach	3
Psychology Department	2
Total	**166**

At the time of registration at The Haven the reason for referral was given and is shown in Table 12. These were the presenting problems for clients and most clients fall into more than one category.

Table 12

Reason for Referral	
Presenting Problem	**Number**
Severe Depression/Anxiety	139
Suicidal Impulses	69
Self harm	59
Substance Misuse	45
Antisocial/Violence/Aggression	34
Isolation/Inter-personal problems	30
Volatile Moods/mood swings	28
Paranoia /Voices	23
Eating Disorder	18
Institutionalised long hospitalization/prison	6
Manic Episodes	6
Obsessive Compulsive	4
Gender Dysphoria/Gender Issues	3

In Table 13 the age range of The Haven population is shown and compared with the age range of research respondents.

Table 13

Age				
Age Range	**Overall clients**	**Percentage**	**Research clients**	**Percentage**
18-20	5	3%	1	1.7%
21-24	9	5.4%	2	3.3%
25-34	41	24.7%	11	18.3%
35-44	66	39.8%	24	40%
45-54	34	20.5%	16	26.7%
55-65	11	6.6%	6	10%
Total	**166**	**100%**	**60**	**100%**

Similarly, Table 14 shows gender for the overall Haven population compared with gender for research respondents.

Table 14

Gender				
Gender	**Overall clients**	**Percentage**	**Research clients**	**Percentage**
Male	43	25.9%	13	21.7%
Female	123	74.1%	47	78.3%
Total	**166**	**100%**	**60**	**100%**

Table 15 illustrates the ethnic origin of the overall Haven population compared to that of the research sample.

Table 15

Ethnicity				
Ethnic Origin	**Overall**	**Percentage**	**Research**	**Percentage**
White British	156	94%	57	95%
British Born Pakistani	2	1.2%	1	1.7%
Irish	2	1.2%	0	0%
Irish/English	1	.6%	0	0%
Dutch	1	.6%	1	1.7%
German born Romany Gipsy	1	.6%	0	0%
Mixed race white/Afro Caribbean	1	.6%	0	0%
Mixed race white/Asian Indian	1	.6%	0	0%
White American – USA	1	.6%	1	1.7%
Total	**166**	**100%**	**60**	**100%**

The following tables illustrate some of the circumstances in the life domains of research respondents, beginning with Table 16, accommodation.

Table 16

Accommodation	
Type	**Number**
Rented accommodation	41
Owner occupier	12
Supported accommodation	4
Living with parents	3
Total	**60**

Relationships and children are presented in Table 17, which shows whether research participants were, single, separated, in relationship, if they had children and whether they retained care of their children.

Table 17

Relationships and Children	
Situation	**Number**
Single and no children	23
In a relationship and children	10
Single and children	9
Single with children in care	8
In a relationship with children in care	6
In a relationship and no children	4
Total	**60**

Table 18 shows some of the history of the research sample in relation to whether they were in care as children, have a forensic history, have ever been employed, or were in employment at the time they registered at The Haven.

Table 18

Some Life Circumstances					
Life Circumstance	**Male Yes**	**Female Yes**	**Total Yes**	**Total No**	**Total**
Been in Care	4	17	21	39	**60**
Forensic History	10	9	19	41	**60**
Ever been employed	9	23	32	28	**60**
In employment when came to Haven	0	2	2	58	**60**

The last two tables, 19 and 20, concern the sample's use of statutory mental health services by the end of the study. The first, Table 19, shows hospital admissions for respondents during the last year of the study.

Table 19

In Psychiatric Hospital During the Last Year of the Study	
	Number
No	53
Yes	7
Total	**60**

The very first table in this chapter, Table 10, shows that 144 of the overall population of 166 clients were engaged with mental health services at the time of registration at The Haven. The final table, Table 20, shows that more than half of the research sample was completely discharged from mental health services by the end of the study.

Table 20

Discharged from Statutory Mental Health Services by End of the Study	
	Number
No	28
Yes	32
Total	**60**

Findings from the Questions to Research Participants

As outlined in the Methodology Chapter, because of the vast amount of data collected at research events during the course of the study, findings from the research questions have been compiled into appendices.

Data from the 34 research events has been categorised against the questions asked. Responses to each question have been further broken down into categories or themes suggested by the responses. These have been listed numerically in descending order from highest to lowest. Appendix VII shows the *Findings from Client Questions* and Appendix VIII shows the *Findings from Family and Carer Questions*. A rich quantity of participant quotations is included. All participants chose a pseudonym, to protect identity, and pseudonyms are consistent throughout the data in the appendices and chapters.

Mapping the Process of Recovery

Findings from the groups and interviews, in the research transcripts and in Appendices VII and VIII, together with all data collected during the study, has been subject to thematic analysis, as described in Chapter Three. An examination of emerging themes within and between transcripts and questions, and the interplay between themes, gives insight into what respondents consider to be the key steps in the journey of recovery for someone with a personality disorder diagnosis. Themes are initially presented diagrammatically, below, as a pyramid representing a hierarchy of progress.

Diagram 1

Transitional Recovery

Achievements

Hopes, Dreams and Goals

Containing Experiences and Developing Skills

Learning the Boundaries

A Sense of Belonging and Community

Feeling Cared For

A Sense of Safety and Building Trust

HAVEN HIERARCHY OF PROGRESS
The Journey of Recovery for Personality Disorder

The themes are now considered, each in turn, and are illustrated by data extracts in the form of participant quotations.

A Sense of Safety and Building Trust

Feeling *safe* emerged as a central theme, and foundation stone, on the journey. Sub-themes in the analysis concerning this theme included feeling *safe* from outside influences and from one's own thoughts and actions. The importance of *a sense of safety* was frequently mentioned as a response to a variety of the questions. Comments below include a general sense of being in a *safe place*:

> **Igor:** *You can feel it when you walk in that door, you can feel that safety. It's a safe place. It helps you to be safe.*

> **Crystal:** *I think The Haven is my place of safety, I feel relaxed.*

> **Gemma:** *When I've felt really vulnerable or in a crisis all the staff, I can't say anyone who hasn't, have made me feel secure, safe and put me at ease and just give me that secure feeling.*

> **Phoenix:** *It's probably the first time in my life I've felt safe enough to be in a group and taking part without constantly looking over my shoulder.*

> **Leska:** *When I've been feeling vulnerable I've always had someone come to talk to me, been reassured that I am safe, and that there are people here to support me and I'm not alone.*

An awareness that *feeling safe* protects from harm to self was also expressed:

> **Katy:** *Sometimes, just what I need at night time is to come in and know I'm safe and it stops me from doing anything at the moment.*

> **Harry:** *The Haven's my safe space when I get really panicky and instead of running off in my car and ending up in the middle of nowhere, I'm more likely to come here now, which actually helps my family a lot because they are not so stressed because they know I am somewhere safe.*

New clients at The Haven also identified, at an early stage, that a *sense of safety* was an important factor in preventing harm:

> **Roosle:** *I'm new to The Haven so I'm just learning what it can do right now. I'm using it as a safe place from myself, because I'm in a very dangerous and unsafe state, and it's a place where I can go where I know I won't come to any harm.*

Additionally, family members highlighted *safety* as an important element:

> **Alex:** *I feel, definitely, it's helped my daughter. It's somewhere safe for her to come, somewhere without any bad memories.*

> **Sarah:** *I knew that I could probably go to sleep and that he was going to be okay and safe.*

Participants also identified that *responsiveness* engendered a *sense of safety*, enabling feelings to be expressed, and *trust* to be built. *Responsiveness* was cited both in terms of the vital necessity of 24 hour service availability and as emotional responsiveness:

> **May:** *It makes me feel very safe and secure to know it's always there. To me it's safe 24/7, it's a haven. That's what it really means.*

> **Abigail:** *Its all round 24 hour support is something that I've really found helpful, knowing that there's someone there, it gives you a sort of safety net.*

> **Daniel:** *If you are in crisis, knowing that you can phone up, or whatever, and get help and knowing that there is people there, that you can feel safe.*

> **Gemma:** *I came in here on Monday and burst into tears, and I hadn't done that for some time beforehand, and a member of staff took me into the Safe Centre and she said, 'You're here now, you're safe, you can let your feelings go, cry all you want, you don't have to pretend anymore', and that was such lovely words to hear that I didn't have to wear this mask or put on a smile or brave face.*

Participants also described the helpfulness of a *consistent* approach in relation to *trust* and *safety*:

> **Brunhilda:** *I've been very upset and, each time I've spoken to a staff member, I haven't had to go through the same story each time, they all seem to know what's happening with me, so it's very helpful.*

> **May:** *I think that the way things are handed-over, when you are in crisis you don't have to tell your story all over again from the beginning, because the people you speak to on the phone, or in a one to one, know enough about your symptoms and situation, and that makes it much easier.*

Conversely, the analysis showed that *trust* can be easily shattered if someone is let down by a lack of availability, consistency or responsiveness. In the Organisational Learning and Change Chapter, page 168, adjustments in the telephone crisis service were made because of participant responses below:

> **Collie:** *I was supposed to get a support call and it didn't come at all yesterday and I've got no answer to why it didn't come. I just thought that I ain't worth nothing. It feels like I don't belong here.*

> **Chloe:** *But, if you're seeing someone in a one to one you can't have them constantly jumping up to answer the phone because it just doesn't work, you know, like there's no continuity. You're made to feel unimportant and the phone takes priority and that's not good enough.*

Carers and family members also highlighted the crucial importance of building *trust*:

> **Alex:** *You've gained the trust I think, which is one of the things when people come out of hospital, or before they come here, that they haven't got trust in anything. I mean the people that love and care for them, not in the mental health system, they don't trust anyone. But when they come here it's a gradual trust in people. They don't feel they are going to be let down and that's a big positive and then they gradually can begin even to trust themselves to do things and take responsibility. But that only comes when they begin to trust other people, and then other people begin to trust them. I feel it is important that she knows she can always come to you no matter what and that you are never going to tell us*

anything that she doesn't want us to know. This is her haven; this is her one place that nobody ever lets her down.

The degree of *trust* experienced, in relation to past services, was described by one respondent, as follows:

> *Tom: It's a lot to do with trust though isn't it? I trust, completely, I trust every one of you. Whereas, with the other places, it's phew, there's no trust there. They let you down, and it's gone.*

Participants described how feeling *safe* and learning to *trust* enabled them to stop hiding their emotions and to begin to explore their feelings and experiences:

> *Igor: For me The Haven has taught me to trust again and respect other people. It's through this place that I've learned I don't have to hide my problems; I don't have to hide behind a smile anymore. I can come in and cry, I can be me for once. I think the important thing really is that coming here makes you safe enough to change.*

> *Boris: I can be honest, can let my emotions go and still feel safe, and it works really positively as long as you've got someone to work with that you trust. I think I'm more honest, I'm more open, I'm more trusting since coming to The Haven.*

> *Fred: I used not to talk, it made me vulnerable in speaking, you know, you are opening yourself up for ammunition or further abuse, but I'm learning to trust more, and to ask for help.*

> *Rose: It makes me feel safer which helps me take more risks than I ever have. It's really working, I've learned to trust which enables me to talk instead of taking things out on myself.*

Feeling Cared for

Feeling *cared for*, although bearing a relationship to developing a sense of safety and trust emerged as a separate theme with attendant attributes. The importance of being

welcomed from first contact, or the moment one arrives at the door, was mentioned by some participants:

> *Phoenix: They always look pleased to see you coming through the door.*

> *Jonny: Last week I wasn't well and I get somebody from The Haven on the door, at the same time, it's just, they care, and that matters one hell of a lot.*

> *Daniel: Every time I've come here everyone has made me feel really welcome, which is a positive.*

> *Fred: I've phoned when I've been in crisis and I've always been welcomed no matter what my mood or what's going through my head.*

The importance of the response at the door was also cited as a negative when it does not happen in a welcoming way:

> *Harry: I've only had one negative experience, my first response when I got at the door was, 'What time are you going home?'*

> *Leska: Sometimes being let through the front door and nobody actually coming to speak to you for about an hour.*

A kind word and simple *caring* actions, such as a cup of tea and a cuddle, were highly appreciated by participants, showing that both physical and emotional caring was given high importance:

> *Doris: It's been excellent, a kind ear, a cuddle, cup of tea, respite when I need it.*

> *Chloe: I don't do hugs, but I do now.*

> *Norris: It's the sort of place you can get a hug or give one. When I first came here I couldn't let anyone near me, or in my space, without being completely drunk, this was outside here, and now I can. Most of the time people can hug me*

and be close to me without, you know, that would have never happened before I started coming here, without me being under the influence.

Elise: The cups of tea when I arrive have been quite nice as well.

Sally: When I have been really down I have been taken into a room and they have made me a cup of coffee and they wouldn't let me out of the door until I have got myself together.

Gemma: The calmness, softness of the staff they make you feel…… they make you a cup of tea or coffee and they listen, they listen. They let you talk, they let you speak, they let you cry and they hand you tissues. You know I never …… care and genuine care, absolutely wonderful.

Aspects of this theme, highlighting appreciation about the *care*, genuineness and compassion at The Haven, were also expressed by participants:

Brunhilda: One of the most important things is the humanness of The Haven staff and other clients, there's a kind of warmth and compassion.

Doris: They make you feel that, for half and hour, you are the sole focus of their attention. You're not just a number and you've got these issues and they are going to sit there and listen to you. Even if it goes over, they are not clock-watching. There's no "I'm going to get my lunch now". You are important.

Wilf: It is important that you have got caring staff here, if you didn't have people as such caring staff I don't think it would work.

Charles: There are people who give a shit, you know.

Ben: I have been met with universal kindness and support.

Cosmic: I couldn't wish for more help, more care.

Leska: Since I've come to The Haven I have never met such a wonderful bunch of people, and staff especially, and the kindness and everything that you can imagine really, that a lot of people haven't had, it's just out of this world and, if it's okay, I would just like to add a great big thank you, and I hope this is the way it will always stay.

Family members and carers concurred regarding the importance of the warm, friendly and *caring* response at the Haven:

Sarah: *I have to say that I just think The Haven is just a calm, happy, just a caring place. To be honest I found the hospital a hustle and bustle, and just total chaos. I personally feel that, total chaos, and nobody really, I don't know how to explain it really, nobody really, I'm sure they are trying to help, but I have reservations on that, because they just did not help my son at all, and if I asked for help I don't really think I got any help at all. I can honestly say I got nowhere, absolutely nowhere. I have to say, I might have a tear in a minute, I have to say that The Haven is just, it's a wonderful place really. I really mean that.*

A very important aspect of the physical nature of *feeling cared for* was described by participants in relation to pampering activities and alternative therapies:

Chloe: *The only time I'm really touched is when I come here, because I live by myself and don't have a partner. The pampering is a clear example of somebody actually touching you and that makes you feel that you are valuable as a person by being actually touched. Touch is really important.*

Kim: *I love the face packs, or my hands being done, I feel like a queen.*

Rose: *Pampering, you feel so much better you do, you feel like a real person. I spend less time disliking myself when I've had things like the therapies and the treats, it actually makes you feel like you're worth something.*

Harry: *I found pampering particularly good because I don't pamper myself and it's nice to feel you're worth something through having that done. I'm starting to learn that I'm not just what I do, I am a person as well and that I have needs.*

Participants also spoke about how *feeling cared for* made one feel special and valued and how this has contributed to beginning to feel better about oneself:

> **Rose:** *I think they make you feel special and that's quite a hard thing to do.*

> **Tiffany:** *The staff try their hardest to make you feel very special in your own individual way, and they give you loads of boosts of confidence you know, they make you feel special in your own way.*

> **Doris:** *You are important. You feel like you are important to them and what you say is being listened to actively rather than passively. The staff treat us as humans, so we think we are human, rather than part of a different species. Since coming to The Haven I got to a period where I thought, yeah I do like myself a bit more.*

A Sense of Belonging and Community

The analysis showed that feelings of *belonging* and a sense of *community* developed as one began to feel safe and cared for. A component of this theme was the common ground that was appreciated by participants in terms of diagnosis, experiences and difficulties amongst members of The Haven *Community*:

> **Carl:** *I find when you walk into the room the thing I like about all of them is everybody has got the same illness, same problems, and this is where The Haven comes into its own, because they recognise those problems, and they are able to help you.*

> **Emily:** *I isolate and can't mix with people, but I can see people in The Haven, you are the same as me.*

> **Cosmic:** *I feel more secure. I used to feel like a freak. Why am I so different from the neighbours? But this is a whole club full of them and I keep in mind that I'm not alone.*

> **Wilf:** *You can see by some people that they have been as low as you have, you know what I mean, we've all been down right to that bottom, you know, well, hell*

really isn't it, and then some of us more than once, and that I think helps you talk to people, open up I think because they've been through the same sort of pain, not for the same reasons but the same sort of pain as what you have been through.

Participants expressed how this has led to a sense of *belonging* and fitting in, perhaps for the first time:

> **Lara:** *It's taken a long time, but I finally feel that this is the place where I fit in and I feel comfortable, I feel comfortable around the people here, it's very nice.*

> **Anne:** *One of my hopes, dreams was to fit in, into this world, and being at The Haven I think I've finally started to fit in.*

> **Doris:** *Before coming to The Haven I didn't feel like I belonged anywhere, I always felt like a square peg in a round hole, I never felt anywhere like I was accepted as Doris, accepted for who I am, and so I think since coming here I've found acceptance, and I've found my round hole to go with my round peg, so maybe I have changed in the way it's helped me to find acceptance, to find a sense of belonging, and since, I'm more comfortable within myself.*

Family members and carers also pinpointed the importance of The Haven as a specialist *community*:

> **Sammy:** *The Haven serves a specialist community in a very specialist way. The hospitals and the community mental health teams, their only speciality is mental health, where The Haven is catering for a group of people and a limited number so, actually, you can work far better with those individuals and be more focussed, so we certainly don't want it to go away.*

> **Rob:** *I think that's the definition of a community as opposed to a service.*

Participants voiced a clear awareness and understanding that they were part of a *community* and that this was very different from other services they had experienced:

> **Rose:** *I haven't seen any NHS mental health people run things like this.*

Jenny: *I don't think I've ever been any place where there's been people around me that have got mental health problems and there's been such a good strength of community.*

Daniel: *Without the community spirit that's here I think a lot of people would be in (hospital), or even worse than that, if it wasn't for the people here.*

The fact that *community* is about being part of something worthwhile was also highlighted by respondents:

Elise: *About the community, I do think it does work very well, I do think the friendship groups are a fantastic idea and have worked very, very well. I do think that all the things that were introduced, like the Christmas dinner for people, gardening group, all little things that are going on are actually creating a sense of community, and that's great.*

Abigail: *Having been recently with one of our neighbours who we showed around the garden, he was very proud of the work that the gardening group have done, especially looking at the vegetable patch, but the work that has been done by everybody that goes and personally I was shown photos and I saw photos of people that I have never seen smile before, which to me is what it's all about.*

Community as a bond of friendship, acceptance and precious company was also cited as a component of this theme that was very important to participants:

Katy: *I think it's very important it's a community. I think being non-judgemental against each other is very important, and I think it's very important that it's become a very close community.*

Doris: *It's all about human contact. I think a lot of people here realise what it's like to be lonely, we all know what it's like so we all make an extra effort to be friendly, to be nice, to make a cup of tea. Ah bless, I love the community at The Haven. I love all the friends I've made. I love all the people I wouldn't normally have spoken to.*

Jenny: *The community here is so supportive, there's always somebody to talk to and something to do, so you're not sitting and dwelling on how you're feeling. Whereas at (hospital,) and other hospitals I've been to, you do.*

Bling: The community aspect is really good, no-one picks on anyone, it's not a place where people pick on each other, there's no piss taking, there's no nasty bullying which you get elsewhere.

Tiffany: In fact no-one's putting a label on each other like they do everywhere else.

Calvin: I don't feel alone, I feel we are in the same boat and it's a safe boat.

Gemma: There's always people around and you can hear them laughing, precious company.

Learning to socialise and being able to have fun were also cited by participants:

Alexis: I'm getting out and doing things and meeting people and learning new things, before it was just vegetating at home.

Karen: If I didn't have The Haven to come to I'd be locked in my house most of the time.

Chloe: The comparison that springs to mind is with the groups that are run here, with the groups run in typical institutions and hospital settings that is, and it's just worlds apart and you don't feel like you're in a group. Well personally I don't feel I'm in a group just to pass the time, there's loads more to it than that. It's about social interaction, it's about learning, it's about all sorts of things, and you feel, you know, you do feel good afterwards. I haven't laughed as much in years at the last Friendship Group I came to here. It was just hilarious.

Carl: I can now have a conversation and make a conversation. I'm learning to re-socialise, have fun with other people, joining in and laughs, and general well-being.

The mutual support available from the *community* was also described by participants:

Katy: The support we give each other is absolutely fantastic.

Meg: Client interaction is vital. We are all prepared to assist each other.

Charles: Ever since I've come here, even down to weird stuff like getting light bulbs changed in your car, you know, there's always somebody that can actually help you with something, you know, there's always somebody here, because we all come from all walks of life, and all different backgrounds.

Pablo: We have a cup of tea together with another male member and he then speaks to another woman member, and between the three of us we are moving a wardrobe, and all of us are going to benefit, I'm going to benefit from, you know, having like minded people with me, a bit of fun for a couple of hours, moving a wardrobe, and they are going to benefit from moving a wardrobe, the recipient of it's going to benefit, you know.

Doris: It's not just about the staff. If you are feeling down another community member will come up and say 'are you alright' and you'll say 'yea full of beans' and they'll say 'no you're not'.

Anne: It's what The Haven is all about; it's being there for each other through good times and bad.

Lara: I just love helping people. I feel that when I'm helping someone it makes me feel better.

Some *community* members were, however, also aware of the dangers of becoming overburdened by each others' problems:

Daniel: I would like to put over to everyone you mustn't take onboard everybody's problems for the simple reason that I've done that in the past, I've helped people, and it's made myself go down, so you can help people, but you can't.

Gemma: I think that because everybody here, clients or friends or whatever, are so recognised, so alike in lots of different ways. It's common ground where we can all talk to each other and we can all off load, but like you say, only to a

certain extent. We all have it within ourselves that we are so hypersensitive and feel so much for each other that we all want to reach out to each other and help each other, so it's like a vicious circle, it can drag you down, but because of so much sensitivity that we have with this condition, that your heart goes out to everybody.

Abigail: I think the danger is letting the disorder take over; the nature of the disorder is to want to rescue.

Connor: I'd like to say something regarding basically trying to help other people to distract from your own personal issues and problems and facing up to your own demons. I thought many months ago that I was an exception to the rule and tried to help. I suppose the operative word would be, upset, other people although I felt in my heart that I was trying to help, and what I was doing was causing a tremendous amount of pain to other clients by trying to help them and really what I was doing was making them worse and for that I apologise.

Elise: I think it is a very fragile group of people you are working with and while it's lovely to think that shared experiences might be helpful, they are not always helpful, sometimes it can burden people that aren't in a position to be burdened, and therefore the policy about not speaking about contentious issues in public areas is actually quite a helpful guideline.

Negative aspects of *community* were also expressed by some, initially, as a sense of alienation engendered by seeing others making friendships and joining in:

Sheila: I would like to be able to join in the community more, but I'm not very good at interacting with other people I suppose. I see everyone interacting with each other and caring for each other, and everything, and I'm sort of on the sidelines wishing I could join in and not able to.

Kim: Sometimes I do feel alone at the groups, I feel there's a lot of cliquiness and bullying going on. Maybe it's a clash of personality.

Phoenix: I struggle with this idea of community. Sometimes I feel very, very threatened, and sometimes I feel very safe, sometimes I feel comforted, but there are times I feel threatened and vulnerable.

Equally, a perceived sense of neglect was cited, by one participant, because too many others were vying for attention:

> **Stony:** There's people who are ill vying for attention. I feel the one who shouts the loudest gets heard. The Haven as a community isn't that good really, to be honest, because people are, like I said over again, focusing on the actual illness rather than trying to move forward with everything, and everybody's competing on how ill they are rather than trying to be better.

Stony's perspective is examined further in the Discussion Chapter, page 154.

Respondents expressed satisfaction in the *community* working and striving together for common goals:

> **Brunhilda:** It's such a great representation of what you would call a community, and I personally have looked for a community for several years and this is really what I think community ought to be because it's staff and clients all together have created this place.

> **Fred:** Everyone pulls together; I feel part of it now.

> **Boris:** It's a whole big box of people together that are all striving for the same thing and the community is what you make it, and what you give to it, and how much people are willing to put into it.

Many participants, including family members and carers, identified that a central component to this theme was that The Haven *Community* had given members a sense of home and family:

> **Pablo:** The Haven provides for me a replacement role of my parental home.

> **Poppy:** I'm now learning to use The Haven to help myself and it's like an extended family that I haven't got really.

> **Ben:** It feels that you are a replacement Mum and Dad that I never had.

Brunhilda: Community is, I suppose, a bit like having an extended family.

Alex: She's got friends here, I think she feels even the staff are her friends as well, and I just feel that she feels that is more of her home now, this has taken the place of her home.

Daniel: Like Sunday, I done a roast dinner for everyone that was in a bed, and that, and a few other people, and I like doing that because it gives me something to do and it's appreciated by everybody else.

Donald: A Sunday roast because it was my birthday on Sunday made me feel really good and happy. It was one of the best birthdays I ever had.

Boris: It's like one big family together. You support one another through your needs.

Leska: The Haven community, it means a lot to me, it's like having a family all under one roof.

May: It's the family I never had.

Learning the Boundaries

Within the spectrum of *learning* are lessons inherent in a therapeutic community concerning *boundaries* and acceptable behaviour:

Boris: I suppose the biggest issue for me would have to be the boundaries of The Haven, and the policies need to be kept because to aid someone's recovery you need boundaries and that's what so many people lack.

Doris: We all do things that are socially unacceptable but it is really better to make them a little less acceptable, like they are in the big wide world.

This theme emerged as a potential lesson, or barrier, on the journey of recovery. This was discussed by the Research Group as the first four themes began to emerge (Research

Diary p28). In this part of the data analysis Haven polices and minutes were included and used to augment data collected from groups and interviews.

The Haven's Acceptable Behaviour Policy was created in collaboration with its clients and is administered by the clients. If a Haven Community Member breaks the rules laid out in this policy there are consequences, and that client will be invited to a Community Discussion with peers if a *boundary* has been clearly transgressed. Minutes are kept for Community Discussions and sent out to all Haven clients. During the first year of operation at The Haven, research participants began to discuss behavioural issues, at Community Discussion Meetings, as follows. The issue under discussion, below, was that a client in a crisis/respite bed at the project had self harmed:

> ***Jonny:*** *It made me feel so upset that I felt like not coming to The Haven again. Although I do want to stress that I know this person is very unwell, really suffering and in need of help.*

> ***Abigail:*** *I have struggled against unacceptable behaviours because a crisis bed is a privilege and, if someone breaks the rules there are usually many others trying to keep the rules who need the bed.*

> ***Alexis:*** *What if someone breaks the rules by, for example, self harming in their sleep?*

This latter query was answered by staff: 'You tell me, you are the ones making the rules'. The conclusion from this early discussion was that a stay in a bed should be terminated if a client self-harms. Other bed stays would be booked in the future for this client, but further occurrences from any client should be acted on immediately, as above, thereby providing a clear *boundary* and consistency of approach.

Community Discussions during our second year of operation included alcohol issues, resulting in a several week ban for one client, for which this was a second offence, and who had caused serious upset and disruption in the project and outside in the car park.

On return to the project at the end of the ban the client requested a further Community Discussion and made the following statement:

> **Calvin:** *All clients here have issues and one of them is alcohol for quite a few people. The last thing you need is for someone to turn up under the influence of alcohol. I sincerely apologise and I'm really sorry for all the upset I caused.*

Another research participant reflects on lessons *learned* regarding acceptable behaviour and alcohol:

> **Karen:** *About my bed, unfortunately, through my own stupid fault I consumed alcohol on my fifth day and had to go home. I was excluded for six days, but was offered telephone support and then I could come back after six days. A bed here I think is a great privilege and I have been told that I can have a second chance which I am extremely very, very grateful for, because it was a very stupid thing to do. I shall never lose my bed again. I've learnt my lesson.*

Issues of drug misuse have also been brought to the Community for discussion. On one occasion it was discovered that a client had brought cannabis to the project while staying in a bed and had given it to two other clients. Strong feelings were expressed by both staff and clients regarding the fact that illegal drugs on site put the whole project at risk:

> **Brunhilda:** *Drugs are not the same as alcohol.*

> **Leska:** *Closing the beds or police involvement would be punishing clients who are blameless.*

The Community decided to impose a four week ban with telephone support and additionally a six month veto on bed stays for this particular client. The discussion was also followed by the decision to institute an amnesty regarding all offences against the Acceptable Behaviour Policy since the project's inception. This yielded a cathartic harvest and the Community agreed that, thereafter, any instances of illegal drugs on the premises, or any discussions or phone calls occurring at the premises about obtaining illegal drugs, would mean that the police were contacted immediately:

Wilf: It's brilliant that we run it, and we decide what happens. It's never nice to ban people and things like that, but at certain times we have to, you know, be stricter and I think that's starting to happen now, and I think, well since the amnesty, I think it has cleared the air, and I think we've become stronger now.

Discussions and *Learning* about overdosing at the project usually prove more emotive, as clients examine and empathise with desperate emotional states which can precede this kind of behaviour. Although such occurrences have been rare at The Haven, one client repeated this behaviour in just over a period of one year. The first instance prompted support and sympathy at the Community Discussion and the vote was in favour of no ban but rather community service at the project in the form of work in the vegetable garden. The next occurrence happened overnight, while the client was in a bed, and excerpts from the subsequent Community Discussion are as follows:

Katy: It's very hard to discuss this kind of thing because we have all been there and can sympathise and understand.

Tiffany: I wonder why we have to punish someone for something like this.

Emily: We can all sympathise and empathise but someone has to take responsibility for the consequences of their actions.

Crystal: Everyone will think they can do it. Thank goodness the person has not passed away. How would staff have felt if they had found them and how would clients have felt?

Daniel: If that had happened there would have been a Board of Enquiry and our funding could be taken away.

Doris: The person who has done this is a very dear friend and I love them to pieces, but we are all aware that when you feel like that you can go and talk to staff, and I'm not sure we can be too sympathetic as people will be cutting themselves and hanging from the pergola.

> **Boris:** *The decision we make today is very important and that's why we set the boundaries. We have got to keep the place safe and treat everyone exactly the same.*

The Community decided on a one week ban, obviously with all necessary external support, and although the client left the meeting in tears, they have not since that time taken an overdose, either at The Haven or anywhere else.

Now, in The Haven's later years, Community Discussions are well attended, with usually over 20 clients who see this function as part of the responsibility they hold as Community Members. Some clients are seasoned in the process and quite skilled at, in the words of one client, *'tempering justice with mercy'*. An example below concerns a client new to the project who displayed excessive attachment difficulties, refusing to leave the site on various occasions and even prompting staff to call the police for assistance, and who also overdosed en route to The Haven:

> **Brunhilda:** *We need to remember that this person is relatively new to the project and very young and that it can take quite a long time before someone truly understands how the community works and that it is a two way thing.*

> **Doris:** *Many of us have been like this in the early days and demanded a whole heap of attention by reacting to boundaries. This person is still on a learning curve.*

> **Boris:** *Would you like to have a buddy at the project, because I'm willing to act as your buddy?*

In this instance the client was given a contract specifying points that needed to be adhered to, rather than a ban.

During research events, participants expressed a clear awareness of rules and a sense of safety and security about *boundaries*:

Sheila: I feel safe at The Haven because I know you're not allowed to get away with stuff, are you, like cutting while you're here, which means I don't try. It's about being protected from the negative parts of yourself.

Cosmic: I do get a real sense of freedom here, but I know that if anybody doesn't tow the line then they will be pulled up and they'll be at a meeting about it, yeah.

Boris: Community is about treating other people as you would like to be treated yourself. The urge to do destructive things to yourself takes over. When very strong boundaries are imposed it's the respect that we have for The Haven that stops us from breaking them. This makes you go to staff to ask for help rather than going down that destructive path.

Further observations from research participants, in relation to behavioural choices, include both the deterrent explicit in the rules, which may bar access to the project if the *boundary* is broken, and also *learning* about the impact one's behaviour has on others and taking back responsibility:

Jasmine: When I had my last stay here I actually self-harmed and got sent home. I took that very hard as a bed is like gold dust and I hated myself for doing that to the point where I was so scared to come back, but the staff kept persevering and managed to talk me round and I realised how much I was missing while I wasn't coming here. I used to use alcohol as a coping mechanism, and since The Haven I hardly drink alcohol anymore because if I've had a drink and I need to come in I won't be able to come in, so I make a real effort to keep off alcohol.

Jenny: It's good because you really get on with the staff so you actually respect them, you don't want to hurt them as well. You don't want them to feel bad. And it's not then just about you. You start to see that you are affecting other people as well. I think that's the reason why they manage to sort us out a bit, because we actually like them all.

Pablo: It goes back to you taking your responsibility back really, that's what it's about. It's about giving you your responsibility back, not about losing responsibility.

Brunhilda: Sometimes there have been some ad hoc community meetings to discuss really dodgy issues and they have been quite emotional and quite difficult.

But, just like a good partnership, going through difficult times but coming out the other end, makes the community stronger. Community isn't all about harmony and everyone loving each other and that sort of thing, because life is full of challenges and difficulties and rubbish and so inevitably that comes up within the community. The group encourages each individual to fulfill their potential. At the same time, each individual thinks not only of themselves as an individual, but thinks about the good of the community as a whole.

Doris: *We understand why people want to come in, for example, under the influence. We understand the struggle and the difficulties but we have, on those occasions, stood together as a community and we have said 'this is unacceptable'. People aren't abandoned at such difficult times, but the learning is about what is acceptable and unacceptable to the community and what is healthy and positive for the individual. We all take responsibility for The Haven Community but, at the end of the day, the message is that each person has to take responsibility for themselves, with our support.*

Some family members and carers discussed the kinds of behaviours that represented the burden of personality disorder, presenting severe stress for loved ones:

Rob: *She tried to kill herself desperately under the care of the hospital and previous regimes.*

Tony: *She was stoned on Wednesday before her (family) turned up. I'm afraid that I'm at the end of my tether because of drugs and, as far as I'm concerned, are keeping her ill and she doesn't seem prepared to let it go. So, if you can help her in that aspect that might help. I'm also aware she's sold drugs, I'm really concerned, I caught her out at Christmas time drug dealing to children.*

Sarah: *At one stage, with my son, it was just like a rollercoaster, and I had family members saying to me, 'just let him get on with it', you know, because my son would always ring me, and I would be going up to the hospital picking him up, or whatever, ambulances and all sorts, and I suppose as a Mum I couldn't not go.*

Dinah: *It's coping skills that we need and those are the strategies I hope The Haven will give to my partner. My partner has a ferocious temper and aggressive behaviours, and it's frightening, I find it very frightening, and for years I've put up with it, frightened in my own house, when she goes into one. We get these suicide attempts and we've been to hospital numerous times. I've run out of sympathy quite frankly because the first time it's, 'oh my god', you know, the*

second times it's, 'oh', the third time it's, 'not again'. I'm not going to play the game anymore. I'm being pushed to a point that I'm having my strings pulled and I can't, I can't cope with all that manipulation that's being put on me.

Client participants also discussed aggressive and violent behaviours:

Abigail: *I've yelled at people, because I get frustrated and it comes out as anger. I left because I actually hit somebody.*

Harry*: I used to run away a lot when things got too much at home, because I have violent tendencies and I didn't want to be violent to anybody.*

Fifty-one client respondents discussed the use of negative coping strategies during the course of the research and 46 reported a reduction in their use. Twenty-three of these described a dramatic reduction, suggesting that the concept of boundaries had been internalised:

Pablo: *My sobriety is unbelievable, my conscience is clear, I wake up clear. I mean the two things in my life that I do now that keep me together is that I eat well and I sleep well.*

Rose: *I haven't cut for more than two years now, my overdosing has gone down significantly, and my drinking is getting to be more normal.*

Leska: *Before I came to The Haven nearly every other day I was tying things around my neck, overdosing, cutting myself and since coming to The Haven I don't tie anything round my neck, I've had maybe one overdose and I've learned to talk and, when things get really bad, to phone and ask for support instead of acting on impulsive thoughts.*

Alexis: *I haven't touched alcohol for almost two years. I haven't self-harmed for almost 19/20 months with the help of The Haven's crisis line.*

Fred: Taking drugs, before in the past, that was all I knew from the age of 13, what I'd learned in order to survive, basically, on the streets. I've come beyond that and my coping strategies are to talk I guess, and phone for help.

David: I'm not so aggressive as what I used to be like because I used to be a big bully.

Donald: I used to overdose probably once or twice a week and, in the last four or five months, that's stopped completely since I've come here. I never used to think about the consequences, I never used to think about who I was going to hurt, I never used to think there was other ways of dealing with things, and that you could actually talk to someone about things, instead of just doing it, so it's changed my life no end coming here.

Elise: Before I came to The Haven I used to overdose on a reasonably regular basis, I used to cut myself when anything went wrong, and I used to stop eating when anything went wrong. Basically, it was a whole host of maladaptive coping mechanisms and since coming to The Haven I have sort of redressed these. A lot of the reason has been because of the ruling about coming in when you have cut, or coming in when you have drunk alcohol. So you have to respect the values of the place. I now don't cut. To me to cut would be such a backward step I don't even want to go there.

Containing Experiences and Developing Skills

The first four levels, in the hierarchy of progress, have been about creating a setting where traumatised people have begun to feel safe and cared for, where they have developed trust and a sense of belonging and acceptance, and where learning has begun about what is acceptable and unacceptable to others, and what is healthy and unhealthy for the individual.

Only when these levels were in place did respondents begin to learn to *contain* their past experiences and build necessary *skills* to progress. Below, in Diagram 2, the pyramid of progress can be viewed in an alternative way, where the first four layers represent the foundations stones, or pillars, on which progress in the higher levels is built.

Diagram 2

```
                        Transitional
                          Recovery

                        Achievements

                   Hopes, Dreams and Goals

          Containing Experiences and Developing Skills
```

| Safety and Trust | Feeling cared for | Community and Belonging | Boundaries |
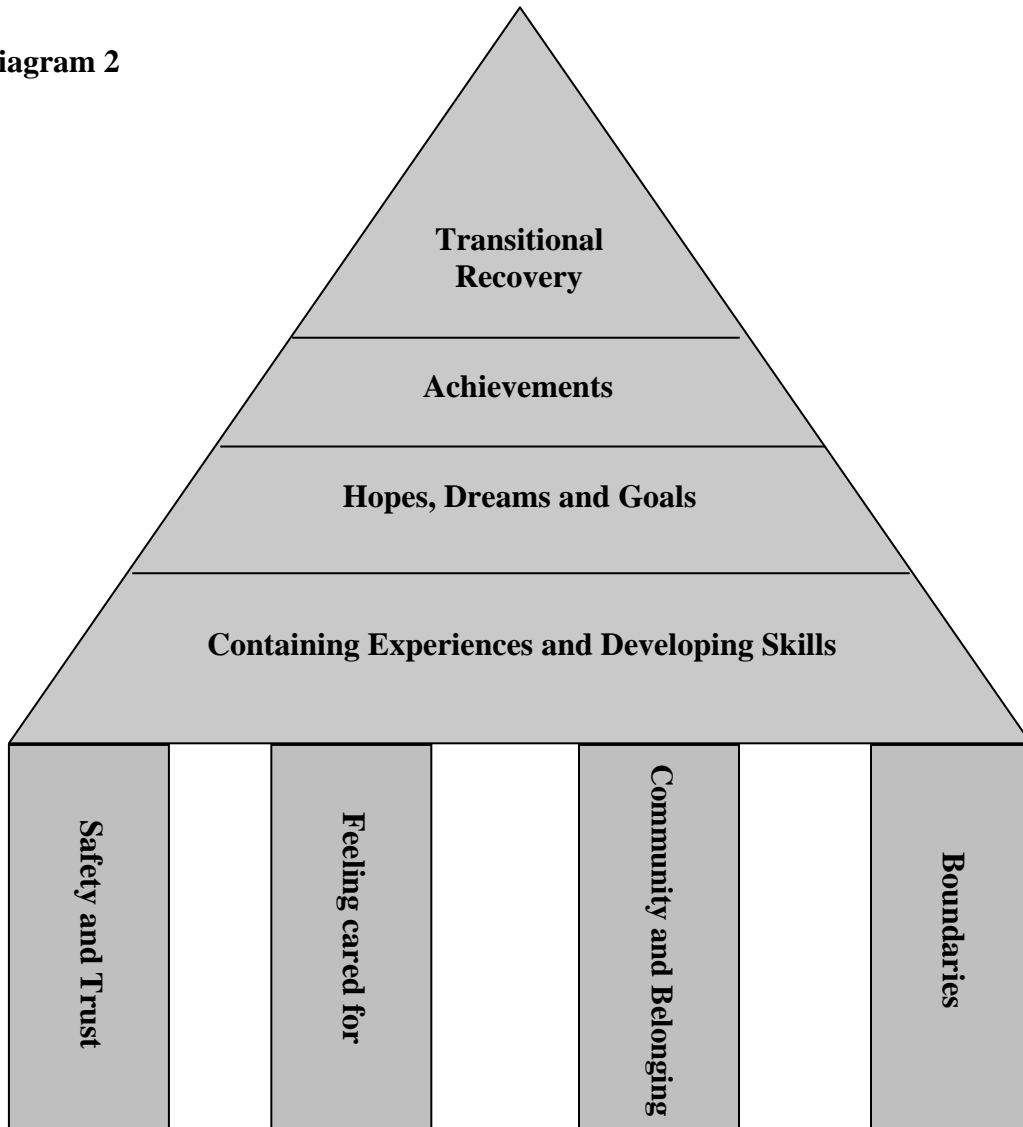
Prior to progress on the first four levels of the pyramid difficulties had been experienced, by many, in simply being able to ask for help:

> *Sally: Sometimes you can see that staff are all busy, but you're too scared though, and you go home feeling worse, but it's too late. Then it's hard to pick up the phone.*

> *Rose: Sometimes it is hard to pick up the phone so it is better that someone is phoning you.*

When this began to change for participants, sometimes after a year or more of using the service, they began to develop, what to them were, the new *skills* of being able to ask for help and accept support:

> **Sally:** *I just used to sit in my flat and suffer in silence, but now I'm picking up the phone.*

> **Rose:** *I am learning to actually ask for help before I act on things.*

Statements from the following participants indicate that their shift in the use of negative coping strategies is now intrinsically linked to asking for help rather than acting out:

> **Jenny:** *I used to self-harm a lot before I came here. Instead of doing that I've managed to pick up the phone. I used to like drink quite a lot as well, and knowing that if I do I can't come in here and speak to somebody, and I'd rather speak to somebody rather than pick up a drink.*

> **Fred:** *I'm also clean and have stayed clean. I could have gone back to using without even knowing it was wrong, which I have done in the past, whilst I've been psychotic still. Kind of like instead of popping a pill, I come here. Stopping drugs, feeling the emotion and learning from it.*

In relation to feeling safe and building trust, participants had already spoken about beginning to let emotion out and take risks in talking about difficulties. Next there came the process of beginning to analyse the experiences and emotions that were underlying their feelings and behaviours:

> **Bling:** *I was having an adult conversation, as a normal thirty-three year old would. All of a sudden something in my brain said, no that's not alright you effing cow, who do you think you are to judge me, well I'll see you in the effing hospital then when I've taken another overdose, bitch. When I got angry it was how the thirteen year old child, how the teenager would deal with things, instead of what I'd call a normal adult, and it would be something like, well I hope you die in a car crash on your way home, until I got the help that I wanted.*

> **Elise:** *I think my new skills have fundamentally been to be able to stop and question the reality of the situation and the most logical conclusions, and the most*

logical assumptions, and to think the whole situation through, rather than jump into the first panic stricken thought that comes into my head and act on it. It's the actual stopping and analysing the situation for what it really is, not what emotionally it's built itself up to be. That's the best skills I've learned.

The statements above highlight that changes in the use of negative coping strategies, and the ability to *contain experiences*, have not emerged in this theme simply by learning the boundaries but also by reflection and realisations during therapeutic work in groups and individually. Participants spoke about building therapeutic *skills* in a variety of ways, for example, by learning to write about their emotions:

> *Anne: I am finding Creative Writing extremely helpful, it's helping me to get a lot of my emotions out on to paper and being able to share them with other people as well has always been hard for me, but I've started to read out my work.*

> *Boris: Here I have broken the cycle of the pattern of behaviour into more constructive ways of dealing with it. Self harming, or picking up a bottle of wine, I tend more now to put pen to paper and let it out that way.*

Participants also spoke about learning *skills* in groups such as Life Skills and DBT Skills Group (Dialectical Behaviour Therapy):

> *Alexis: I feel I've really benefited from the Life Skills Group, it's reduced my obsessional behaviour and encouraged me to mix with others and has really boosted my self esteem. It's been very beneficial dealing with anxiety, positive thinking, how to control panic attacks, confidence building and particularly in dealing with anger.*

> *Lara: I'm learning an awful lot in DBT, mindfulness, thinking before you speak, trying to change your actions and the way you think. I used to go off the handle at anything, now I stop to think of a different way of coping with it and a different way of speaking to people and it's much more effective than just lashing out.*

Sharing with others, in a group situation, was particularly appreciated by some participants:

Emily: Substance misuse group is brilliant and everyone was so honest last week at what stage of their, where they were at, I found it very humbling and overwhelming the honesty in that group.

The response of one participant, below, is also considered further in the Discussion Chapter, and shows that a group situation was not appreciated by all participants at some stages of their journey:

Ben: I find the Life Skills Group very threatening. So much so, I haven't been able to sit through a whole one yet. All my one-to-ones are spent with me bubbling and them offering me tissues, but no way I've been taught techniques to help myself.

For others, one-to-one work was cited as the kind of support that had proved particularly effective:

Rose: The counselling I'm receiving, I have been for quite a while, is just fantastic. I had ten years of psychotherapy and I still managed to avoid the issues. With the counselling I think it's the fact that it's here. It makes me feel safer which makes me take more risks than I ever have.

Crystal: I find the one to ones very useful, although it can bring up the past and it's extremely painful, but is helping in the long-term.

Boris: I like my one to ones because I have a chance to be me, I can let my barriers down, I can say how I am really feeling, I can vent myself when I am angry, and I can talk through every emotion that I am feeling and the troubles I am struggling with at the time.

Family members and carers did not identify specific *skills* in the person they cared for, since coming to The Haven, but did cite an upsurge in motivation and a change in behaviour:

Rob: Since getting the help, she has got much, much better, and coming, she doesn't just come if she's in crisis, she comes and has a bed which she arranges in advance and uses that, and she really does work hard while she's here, talking

and making use of everything that's here. She's doing things at home she wouldn't do before.

Sammy: *I think it's been absolutely useful her being here, my wife. It's actually given her motivation that for many years prior to coming here, that we tried to get her to get up and do things. To actually see her wanting to do different things and actually doing different things in-doors now is far better. It's the motivation we've been trying to give her for years.*

Rob: *The person hasn't changed, the behaviour has changed.*

Alex: *Yes, I agree with that, the person hasn't changed, the behaviour has changed.*

Tony: *The self-harm and suicide attempts aren't as frequent.*

Finally, one of the components participants spoke of in this theme was a growing self-awareness regarding both the source of their problems and their negative behaviours or ways of coping:

Charles: *I've learned a lot about myself, that I've got problems in certain areas, sort of anger and stuff like that, and you know, alcoholism.*

Katy: *I've changed in lots of different ways and I've learned that the voices I hear are actually in my head.*

Harry: *I've been learning where a lot of my difficulties have stemmed from which is, hopefully, in the long term, helping me to overcome them. I am a lot more insightful into my condition. I pick up on things earlier so I can sort of try to change, avert a crisis before it happens.*

Chloe: *I actually feel that my behaviour has changed. It's become, in nursing jargon, more appropriate, it's less extreme, the majority of the time. I've self-harmed once, I've overdosed once, since you've been open and before it was numerous times. I'm now able to ask for help before I get to that stage. So I think that would say, perhaps, I am maturing a bit. My coping strategies are completely different now. I probably cope better than the average person on the*

street because I am more aware of triggers, I am more aware of negative coping, if you like strategies, rather than skills. I channel my feelings and emotions more constructively.

Hopes, Dreams and Goals

Finding *hope* is inherent within a number of levels of the pyramid, or hierarchy of progress, and this was expressed by respondents as a spectrum ranging from a sense of *hope* for the future to specific *hopes, dreams and goals*. However, realistic *dreams* and *goals* began to find their place in the themes only after progress on the lower levels of the journey. The Research Group had highlighted this in their sub-analyses of categories and had discussed the unified theme at the Research Group meeting in March 2009 (Research Diary p28).

Early expressions of *hope* included statements about wanting to stay alive:

> **Stony:** *When I first attended The Haven I didn't like myself, I was wanting to commit suicide. I never thought anybody would like me or love me in any way. Now I don't even, I don't want to die.*

> **May:** *Before The Haven I wanted to die. Now I want to live.*

Some family members and carers also discussed issues of mortality:

> **Rob:** *It's keeping her alive. I don't think she would be alive without The Haven. I know with my wife, she didn't want to be around, so there was no tomorrow and now she has hope.*

> **Sammy:** *We've had the conversation more than once, 'yes I am glad I am now alive, I want to be alive now, I want to be well, I want to carry on living'.*

Participants began to express the concept of *hopes, dreams* and *goals* in a very tentative way, often referring to the ability to simply get through the day:

> **Stony:** *I want to get on a bus and breathe at night without panic.*

Sally: To be happy, lead a normal life, and come off all meds. I can only cope with one day at a time.

Cosmic: My goal for many years was just getting through the day. I wouldn't know where to start.

Christine: The dream for me is taking one day at a time.

Lucy: Trying to feel next week like I've felt this week.

Some participants highlighted the fact that *hopes, dreams* and *goals* were a new and, until now, alien concept:

Emily: Do you know what, I never dreamed I could have hopes and dreams and goals for the future until sitting with this lot.

Tiffany: I can only say that since I've come to The Haven that I've actually got hopes, goals and dreams, because I've never had them before.

Participants then began to link *hope* to a concept of the future:

Rose: I look to the future more than I ever did. It exists now. My vision has changed. I didn't even think about the future before I came here. It was as much as I could do to survive today. I hated the thought of tomorrow. I never wanted it to come. I feel I am learning a lot and I would like to put that to some use.

Jonny: I think, well I know, I've survived it. The other thing is, I think The Haven gives hope to everybody, that there's something better in the future. So you're not written off.

Leska: I actually thought that I have got a future now, it was really bleak before, but it actually looks like there is something now. Now, when I am just unconsciously sitting there, I do find myself wondering and thinking about the future.

Family members and carers also identified *hope* both within themselves and for those they care for:

> **Rob:** *I think hope. They have hope. She can see the future.*

> **Sarah:** *They can see light at the end of the tunnel, they can see a bit of future really.*

> **Sammy:** *Yes, I do have hope for the future.*

> **Alex:** *Yes, I have never given up hope, ever, and recently, for the last six months I've had more hopes than ever. My daughter's turning the corner and able to live a fairly normal life, as normal as she can. I would say she seems better in herself, more able to perform the normal things that people do.*

However, one family member felt that hope had been lost and could not be invested in the future:

> **Tony:** *No, I'm so sorry, until (family member) puts drugs out of her life, no, none whatsoever. I'd love to be positive and, to be honest with you, it's hurt so much over the years I can't invest any more hope in (family member).*

Initially, some client participants also felt devoid of *hope*:

> **Igor:** *I've got no dreams apart from nightmares.*

> **Crystal:** *I've got no hopes dreams and goals. I feel empty inside.*

Some espoused the desire to show others who had harmed them that they could progress in spite of this:

Boris: *I have one goal I know I'll achieve and that's to turn around and say to all the fucking twats that have fucked up my life and say, fuck you, I've won, you've lost. If I can't achieve anything else in my life that's what I want to achieve and will achieve.*

Some expressed *dreams* about finding family life:

Stony: *I want to find someone to love me, someone to share my life with, and have a family and things like that, and be in a family.*

Poppy: *My dream is to find a nice bloke, get married, have kids and a dog.*

Some highlighted that hearing the progress of other clients at groups like Transitional Recovery gave them *hope*:

Milly: *I think that Transitional Recovery Group gives you a lot of hope.*

Wilf: *Seeing the people who have moved on to college and stuff, you can set yourself a little goal then, can't you. They've done it, so you know, maybe there's a chance.*

Over time, participants began to confidently and clearly define *goals* in education and for a career:

Ben: *Since coming to The Haven I've had an idea implanted in my head to go back to university and I'm at the stage now where I'm getting the curriculum and believing I might be able to do it.*

Alexis: *I hope to do Mathematics.*

Poppy: *My goal is to get through college and do my degree.*

Katy: *My goal is to go back and do my MA. That's my long term goal.*

Boris: I would love to train to be a social worker. I want to work with children. I'd rather help children younger, try and steer some kids at a younger age to go out there and chose the life they can.

Jenny: I now want to do my Access Course and I want to work in care.

Harry: My goal is to actually work here on bank staff.

Also, participants were very clear that, over time, their *hopes, dreams* and *goals* began to be more realistic:

Elise: For a long time my little aim was to come back and work at The Haven. I do think it would be a very noble thing if we did have people who were former clients coming back to work but, as I've gradually got better, I've discovered there's a whole world of possibilities and employment prospects out there and it doesn't have to all centre around this sort of several walls The Haven is, and I think for me the significant breakthrough is realising there's other things in life that would be just as enjoyable as coming back to work for The Haven. I'd actually like to go and get a decent job and earn a reasonable amount of money so I can have a nice life style to go with it.

Katy: My hopes and dreams are becoming a lot more realistic.

Chloe: Everyone has the potential in them to succeed, but it's about taking it each step at a time. It's about setting achievable goals.

Achievements

This emerged as an obvious theme to be placed near the top of our pyramid of progress. What participants felt they had accomplished included components that represented both internal and external *achievements*. This interplay between the development of personal qualities, such as confidence and self-esteem, and their external expression, characterised their responses.

The importance of building practical skills which have a bearing on life outside The Haven was highlighted:

> **Sheila:** *I am learning to talk a bit more and that helps me outside. Just mundane things like going to the bank, I can actually speak to people behind the counter without just standing there and grunting at them.*

> **Leska:** *One of the biggest new skills I'm learning is how to be a Mum, and I suppose another big skill I'm learning is to try and stand on my own two feet and try to deal with stuff, instead of asking The Haven for so much support, how to be patient, how to interact with someone who can't talk, and to love someone who's so dependent on you, learning to love you could say.*

> **Tiffany:** *When I'm in a crowd I used to have to walk out, now I find I can stay in a crowd a little bit longer. It's a skill for me to actually get on a bus and a train.*

> **Jasmine:** *I never used to like going on public transport or getting in a car because of panic attacks, but since I've been here I've been able to get on trains and on the bus.*

A sense of empowerment and having choices, and a voice, in relation to gaining confidence and self-esteem, were also cited as an *achievement*. The analogy of finding one's backbone was mentioned more than once:

> **Boris:** *The Haven is completely different to any other service I have ever used. In every other service you don't actually have an opinion or your voice isn't heard. At The Haven your voice is heard and your opinions taken into consideration, and everyone is treated individually here and you're not a number anymore here, you're your own person. I suppose the dominant skill I'm learning at The Haven is being more confident that I can achieve more than I think I can. I am stronger in my beliefs and I fight for what I think is correct.*

> **Elise:** *It's been the backbone to make life changes that I've needed to make for a long time. Fundamentally, it's given me the confidence to go and be my own person and to leave the relationship that was holding me back as a person, and that's been because I know I've got the support here that I can now go and stand on my own two feet. I've got a lot more self respect, my self-esteem's definitely improved, but it's basically self-respect.*

Ross: It gives me support, boosts confidence and gives me something to focus on. The Haven, for me, it's like having an extra backbone.

Discussion occurred, during the course of the study, regarding whether participants spent less time disliking themselves which, considering a starting point of what was often a high degree of self loathing, was considered an important *achievement*. Here results were plotted against time at The Haven. Forty-eight clients responded to this question and 36 answered 'yes' or expressed tentative improvements. Twenty-one of these had been at The Haven for at least two to three years:

Harry: I think I used to dislike myself a lot. I don't actually dislike myself now, although I dislike my behaviour at times, which is a massive difference and I'm actually able to go out and buy new clothes. So being able to spend money on myself has come from being at The Haven and being made to feel worthwhile.

Brunhilda: At The Haven you get so much positive feedback and just logically, if quite a lot of people think that you are a decent human being, logically you must be. Eventually, yes, you get re-programmed, it definitely does filter through.

Doris: I've learned a lot about myself. I rediscovered the fact that I am good, I am not as bad as I think I am.

Fred: I think how far I have come. When I think of that, I think no, I have done really well, and I know now, it's not an excuse, things that happened to me while I was in care and on the street, it wasn't my fault.

Chloe: There are things about myself that I do like. There are qualities and parts of my character that I think of as valuable and specific to me. So I value myself, so yes I do spend less time disliking myself.

This was sometimes combined with a sense of finding oneself, or 'the real me':

Rose: The change is due to actually learning who I am, I've been something else before now.

> **Donald:** *People have helped me to reach inside myself and get back to the cheeky little monkey.*

> **Leska:** *I've started to find my identity and I've started to live life again.*

The remaining 12 participants, who answered 'no', included some who had not been long in attendance at the service. Resistance to recovery is considered further in the Discussion Chapter in relation to four of the 12 respondents who had been at The Haven for two to three years and, although other improvements had occurred, this did not yet include *achieving* a change in their internal sense of self:

> **Sally:** *I still dislike myself. I don't know if it will ever change, it's always as far as I can remember for such a long time ago, that's just how I feel about myself.*

> **Jasmine:** *No I still hate myself but my feelings here have changed, I'm not 136'd so often now, the police station used to be my second home.*

One participant reflected on a spectrum of progress from negative hopes, dreams and goals to *achieving* further education:

> **Jenny:** *Before I came to The Haven I was locked up in a secure unit and my only hopes and goals were to end it all. I've changed everything really, my hopes, dreams and goals, and the whole vision. Before I came to The Haven I used to wake up every day wanting to die, finding a way, thinking of a way that I could harm myself while I was in hospital, trying to trick people into thinking I was okay, trying to sneak things in. That was my life, trying to find a way to actually harm myself, to actually end it all, and now I'm actually going to college.*

Others spoke of *achieving* the confidence to start voluntary work, tackling stigma by training professionals, and reflected on not just having hopes, dreams and goals, but *achieving* them:

> **Cosmic:** *I've had the confidence to start voluntary work because you had the confidence in me to show me the advert, see, for the job, so there.*

Harry: My confidence has risen enormously. A year and a half ago I was never leaving the house. I like the fact that when I do the Personality Disorder Awareness Training all the professionals there, they're actually looking up to me, and that's a big thing because I've always had very low self-esteem. I've always been a campaigner for mental health and I want to try and make a difference nationally. My hopes and dreams, they're not dreams anymore because I'm doing it with the Personality Disorder Awareness Programme.

In a report, compiled after the first year of operation of the Social Inclusion Unit at The Haven, research participants spoke about their *achievements* in the different domains of social inclusion. We decided to use quotations from the report which had been made by clients who were also participants in this study. This included activities aimed at tackling stigma and discrimination, where their words quoted below, about a photography workshop and other creative activities held at the project, were also featured in articles in the local press:

Jenny: I'm glad this workshop is happening because it will help deal with the stigma we face. People tend to be quite funny with you when they find out you have a personality disorder but that's because they don't understand what it is.

Boris: If by doing this exhibition we can change one person's opinions about personality disorder then we will have done some good.

Another participant spoke about her *achievement* in finding a real home for the first time in her life:

Brunhilda: This is the first time I've had a place that feels like home. It's therapeutic in itself to be at home with my cat and potter about in the garden. I've never had a garden before and you never know what is going to grow and some things surprise you when they grow. It's such an excellent de-stressor. You know Maslow's Hierarchy of Needs, the pyramid, I've always tried to live on the point and things have been upside-down. At last I'm getting my foundations correct.

One participant highlighted *achievements* in leisure activities:

Poppy: I've been on Theatre trips, Kew Gardens, Zoos, Garden Centres, Wild Life Centres and other towns and cities like Norwich. It's just nice to have found friends who have the same interests. I feel more part of the outside community. I have widened my horizons and it has definitely increased my confidence and enjoyment in life. I feel I can socialise more because I have interests and hobbies. I have things to talk about other than mental health. In fact I don't talk about it anymore and I have been discharged from mental health services now anyway.

Another reflected on *achievements* in building skills learned at Parenting Classes:

Jimmy: One of the traits of having personality disorder is seeing things as black or white, good or bad, so it was hard to relate to the lessons to begin with. I think we've all learned a lot of positive tips and positive practice, like not rewarding negative attention seeking. I think we are here to learn to see our children as human beings who are owed respect and, in that way, they will learn to respect us.

Some participants reflected, in the report, about their *achievements* in education:

Natasha: 2007: I started Access Planning Period on 17th April. At first it was quite nerve wracking, sweaty palms, I could hardly hold a pen for the first two weeks. During the first week, after the first two sessions, when I got home I had a panic attack. It's improved now and I'm starting to relax more easily. The academic side is fine. I'm not struggling too badly and came second in the class for English test, not too bad. That was A to C standard GCSE, the best you can get, and I got that for English and Maths. I didn't do too badly at school, so for me it's not so much course content, it's more about confidence and managing anxieties. I feel good about it. I kind of feel proud I suppose, that I've managed to get this far. 2008: I am now on the Access Course and I've got an exam next week which means I'll be finished the first year.

Pablo: I've been on a hairdressing course for the last few months. To start with it was really difficult and this was the fourth or fifth time I've tried and never got past the second session, second minute! I'd just go in there and say …… "ah, I need the loo" …… and I was gone. This time I went with the pain and the panic in a way. It's like a drama in your head, a self-whipped-up drama. I toughed it out this time. It's different when you're not influenced by any intoxicants in your system. I feel confident now. I just cut four people's hair this morning. It's not really confidence, it's being absorbed with the skill you've learned, but it comes across as confidence. I used to be like an oak tree with twisted roots. Now I'm a sapling beside the old oak tree and sometimes I still live in the shadow of it. But the sapling is growing. I've even planted an oak tree in my garden to symbolise it.

Another described *achievements* in voluntary work:

> ***Tiffany:*** *A visit was arranged to a local Animal Rescue and Rehabilitation Centre. I successfully secured a place for two days a week which I thoroughly enjoy. It has given me a routine, some structure to my week and most of all increased my confidence. When I work with animals, I feel different, I know that I will not get any hassle, any abuse, I get unconditional affection and love which I sometimes do not get from my family. I had no purpose in life but over the two years of being here at The Haven and getting support and working with animals. It has helped me to overcome my agoraphobia, my panic attacks.*

Others spoke, in the report, of perspectives and *achievements* in employment:

> ***Milly:*** *I want employers to recognise that, given a supportive working environment, mental health service users are employable, reliable and responsible people. I feel it is now up to mental health service users to be more open and honest about their diagnosis and have a say. It is up to us who we tell and what we say but by being open and honest I feel I have started my journey of recovery. I am still on my recovery journey and have outside support for my diagnosis from The Haven, which is helping me to stay well.*

> ***Elise:*** *I'm actually working now and earning a reasonable amount of money, but there is a massive stigma around this diagnosis and I wouldn't disclose to any of my colleagues that I had personality disorder. I have been working in the education sector for over a year now. The Haven was instrumental in helping me to make a breakthrough in my life and learn to stand on my own two feet and support myself financially. Working gives me a sense of purpose. It's very easy to slide into the diagnosis and not try to do anything. Although it has been difficult, so difficult, my self-esteem and confidence have risen massively.*

Transitional Recovery

The Research Group had begun to discuss the concept of *Transitional Recovery* in 2006 (Research Diary p13). By 2009, the consensus within the Research Group was that this theme should form the final, and all embracing, apex of the pyramid (Research Diary p28).

Although steps in the journey of *recovery* are expressed throughout the pyramid of progress, this theme concerns how participants defined *recovery* and shows the fears, barriers and progress on the journey. Some family members and carers expressed strong and clear opinions about the concept of *recovery*:

> ***Sammy:*** *Recovery is an individual thing. It is not necessarily, as a lot of professionals will lead you to believe, about getting a job. At the end of the day, for some people, it might just be getting out of the house for the first time in five years. It's an individual thing; it isn't a model, although some people try to tell you it is. It's a concept and it's an individual concept. It's not about government targets of getting a million people off of incapacity benefit. It's about a journey that somebody takes, and The Haven is assisting people in making that journey. Recovery is a goal for the individual and little steps along the way.*

> ***Dinah:*** *I don't think recovery will ever be a position where you are declared well and put all this behind us, it won't be like that. I think this is going to be one of those things that will go through my partner's life forever and that certain trigger points, crisis points, certain issues will set her off again and we'll take a step back and there'll be times when we take a few steps forward and life's comparatively easy. How I define recovery for my partner is that she has her own life, and she feels capable of doing things outside, meeting friends, having a bit of a social life, where I'm not standing behind her propping her up or anything, and she has a little bit of a life of her own, and doing the shopping without having a major panic, that's recovery, it's not a set definition. She's never going to hold a job down in a million years. I think my partner's always going to be happy to do a bit of farming, or looking after animals, a much easier life, where the demands are there but in a different way. I think that will be recovery.*

> ***Rob:*** *Once you start understanding what the problem is then you can start to work towards a better way of carrying on, mustn't say cure must we. I just think it's the individual thing. One thing I did think is there's no definition, but while they are moving forward they're in a state of recovery. If they keep moving that's good.*

One family member did, however, conceive of *recovery* as regaining employment:

> ***Tony:*** *She used to be in a good job, and I don't understand what happened. We had a series of difficult things happen, but then we've always had a series of difficult things if you go back through our family history. We've had physical abuse, sexual abuse, through my family, children given away, so we've had so*

much stuff going on. What I don't understand is how she functioned for so long. So why have we got this shell of the person we had before?

Some client participants also defined *recovery* as normality and achievements in the outside world, such as employment:

> **Stony:** *Getting on with life, having a career or a job that you like, and liking yourself.*

> **Katy:** *My recovery would be having my family back with me, going back into education, having positive steps forward and regaining my employment status.*

> **Natasha:** *A more normal life, perhaps even working.*

However, many respondents felt that the concept of *recovery* was very frightening because of a fear of failure:

> **Sally:** *I'm thinking do I want another job or don't I want another job, am I capable of wanting another job, would I be able to do it, would I have the confidence, or how long would it be before it goes wrong?*

> **Boris:** *I think recovery is frightening because for so long in my life I had so many people telling me I was never going to come to anything, spend my whole life in hospital. I am petrified that I am going to fail and I am going to prove everyone right. I sit there and I work on my journey to change things with the whole doubt in my head going, what happens if I don't achieve this, what happens if it goes wrong, what happens if I still go backwards?*

> **Chloe:** *Success can be frightening. What if I fail?*

> **Fred:** *The world I was in before was so black. I was petrified of becoming well and failing every time. Before I wanted to be dead rather than fail again because I just couldn't handle anymore failure.*

A fear of the unknown was also cited by participants as a barrier to *recovery*:

Elise: I think there's an awful lot of people at The Haven that have lived in a world of inner torment for so long, and have lived a psychiatric based life for so long that to move away from that, even though they don't particularly like the life they have at the moment, but to move away from that and take on something new, with a whole new perspective and everything, it's always going to be scary. It's like moving to another country or a new flat. The change is what's so scary because it's so unpredictable.

Crystal: With recovery you've got to change, and change through life, there's always changes, but if you are the type of person who doesn't know how to change, or has never been taught to change, then it's very hard and you are stuck in that time warp and you have got to find a way of trying to move on.

Alexis: Extremely frightening! We're used to living with what is most familiar to us, it's our routine and it's what goes on day to day, month in, month out.

Eustace: Maybe the process towards it is frightening. Where does it lead you to?

Fear of the unknown was also described as being linked to a sense of identity, not knowing who 'the real me' is, and whether this will be acceptable to self and others:

Sally: Sometimes you don't know, it takes time to find out who you are and to start to try to change who your are, that takes quite a while.

Abigail: I find recovery is knowing yourself and it's very frightening because you're suddenly finding something that you have never known before and accepting them for who and what they are. I think the frightening thing is that you haven't got that person that's at the end of the line.

Boris: I know I am only the person I am due to where I've come from. I'd like to think that once I had recovered that I was always the same person but there's always that fear inside me that I might not be that person.

Milly: It's frightening for me because I don't know whether, by recovering, I'm going to lose my relationship, because I don't know whether my partner can accept me if I change.

One family member spoke of how the diagnosis of personality disorder had come to define the person they cared for:

> **Tony:** *Since she's had the diagnosis, the title, she has completely given in to it. Whereas prior to that she used to fight, she used to try and do things to rationalise things, to work through them, whereas I've found, since she's had the personality disorder diagnosis she, I know it sounds hard, but she almost uses it as an excuse, 'I'm in crisis, I'm not going to deal with this, I've got a personality disorder', and gives up, and never actually challenges what it is that's causing the problem.*

Some client participants also made powerful statements about being defined by the diagnosis and a world of mental illness being all they had ever known:

> **Ben:** *Very frightening! Personality disorder is all I've got. If you take that away I've got nothing left.*

> **Sheila:** *Yes, because it's all I've ever known, is this personality disorder, all this mental illness, ever since I was very young.*

> **Kim:** *Fucking scary, cos I've never known recovery. I've been in and out the system since sixteen.*

Some respondents clearly stated that they felt it was too late for *recovery* and, again, this barrier is discussed further in the next chapter:

> **Gemma:** *I think when you've spent half your life, it's a real struggle. I've found that, since the age of fourteen when I started self-harming, over the years I have picked myself up, and now I have gone down again without realising it. In the end you can be so sick and tired of the struggle. You know the will to do it is so hard, it's just so hard. I don't have the energy the strength or the will. Literally last week I tried to end it. I woke up three days later. If I'd had the support, like there is nowadays, with phone lines you can ring, with better understanding of mental health, if that was the case when I was fourteen. I was in hospital when I was sixteen. If I was sixteen now I would not have gone backwards and forwards into hospital all my life. It would have made my life completely different if I'd had the understanding and not just be called attention seeking because it wasn't, it wasn't.*

Abigail: Yes it's frightening, I can't change and I don't want to change.

Phoenix: I hope that I recover enough to define recovery because I really do not know what it is and where it is or if it's possible anymore. If I was able to do something like cure world poverty I don't think that would ever be enough. I know a good line from a song which goes, 'dying is easy it's living that scares me to death', and I think that maybe says it for me.

Despite progress on the lower levels of the pyramid, significant barriers to the concept of *recovery*, as employment, were also highlighted by some of the more mature participants in relation to risking what progress they had made:

Tiffany: I'm frightened of getting well then not being able to work. Like coming off benefits, that's what frightens me most.

Cosmic: At fifty-one to say that I've recovered is putting a hell of a lot at risk. I'll have to be forced out of this safety net, not that I'm lazy. It's the Government want to get people back to work, and that's what this is, isn't it. I'm getting DLA (Disability Living Allowance), rent paid, but I've got a dread of going back to what it was like before. I would overwork, do all the hours under the sun, then come down with depression and alcoholism. I might self-harm then two weeks later get back on my feet and be able to do agency work, work myself to death again. To become a more ethical person, yea, to be able to live in the here and now, to be able to forgive, to be a better Dad, but a career, because of my age, I think I'm over the hill on that one.

Brunhilda: I personally haven't been much to the Transitional Recovery Group. I actually don't feel very comfortable to be in that group. I think it might be something to do with being older and perhaps, I've done courses, you know careers, that kind of thing doesn't seem quite appropriate for me, so I don't know. I think recovery is frightening because in my imagination it means losing security that I've now got, which I've wanted for so long. I am aware that for a lot of the time nowadays I feel like I am in a comfort zone, but that's such a novelty, something that I've never experienced before. I've never experienced this sense of contentment that I sometimes get. It's such a novelty and I feel that I want to just actually allow myself to enjoy having a comfort zone.

One of the participants in the study, who was now working, confirmed that the world of paid employment can be a large leap to take:

> **Elise:** *Under the current benefits system you are either at work or on benefits, there doesn't seem to be anything in between. There have been some welfare rights concessions, but this needs to go much further. I could not have gone part-time and back to work gradually. I live on my own and organising partial benefits isn't an option, yet a staged introduction to work would encourage many more to try it. Instead it's a complete paradigm shift. Where's the middle step?*

Embarking on a road of *recovery*, possibly against the odds, some participants began to express excitement and desire, despite the fears and barriers:

> **Ian:** *At the beginning I think it is because it means you have to take a lot more responsibility and sometimes it's scary that people aren't around so much, and you have to deal with things a lot more on your own, but afterwards it makes you proud.*

> **Curtis:** *I used to think it was frightening, because it's such a big step, but now I find I'm looking for it, I'm wanting it.*

> **Rose:** *Yes I think it's frightening, but I also think it's exciting now.*

This desire for *recovery* was highlighted by other participants as a key ingredient on the journey:

> **Doris:** *All the help in the world is great but you have got to want to get to where you want to be. It's nothing you can be shown. You have just got to get your own fight back.*

> **Charles:** *Wanting to do it is the main issue. There's nothing wrong with slipping back, it's trying to learn from it.*

A recurring sub-theme in *recovery* for participants concerned fear of losing The Haven. This was expressed by family members and carers as a fear of the service losing funding, or getting too big, or clients getting too well and being asked to leave:

Rob: I always worry about The Haven being there. That it'll grow. Your community has a size at the moment that obviously works.

Sammy: I have a bit of a concern the person I care for expressed to me. What happens if The Haven sort of consider that she has got to a point where they can't help her anymore? The problem is what she's worried about is if she's been under mental health services for thirty years. I think this is the fear of, 'well everyone perceives that I'm, you know, I don't need this anymore'. There are different labels, but within the label everyone is still an individual and that's what gets lost in the majority of services that isn't lost here. It would be if you tried to double your capacity. What's wrong with general services is they are trying to support everyone as best they can, and for some they do it very well, for some they do it very, very badly, but for the majority of people they just do it averagely. Here, for 90% of your clients it's an individual and absolute positive.

Dinah: I do fear for the funding. You continue to get your funding and I know it's difficult in this economic climate. I've seen the economics cut £10,000 where it would save you £50,000 later.

Sarah: I would just say let's hope it carries on being here.

Client participants also expressed concern about losing The Haven and made it clear that progress could be greatly enhanced by knowing help is still on hand when needed:

Cosmic: Well, if I saw a tortoise on its back I think recovery would be putting him the right way up, because that's something he can't do for himself. There's no way a tortoise wanted to get on its back and it was there for circumstances beyond its own control. So, if you help him by putting him back on his feet, and he goes plodding along at his own pace, then who is to say those circumstances won't arise again. So I don't think we can actually confidently say, now I've recovered, you see, but as long as the Tortoise Rescue Centre is still there we'll be alright.

Pablo: One of my first questions when I very first came here, I said, is this a conveyor belt to chuck us in and chuck us out, get us well, I said, or is this a firm base that stays here forever? Just hold my hand on my bad days. I hope that's not too much to ask.

One participant bravely voiced what we felt many Haven clients feared, that is, losing their base and the sense of home some had achieved for the first time in their lives:

> **Brunhilda:** *When I think of recovery I get very frightened because I think recovery is like being on the top of a mountain and if I've recovered it means that I won't need The Haven anymore, and I cannot imagine having no more contact with The Haven.*

Because the word *recovery* could potentially become synonymous with the idea of loss, it became crucial to define the top of the mountain, or the apex of the pyramid, in a human and tenable way, that is, in a way that was going to work. As a result, the concept of *Transitional Recovery* was born, meaning that progress would be defined as a journey of small steps and progression would not be penalised by discharge but rather rewarded by continued support. Remaining registered at the project, despite progress in the outside world, would also be contingent upon using the service less but knowing it still existed as a firm base:

> **Charles:** *I don't think we should clip our wings, we just need a nest to come back to.*

The Haven already espoused a philosophy of not rewarding negative behaviour, as described in the 'Learning the Boundaries' section of the findings, and some respondents also pointed out the necessity of focussing support on positive progress rather than creating dependency:

> **Cosmic:** *The staff could be more accessible and stop spending all their time on attention seekers and people that just go home, get wrecked and come back, and are on that cycle. I think alcoholism isn't named for what it is. I think there's too many people that are not using self management skills and becoming independent. I don't see The Haven as a place to land, it's a place to touch down and spring from.*

> **Elise:** *I think, fundamentally, people with PD need a certain amount of love and care and TLC and pampering and I think The Haven's taken that well on board*

and has supplied that, where other statutory units have failed dismally. I do think it's very easy to pour out the love and concern and that's so important because so many people haven't had that, but then I think there's a danger that that then becomes an emotional crutch and people don't particularly want to move on. That dependency shouldn't be fostered; it should be actively discouraged in a very gentle way. The programme of activities that runs needs to be constantly developed towards developing life skills for people so that, at the end of the day, they can actually go out and live that life.

Participants now began to define recovery as not necessarily being cure or a loss of symptoms, but rather a realistic progression of small steps and achievable goals:

Ross: *To regain control. We spend too much time looking for a cure when there is none. We can only learn to live alongside our illnesses by re-thinking the way we think, to retrain the way we go about our daily lives and to learn to use our past experiences to guide us to where we want to be in life rather than carrying on the way we do.*

Brunhilda: *Is personality disorder an illness or a disability? Because, if it's an illness, there's a possibility of a cure but, if it's a disability then the way to approach it, just as it is of a physical disability, is that it's possible to learn to live a fruitful life.*

Chloe: *Everyone has the potential in them to succeed, but it's about taking it each step at a time. It's about setting achievable goals.*

They also began to describe their progress as a journey of *recovery*:

Doris: *I think the journey to recovery is like a road up, a country road that's full of speed bumps and windy corners, and you travel along it and you think, yea you're getting somewhere, then you go over a bump and you get set back a bit, but you have to keep going and eventually you'll get to the end of the road and you'll find another road that goes somewhere that might be less bumpy.*

Elise: *It's an ongoing process, you never actually get there. You are always recovering. For me recovery has been able to actually function on my own, with minimal support, because of the things I've learnt. So, for me, recovery represents now. I'm well into recovery because I've actually developed enough internalised strategy in my brain to cope with things when they go wrong without*

resorting to emotional crisis. So therefore I would say I am in recovery. But, to be honest, I think everybody's in recovery from the minute they enter the door way of The Haven, unless they desperately don't want to help themselves, because recovery is a journey and it starts with admitting that you've got the problem to be there in the first place.

Jonny: *I think recovery is part of the journey and it's like change in anybody's life, it's scary unless you continue with the journey. That's probably the most positive thing that The Haven has given us, the chance to continue our journey and to progress, and that's the most important thing, the journey.*

Jenny: *It's probably the hardest thing I think I have done in my life, and I'm not even there yet. I don't even know if I'm half way there. I don't even know what 'there' is like. I believe it's a journey, but I don't know if the journey ever ends.*

Research participants now spoke of their progress in the clear knowledge that the concept of *Transitional Recovery* meant support would be ongoing, as they moved forward:

Doris: *I love Transitional Recovery, I absolutely love it. I think it's the group I get the absolute most out of, and I know that quite a lot of people here feel the same. It's a very empowering group, it's a group that gives you a chance to move on, it helps give you the tools to move on. Since the Social Inclusion Department has opened at The Haven I have been in college for almost a year and I have had considerable help from the Transitional Recovery Tutor with my numeracy and I have passed my level two in this subject. Transitional Recovery has aided in re-affirming my strengths in all areas of life.*

Brunhilda: *If you feel well rooted then, like a tree, you can kind of branch out and blossom.*

Cosmic: *I've learnt to take more risks lately, because I've got a safety net here, if things go wrong, there's people I can depend on.*

Katy: *With the risk bit, it's sometimes worth taking as long as you know you've still got support.*

Boris: *Though the past has not left me and there are a number of issues I still have to address, I am starting to get the life I now want, the life I have dreamed of*

since I was little. I am not doing what others ask of me I am following my dreams and my dreams alone. I now attend college and am currently seeking employment. I feel that I have lots to give and would be able to manage a job as well as my illness and I will still seek the support from the Transitional Recovery Group and staff to support me if I ever have a difficult patch and need some help or guidance.

Pablo: *The Haven is consistent, it's been progressive and forward thinking, which is not a stale thing, it's not just something you go back to, it's something you go forward with. Anyone who tries to hold you back, they'll either be back at the (hospital), or back in the situation they were before. If you hang on to The Haven you go forward.*

Transitional Recovery, as the apex of the pyramid, remains a developmental and flexible concept, where clients can continue their journey of *recovery* by defining and pursuing their unique goals and dreams, and where they have a choice about whether to remain registered at The Haven. *Transitional Recovery*, as the apex of Diagram 1, embraces the whole pyramid and, in the following chapter, a further discussion of this concept is included together with an exploration of the relationship between key themes.

DISCUSSION

THE THEMES AND THE RELATIONSHIP BETWEEN THEM

This chapter provides an overview of the hierarchy of themes in the journey of recovery for personality disorder identified from the findings and it discusses aspects of each theme in relation to relevant literature. Participant quotations continue to be used in this chapter to give a sense of the service user voice being maintained throughout the thesis. Maslow's (1943) pyramid of the Hierarchy of Needs is a guide to the growth of an organism and a well-lived life. Although there are differences which reflect the specific needs of those with the diagnosis of personality disorder, this concept has been used as a template which lends itself to the journey and growth experienced by our participants. The journey might have been represented as a chart, reading from left to right, or a stairway climbing upwards. However, the concept of a Maslow-type pyramid captured not just my imagination but was also considered to be inspirational by the Research Group and other research participants, because it seemed to ideally represent a personal journey of growth. Each level of the pyramid is discussed in sequence, from the base upwards, and this represents a synthesis of the recovery concept, as a way of understanding the process of recovery for people with a personality disorder diagnosis.

Attachment and Trust

Basic trust is associated with secure attachment. Campling (1999) proposes that severe personality disorder is related to insecure and disorganised attachment, where an infant

may freeze on separation and be unable to sustain organised patterns of behaviour. She suggests that such experiences yield a future generation of people with personality disorder. Therefore, in working with someone who has a personality disorder diagnosis, trust has to be created in a very tangible way. In the analysis of themes in this study *a sense of safety and building trust* has emerged as the foundation stone on which progress may be built, and participant quotations which demonstrate this are highlighted in the preceding chapter and in Appendices VII and VIII.

When someone begins to feel safe at The Haven and starts to build trust they have entered a safe environment and become part of a containing group. The Haven aspires to be a sanctuary which has a sense of safety and home and which is a place of refuge and protection (Bloom 1997). Participants have expressed the tangibility of the sense of safety they experience:

> ***Igor:*** *You can feel it when you walk in that door, you can feel that safety. It's a safe place. It helps you to be safe.*

Predictability and consistency appear to be important ingredients, as is availability evidenced by participants highlighting the fact that The Haven is there 24 hours a day. The 24/7 availability of the service was explicitly given the highest rating by participants, of 28%, in answer to the question about how The Haven helps them, and it was implicit in other responses:

> ***May:*** *It makes me feel very safe and secure to know it's always there. To me it's safe 24/7, it's a haven. That's what it really means.*

It exists as an object even when someone is not present at the service:

> ***Abigail:*** *Its all round 24 hour support is something that I've really found helpful knowing that there's someone there, it gives you a sort of safety net.*

Intensity of emotional pain and fragility of identity require a leap of faith on the part of an individual to reach out for help. Knowing that somewhere is safe and that people there can be trusted is a necessary enabler:

> *Fred: I used not to talk, it made me vulnerable in speaking, you know, you are opening yourself up for ammunition or further abuse, but I'm learning to trust more, and to ask for help.*

The basis of a safe world is founded on the ability of care-givers to be there for a baby or child throughout episodes of unbounded distress and intolerable feelings (Haigh 1999). Winnicott (1971) describes a secure child as one who is able to express destructive emotions, 'hello object, I will destroy you'. Consistency and containment are cited as essential to the therapeutic alliance. In a therapeutic community this is a fundamental component of the therapeutic milieu. Here, safety and trust are generated when primitive feelings are re-experienced and are accepted without rejection. This is the foundation for a safe world where one can survive:

> *Igor: It's through this place that I've learned I don't have to hide my problems, I don't have to hide behind a smile anymore. I can come in and cry, I can be me for once. I think the important thing really is that coming here makes you safe enough to change.*

Aiyegbusi and Norton (2009) describe the function of containment in a hospital inpatient ward as maintaining physical well-being, relieving someone of the burden of self-control and temporary removal from the stressors of the outside world. However, they highlight the likelihood of suppressing the patient's own initiative and magnifying feelings of hopelessness. Conversely, an authentic *sense of safety and trust* is described by participants in this study as generating an increased ability to take risks and a new ability to talk instead of engaging in self-destructive behaviour:

> *Rose: It makes me feel safer which helps me take more risks than I ever have. It's really working, I've learned to trust which enables me to talk instead of taking things out on myself.*

Creating a Culture of Warmth

The word *care* is common parlance in the psychiatric arena; 'Community Care'; 'The Care Programme Approach'; 'Care Planning'; 'Aftercare'; 'Evidence Based Care'; 'Secure Care'; 'Quality of Care'. But what does *care* mean? The Oxford Dictionary definition of *care* is, 'serious attention and thought; to be concerned or interested'. The concept of *Feeling Cared for*, the second step in our pyramid of progress, also suggests warmth, comfort, nurture and being valued.

It has been suggested that 'care' is not necessarily consistent with a therapeutic community approach and that self-reliance should be the emphasis, rather than making cups of tea for clients or always responding to their pain with soothing words (Tucker 1999). It is true that at The Haven, facing the enormity and complexity of problems, care is not always a sentimental concept. In addition to warmth, other responses are also called for, such as toughness, consistency and honesty. However, The Haven may differ from some therapeutic communities in that respondents in the study clearly defined what they felt were the component parts of *Feeling Cared for* and expressed their need for, and deep appreciation of, such responses and the relationship they have to the first step of the pyramid, building trust.

The staff team, from the administrator and housekeeper to volunteers and the clinical staff, all understand the vital importance of first contact. The warm welcome and

friendliness at The Haven is a frequent cause for comment by visitors, including family members and carers, as follows:

> **Sarah:** *I have to say that I just think The Haven is just a calm, happy, just a caring place.*

Participants emphasised first contact responses as follows:

> **Phoenix:** *They always look pleased to see you coming through the door.*

> **Fred:** *I've phoned when I've been in crisis and I've always been welcomed no matter what my mood or what's going through my head.*

Participants rated the caring nature of The Haven second highest, at 22%, in their answers to the question about how The Haven helps them, and this was implicit in many other responses:

> **Norris:** *It's the sort of place you can get a hug or give one.*

> **Gemma:** *The calmness, softness of the staff they make you feel …… they make you a cup of tea or coffee and they listen, they listen.*

> **Doris:** *It's been excellent, a kind ear, a cuddle, cup of tea, respite when I need it.*

> **Sally:** *When I have been really down I have been taken into a room and they have made me a cup of coffee and they wouldn't let me out of the door until I have got myself together.*

Creating a culture of care in terms of warmth and kindness becomes how a place is. Thoughtfulness and kindness can be infectious and, if clients are treated well, they in turn treat others well and the atmosphere becomes one of warmth and care:

> **Doris:** *I think a lot of people here realise what it's like to be lonely, we all know what it's like so we all make an extra effort to be friendly, to be nice, to make a cup of tea.*

> *Brunhilda:* One of the most important things is the humanness of The Haven staff and other clients, there's a kind of warmth and compassion.

Being believed in and encouraged are crucial ingredients for recovery (Turner-Crowson and Wallcraft 2002). Aiyegbusi and Norton (2009) suggest that validation may take many forms, including the kind of attention that can affirm someone's importance and individuality. Clients in the study cited instances of being listened to and valued as important aspects of *Feeling Cared for*:

> *Doris:* They make you feel that, for half and hour, you are the sole focus of their attention. You're not just a number and you've got these issues and they are going to sit there and listen to you. Even if it goes over, they are not clock-watching. There's no "I'm going to get my lunch now". You are important.

> *Tiffany:* The staff try their hardest to make you feel very special in your own individual way, and they give you loads of boosts of confidence.

What it Means to Belong

The first of the five key principles of a therapeutic community is described by Rapaport (1960) as 'Attachment and a Culture of Belonging'. Secure early attachment gives an infant a consistent experience of existence, which is internalised and provides a greater ability to face later life experiences (Bowlby 1969). When emotional development has

not provided secure attachment for a child, the first step in treatment is to recreate a secure attachment (Haigh 1999). The first two steps on our pyramid of recovery have already begun to construct attachment in terms of safety and trust, and feeling cared for. The third step, *A Sense of Belonging and Community*, is where clients, who have experienced a history of abuse or trauma and poor relationships, begin to value being part of something. Again, this third level of the pyramid is related to the two levels below, in that trust and feeling cared for are experienced as a reciprocal relationship that reinforces a sense of being part of something and *belonging,* as evidenced in participant quotations Appendix VII, pages 21 to 24.

Shared experiences and common ground were aspects of community highlighted by participants as something that made them feel understood. This gave them a sense of being somewhere they felt they belonged, often for the first time:

> *Carl: I find when you walk into the room the thing I like about all of them is everybody has got the same illness, same problems, and this is where The Haven comes into its own.*

> *Emily: I isolate and can't mix with people, but I can see people in The Haven, you are the same as me.*

> *Anne: One of my hopes, dreams was to fit in, into this world, and being at The Haven I think I've finally started to fit in.*

Participants also expressed surprise at how different it was to be part of a community, compared with mainstream services:

> *Rose: I haven't seen any NHS mental health people run things like this.*

> *Jenny: I don't think I've ever been any place where there's been people around me that have got mental health problems and there's been such a good strength of community.*

A sense of company and fun was also mentioned, as a form of shared intimacy, promoting laughter and allowing playfulness that may recapture a healthy sense of being a child:

> **Gemma:**   *There's always people around and you can hear them laughing, precious company.*

> **Chloe:** *I haven't laughed as much in years at the last Friendship Group I came to here. It was just hilarious.*

Winnicott (1965) suggests that a facilitating environment acts as a container where the gap between the container and the contained starts to open up and the individual can begin to explore autonomous identity:

> **Doris:** *What I have found is that other people can like me. I am less serious. I have rediscovered my sense of humour and I have rediscovered my ability to make other people laugh. I rediscovered the fact I am good. I am not as bad as I think I am. If someone is feeling rubbish I will give them a cup of tea, give them a kind word, give them a hug.*

Clearly voicing their newly developed sense of healthy attachment, participants defined The Haven Community as giving them a sense of home and family:

> **Pablo:** *The Haven provides for me a replacement role of my parental home.*

> **Poppy:**   *I'm now learning to use The Haven to help myself and it's like an extended family that I haven't got really.*

> **Leska:** *The Haven community, it means a lot to me, it's like having a family all under one roof.*

> **May:** *It's the family I never had*

Love is Not Enough

On the first three steps of the pyramid, in the stages of the journey of recovery at The Haven, healthy attachment is being built within a culture of safety, warmth and belonging. Norton and Bloom (2004) emphasise the importance of ensuring that the culture of a therapeutic community is not eroded by difficult behaviours, suggesting that tolerance should have its limits. This brings us to the fourth level of the pyramid, *Learning the Boundaries*:

For someone who has experienced early attachment difficulties, healthy attachment may be longed-for but also feared. The concept of attachment becomes idealised as an individual yearns for unconditional love. Haigh (1999) describes this process as a journey through the developmental phases of attachment in a therapeutic community. As an individual struggles with sadness, fear, pain and anger, savage mechanisms can sometimes come into play. The ability to be honest may be blocked by feelings of shame and humiliation. Here, denial, lying, projection and splitting begin to be demonstrated. Someone may display unconscious impulses to envy, spoil, steal or destroy what is good:

> **Brunhilda:** *Community isn't all about harmony and everyone loving each other and that sort of thing, because life is full of challenges and difficulties and rubbish and so inevitably that comes up within the community.*

Living too long with untenable emotions and in a state of chronic hyper-arousal, people with a personality disorder diagnosis also frequently adopt dysfunctional behaviours to numb unbearable feelings and to swiftly bring their mood down to a manageable level. Hurting the body can create temporary calm because of endorphin release. Such behaviours include self-harm and substance misuse. This is how people have coped and, for many, they become deeply ingrained coping strategies. Although containment is achieved through holding someone's distress, that distress may trigger unacceptable behaviours. Bettleheim (1950) suggests that 'love is not enough' and that the damaging expression of pain needs containing measures. To create psychological safety at The Haven these self-destructive behaviours need to be actively challenged. An approach to people's capacity to create negative effects for others must be effective. All this represents boundary setting and the social and moral limits that need to be present to create a safe community. Whatever rules and boundaries are negotiated in an organisation, the vital issue is that the boundaries are clear to everyone and that they are agreed, known and understood:

> *Sheila: I feel safe at The Haven because I know you're not allowed to get away with stuff, are you, like cutting while you're here, which means I don't try. It's about being protected from the negative parts of yourself.*

> *Cosmic: I do get a real sense of freedom here, but I know that if anybody doesn't tow the line then they will be pulled up and they'll be at a meeting about it, yeah.*

The process of democratically setting and applying boundaries is cited by Hinshelwood (1996) as a learning process which addresses respect, not just for the reality of self, but also for the reality of others, enabling an individual to ultimately find the self as the seat of agency and to begin to take control and responsibility. Once more, the interrelationship between layers of the pyramid is highlighted as clients begin to take responsibility, not just for their own behaviour, but also for the behaviour of others. This was particularly shown in an issue of our newsletter (Castillo and Allen 2006) where nine clients contributed their thoughts in an article entitled 'What is Community':

> *Boris: Community is about treating other people as you would like to be treated yourself. The urge to do destructive things to yourself takes over. When very strong boundaries are imposed it's the respect that we have for The Haven that stops us from breaking them. This makes you go to staff to ask for help rather than going down that destructive path.*

> *Doris: We all do things that are socially unacceptable but it is really better to make them a little less acceptable, like they are in the big wide world.*

In terms of primitive emotions and behaviours, Campling (1999) proposes that it may be more difficult to destroy a group. She also suggests that clients are often in a better position to inject realism into such situations:

> *Doris: We understand why people want to come in, for example, under the influence. We understand the struggle and the difficulties but we have, on those occasions, stood together as a community and we have said 'this is unacceptable'. People aren't abandoned at such difficult times, but the learning is about what is acceptable and unacceptable to the community and what is healthy and positive for the individual. We all take responsibility for The Haven Community but, at the end of the day, the message is that each person has to take responsibility for themselves, with our support.*

Evidencing the efficacy of *Learning the Boundaries*, and supporting service users in deciding what those boundaries should be, over two-thirds of participants in the study reported a reduction in their use of negative coping strategies and over one-third described a dramatic reduction:

> *Elise: Before I came to The Haven I used to overdose on a reasonably regular basis, I used to cut myself when anything went wrong, and I used to stop eating when anything went wrong. Basically, it was a whole host of maladaptive coping mechanisms and since coming to The Haven I have sort of redressed these. A lot of the reason has been because of the ruling about coming in when you have cut, or coming in when you have drunk alcohol. So you have to respect the values of the place. I now don't cut. To me to cut would be such a backward step I don't even want to go there.*

Recreating Healthy Attachment and Opening the Door to Therapeutic Work

The first four steps in the hierarchy of progress have aimed to develop healthy attachment in terms of safety, trust, feeling cared for, a sense of belonging and learning acceptable boundaries, limits and behaviour. This is how participants at The Haven have described their journey through the developmental phases of recreating attachment. It is not until a degree of stable progress has been made, in terms of healthy attachment, that clients begin to advance to the level where they are *Containing Experiences and Developing Skills* and, in the preceding chapter, Diagram 2, page 103, graphically represents the journey on the upper levels of the pyramid as being supported by the foundations of the first four levels.

In a client group desperately in need of therapy, trust can be so low, and behaviour so chaotic, risky and destructive, that meaningful therapy cannot take place. Having a history and pattern of expressing distress destructively in mainstream services, this type of presenting scenario can also exist for new clients for some time after joining The Haven. Feelings of unworthiness mean that some find they are unable to ask for help, resulting in crisis presentations such as overdoses and self-harm:

> **Sally:** *Sometimes you can see that staff are all busy, but you're too scared though, and you go home feeling worse, but it's too late.*

As progress is achieved on the first four levels of the pyramid, the overwhelming desire to become free from unbearable feelings, by acting them out, is replaced by the ability to reach out for help, talk and re-channel feelings, as described by one respondent below:

> **Fred:** *I'm also clean and have stayed clean. Kind of like instead of popping a pill, I come here. Stopping drugs, feeling the emotion and learning from it.*

Although The Haven has a recovery ethos and the underpinning therapeutic approach is a psychoanalytic therapeutic community model, arising from attachment theory, staff and clients work with an additional variety of approaches and therapies in group and individual work. Meantime, as clients progress on the lower levels of the pyramid, various groups and one-to-one support exist too at the service:

> **Natasha:** *It's just that there's something to do all the time. They encourage you to do things but there's no pressure.*

> **Anne:** *I am finding Creative Writing extremely helpful, it's helping me to get a lot of my emotions out on to paper and being able to share them with other people as well has always been hard for me, but I've started to read out my work.*

> **Crystal:** *I'm not a very touchy person because I haven't been brought up like that but I found (the hand massage) I had yesterday was really calming and I felt good afterwards.*

> **Charles:** *I've been using the one to ones, it's a way forward for me if I'm feeling angry I vent my anger.*

The Stepps Programme (Blum et al 2008), which appears to be a blend of Dialectical Behaviour Therapy (DBT) and our Life Skills Programme, is not part of The Haven service, but DBT is (Linehan 1993). A DBT Skills Group exists where group members work together to achieve a life worth living. Although there is no dedicated DBT therapist for individual work at The Haven, one-to-one support, or reinforcement, comes from the Team as a whole, where contact is available on a 24 hour, seven days a week basis:

> *Lara: I attend DBT because I can see how much enjoyment people get out of it. I think it's helped me tremendously. I used to go off the handle at anything, now I stop to think of a different way of coping with it and a different way of speaking to people and it's much more effective than just lashing out.*

Additionally, a Life Skills Programme is taught at The Haven which covers skills such as anxiety management, anger management, assertiveness and confidence building, and tools to reduce self-harm, eating distress and substance misuse. Life Skills incorporates features from the WRAP programme, Wellness Recovery Action Plan (Copeland 2001) where individuals can explore their own repertoire of wellness or recovery tools such as sleep, good nutrition, self-soothing activities and uplifting pursuits. The Life Skills Programme involves less commitment than the DBT Skills Group because it is a rolling programme, where attendees can attend missed sessions and re-do the programme, or selected sessions from it:

> *Alexis: I feel I've really benefited from the Life Skills Group, it's reduced my obsessional behaviour and encouraged me to mix with others and has really boosted my self esteem. It's been very beneficial dealing with anxiety, positive thinking, how to control panic attacks, confidence building and particularly in dealing with anger.*

> *Cosmic: The Life Skills is brilliant because it's so varied, and I've learned a lot and it's good to be re-running the course as well, because if there's anything that I've missed, or wasn't paying attention.*

As skills are built at such groups as DBT and Life Skills, a range of individual therapy also takes place. This is provided by Haven staff and sessional counsellors. Approaches range from psychodynamic to cognitive, with the emphasis on the therapeutic relationship. The experience of therapy also highlights the interrelationship between levels of the pyramid when therapeutic work may have a profound effect on feelings, and apparent set-backs may occur:

> *Harry: I've been learning where a lot of my difficulties have stemmed from which is, hopefully, in the long term, helping me to overcome them. At the moment my self-harm has got a lot worse. But I'm going through a very difficult period at the*

moment and the thing I have to realise is that, although I'm getting less judgemental of other people, I'm getting more judgemental with myself. So I'm actually, at the moment, more likely to self-harm but I'm less likely to get myself into a fight with someone else.

Although transference and counter-transference are a focus in some of the therapies at The Haven it does not provide Cognitive Analytic Therapy, CAT (Ryle 1997). However, CAT therapy is available from the Mental Health Trust in our area and some of our clients have taken advantage of the programme.

> **Doris:** *I had CAT for 24 weeks. It's about putting some more tools in your tool box. It doesn't solve your problems; you learn to fix them yourself. You don't always see all the benefits straight away and, even three years later, I find myself using some of those tools.*

Young et al (2003) appear to have very clearly identified the maladaptive schemas we work with on a daily basis at The Haven. Although a small number of staff members have received some Schema Therapy training, the clinical team as a whole has identified threads of the schema approach throughout much of their work with clients. Motivational Interviewing (Rollnick et al 1995) is used by some staff, along with Neuro Linguistic Programming, NLP (O'Connar 2001) and Trauma Incident Reduction, TIR (French and Harris 1998). TIR combines engagement with acceptance and commitment to psychological flexibility. This is another approach that blends aspects of CBT, DBT, Schema Therapy and Mindfullness (Kabat-Zinn 2001). Staff and clients work together with a variety of overlapping approaches that reinforce progress, on the first four levels of the pyramid, *developing skills* and helping clients to begin to *contain experiences*. From a position of trust meaningful therapy starts to occur:

> **Rose:** *The counselling I'm receiving, I have been for quite a while, is just fantastic. I had ten years of psychotherapy and I still managed to avoid the issues. With the counselling I think it's the fact that it's here. It makes me feel safer which makes me take more risks than I ever have.*

Experiences begin to be remembered, understood and contained and skills are developed that start to enable that person to function more rationally and effectively:

Elise: I think my new skills have fundamentally been to be able to stop and question the reality of the situation and the most logical conclusions, and the most logical assumptions, and to think the whole situation through, rather than jump into the first panic stricken thought that comes into my head and act on it. It's the actual stopping and analysing the situation for what it really is, not what emotionally it's built itself up to be. That's the best skills I've learned.

Hope and its Relationship to Recovery

Mental health, like any condition in the health arena, is subject to a cure based approach. Although dealing with symptoms and developing skills has an important place in the journey, they are not an underpinning principle in the user-defined concept of recovery. Waiting until all symptoms have subsided, before trying to discover and use one's abilities, could take a very long time and hope for a cure can overtake other ambitions (Repper and Perkins 2003):

Ross: We spend too much time looking for a cure when there is none, we can only learn to live alongside our illnesses by re-thinking the way we think to re-train the way we go about our daily lives and to learn to use our past experiences to guide us to were we want to be in life rather than carrying on the way we do.

Davidson (2003) talks of living outside mental illness and the importance of not being defined by illness but rather renewing *hope* and believing in a renewed sense of self:

> *Brunhilda: Is personality disorder an illness or a disability? Because, if it's an illness, there's a possibility of a cure but, if it's a disability then the way to approach it, just as it is of a physical disability, is that it's possible to learn to live a fruitful life.*

Coleman's (1999) message of *hope* is about creating a capacity for recovery out of mental illness and distress. The importance of *hope*, and the idea that someday things will get better, is cited by Deegan (1988) as the essential ingredient for those who are recovering.

Anthony (1993) proposes that recovery is possible even when symptoms and disabilities continue. Here, illness and wellness are seen as independent variables where new meaning and purpose are sought in the face of the effects of mental illness (Roberts and Wolfson 2004). This could be seen to give rise to a dialectical debate between the 'treatment lobby' and the 'recovery crusaders'. DBT (Dialectical Behaviour Therapy) aptly addresses this dialectic by aiming to find common ground between apparent opposites. Its central goals are acceptance and understanding, regarding the emotional vulnerability caused by severe trauma, combined with support, belief and *hope* for change.

A focus on a deficit in skills can create a sense of hopelessness which is a feeling easily triggered in the face of past trauma. Deegan (1990) characterises this 'giving-up', indifference and apathy as a way of surviving and protecting the last vestiges of the wounded self:

> *Fred: Things that have happened to me when I was in care and on the streets ... the world I was in before was so black, and that was hard, I was petrified of becoming well and then failing every time, failing myself again, I just couldn't take that anymore.*

When a person has been repeatedly traumatised, or subjected to an environment that is sufficiently out of their control, they will give up trying to make changes (Bloom 1997). Experiences within the mental health system may have compounded such learned helplessness:

> *Abigail: I can't change and I don't want to change.*

Even when support and skills training are on offer someone may feel unable to make use of them:

> *Ben: I find the Life Skills Group very threatening, so much so I haven't been able to sit through a whole one yet … I've hung on to my coping strategies which are distinctly negative because I feel that if I give them up them I'm lost …All my one-to-ones are spent with me bubbling and them offering me tissues.*

The fostering of autonomy for each individual necessarily becomes vitally important. Repper and Perkins (2003) describe this as inspiring the *hope*, confidence and trust needed to activate the internal resources necessary to conceive of and pursue *dreams and goals*. However, being believed in and encouraged (Turner-Crowson and Wallcraft 2002) and the importance of support and friendship, interdependence and connectivity, in the early stages of recovery, are cited as crucial in helping to break the cycle of despair (Russinova 1999). The earlier steps on the pyramid of progress have embodied this type of caring and encouraging approach at The Haven, which has generated feelings of mutuality of trust, being cared for and belonging; see previous chapter and Appendix VII, pages 3 to 10 and 21 to 23:

> *Sheila: It's a lot friendlier. It's a lot more caring and it's also trusting. It trusts me a lot more than other services, and you don't get talked down to and treated as though you are some kind of idiot.*

> *Cosmic: I've had the confidence to start voluntary work because you had the confidence in me to show me the advert, see, for the job, so there.*

Peer support and inspiration are also crucial ingredients in this activation of *hopes, dreams and goals*:

> *Wilf: Seeing the people who have moved on to college and stuff, you can set yourself a little goal then, can't you. They've done it, so you know, maybe there's a chance.*

Milly: I think that Transitional Recovery Group gives you a lot of hope.

Coleman (1999) believes that recovery depends on self-help and collaboration. Perkins (1999) suggests that, in their support, services should shift their focus to the unique nature of the individual journey that each person travels. Nehls (2000) highlights the significant challenges for people who have attracted a personality disorder diagnosis in terms of stigma and the guarded prognosis of professionals. She calls for a fundamental shift, away from pessimism and paternalism, towards a new vision of services constructed by the consumer. The *hope*-inspiring environment at The Haven has been intrinsically designed to share power and restore control to its users, both in terms of how the service is set up and run and how research has been conducted:

> **Boris:** *The Haven is completely different to any other service I have ever used. In every other service you don't actually have an opinion or your voice isn't heard. At The Haven your voice is heard and your opinions taken into consideration, and everyone is treated individually here and you're not a number anymore here, you're your own person.*

> **Brunhilda:** *I think it's great the way clients take such a part in research and setting parameters and policies.*

In terms of *hopes, dreams and goals,* the importance of balancing realism with optimism is stressed (Repper and Perkins 2003). Research participants were clear that, over time, their aspirations began to be more realistic:

> **Chloe:** *Everyone has the potential in them to succeed, but it's about taking it each step at a time. It's about setting achievable goals.*

Pursuing aspirations requires taking risks and Repper and Perkins (2003) also suggest that the ability to accept setbacks, and an uncertain future, is a significant challenge and an essential part of creating *hope*-inspiring relationships:

>*Doris: Recovery is like a road up, a country road that's full of speed bumps and windy corners, and you travel along it any you think, yea you're getting somewhere, then you go over a bump and you get set back a bit, but you have to keep going and eventually you'll get to the end of the road and you'll find another road that goes somewhere that might be less bumpy.*

Hope is also linked to taking control and responsibility over one's problems and life (Repper and Perkins 2003; Turner-Crowson and Wallcraft 2002). Deegan (1988) and Allot et al (2003) describe an attitude, and approach to life, and a moment or turning point in relation to becoming unstuck and beginning to take that control:

>*Charles: Wanting to do it is the main issue. There's nothing wrong with slipping back, it's trying to learn from it.*

>*Doris: All the help in the world is great but you have got to want to get to where you want to be. It's nothing you can be shown. You have just got to get your own fight back.*

Identity and Roles

Identity and valued roles are central to *Achievements* and to giving meaning to life. Deegan (1993) talks of people's contributions that we can perceive and value, but that learning to value oneself is the real challenge. Supporting recovery is about helping people to build self-esteem and identity and to find valued roles in society (Allott et al

2003). The findings in the previous chapter highlighted 'disliking oneself less' as a starting point in what is often a high degree of self loathing. Thirty-six of the 48 participants who answered the question, 'Since coming to The Haven do you spend less time disliking yourself?' answered yes. The majority who answered positively had been attending The Haven for two to three years, suggesting that building self-esteem, even in a hope-inspiring environment, takes time:

> **Harry:** *I think I used to dislike myself a lot. I don't actually dislike myself now, although I dislike my behaviour at times, which is a massive difference and I'm actually able to go out and buy new clothes. So being able to spend money on myself has come from being at The Haven and being made to feel worthwhile.*

A sense of identity accompanied new found self-esteem:

> **Rose:** *The change is due to actually learning who I am, I've been something else before now.*

> **Leska:** *I've started to find my identity and I've started to live life again.*

However, four respondents who had been attending The Haven for two to three years answered no:

> **Sally:** *I still dislike myself. I don't know if it will ever change, it's always as far as I can remember for such a long time ago, that's just how I feel about myself.*

Roberts and Wolfson (2004) talk of the dynamics of resistance in recovery. Aspects of lack of progress for some participants did not always show in research responses and one dimension that emerged is what Bartlett (1932) describes as the phenomenon of people making sense of something retrospectively. In psychological terms he called this 'effort after meaning'. This search for explanations for current conditions may involve rationalisations. We had participants who, after joining The Haven, had disclosed a history of sexual or other abuse for the first time. However, we also had those who appeared to fabricate early abuse or claim they had been subject to recent trauma such as being raped, when this was not in fact true. Such 'effort after meaning' presented

explanations that might be commensurate with the pain and symptomatology being experienced by someone, but this did not open the door to meaningful progress. Staff considered it to be a mark of developing trust and progress when such rationalisations were eventually disclosed by the client as fabrications. They were never disclosed at research events, not even in the privacy of an individual interview. This is likely to be because of the shame associated with disclosing such fabrications and the need for the safety of an individual therapy session in which to do so.

Another clinical facet of rationalisation constitutes a very difficult and costly dimension of the client group and is what the government (HM Government 2009) characterises as MUS (medically unexplained symptoms). Physical illness for people with mental health problems occurs at significantly higher rates than in the general population. Lowered immune systems, due to extended periods of depression, accounted for some of this amongst our participants. Also, self-neglect, constituting more subtle forms of self-harm had exacerbated conditions such as asthma. Some participants had encountered genuine and significant health difficulties during the course of the study, such as cancer and chronic anaemia. Two older respondents died before the end of the study, both of natural causes related to cardiovascular problems. It is to be expected that general health would improve over time as respondents progressed on their journey of recovery. In the first chapter, Table 1 page 12 had shown some degree of reduction in the use of primary care and general hospital admissions. However, medically unexplained symptoms (MUS) existed to a significant degree. This included conditions such as pseudo fits, intermittent wheelchair and crutch use, which caused irritation to some who genuinely needed to use such aids, and other conditions that showed no medical basis when subject to tests. Although this issue was not brought up at research events, the Research Group originated the subject for discussion more than once (Research Diary p28 and p29). Being party to the conversations at the group, I can relate that Research Group members felt there was a section of clients who were very stuck in the sick role. This did not concern only mental health difficulties and having become defined by one's diagnosis, it also concerned physical illness, and some of this was considered to be spurious by Research Group members. This remains a significant challenge, particularly in terms of clarifying

whether physical symptoms have a foundation or not, because those with mental health problems can often have genuine physical health problems erroneously ascribed to mental illness, and have a much higher rate of mortality than the general population of the same age group. The staff team continues to work therapeutically with these underlying issues for those with MUS, whilst being careful not to reward lack of progress with too much attention. In the meantime, to save time and costs, there is an effort to try to avoid unnecessary healthcare referrals where possible, such as calling ambulances. Adshed and Jacob (2009) suggest that people with personality disorders have difficulties in effectively eliciting care from others. Related to early experiences with their carers, this can result in a tendency to try to elicit care in coercive ways.

The concept of resistance can move beyond learned helplessness and the time and patience required in beginning to support people to feel cared for, valued, empowered and making choices. The process of recovery is sometimes fraught with complex losses. Gregory (2004) outlines what he considers to be the four thematic stages in the treatment of borderline personality disorder. Stage one mirrors the early steps in our pyramid in that issues of feeling safe are cited. Gregory then discusses a second stage, a dichotomy, where someone may exist in a state of inner conflict about whether they are a victim or a guilty perpetrator. This internal split is a response to severe trauma. The person may think about how they were abused, neglected or abandoned as a victim, or consider themselves as evil because this would not have happened unless they were bad. Who is to blame? There is nothing fair about trauma, which is tragic and does not imply someone must have done wrong in order to experience it. Traumatised children may also sacrifice their sense of worth in an attempt to maintain a vision of their caregivers as good. This internal conflict can be very difficult to resolve because the person is unable to make sense of their experience, and Gregory considers this to be the most prolonged stage of recovery.   He considers that the next stage of the process of recovery concerns issues about grieving the loss of long and closely held views and fantasies, and worries about self-worth. Giving up a fantasy that care givers or perpetrators were good is a loss and grieving process. Fears of separation, of becoming detached and alone, are also present.   The client may also experience an undermining of progress from family

members during this stage as old patterns of relating are challenged. Roberts and Wolfson (2004) also consider that symptoms carry significant meanings for people and that part of the process of resolution may involve deep loss and grieving. This is also related to sense of identity where a world of illness and psychiatric labelling may be all that person has ever known, resulting in spoiled identity (Goffman 1963):

> *Ben: Personality disorder is all I've got and if you take that away there'll be nothing left.*

> *Sheila: It's all I've ever known, is this personality disorder, ever since, all this mental illness, ever since I was very young.*

Another approach to mental illness or disorder might involve what Tait et al (2003) call 'sealing over'. They suggest that, for those experiencing psychosis, there can be a recovery style where a sufferer may decide that, despite illness, they want to forget about it and move on. Their study showed that insight is not necessarily linked to 'sealing over' as a recovery style and, therefore, is not synonymous with denial. They advocate interventions tailored to recovery style to minimise the risk of deterioration in the absence of long term treatment. Not overtly defining 'treatment', their paper also does not exclude medication as its definition. However, Harding et al (1987), in their seminal study, claim recovery levels of two thirds of people suffering from schizophrenia followed up over more than thirty years. Although not about personality disorder, this study is cited here because it evidences significant claims, for 68%, about freedom from medication as a given, thus proposing a revolutionary concept, that people with schizophrenia may eventually recover and may become medication free. The National Institute for Health and Clinical Excellence advises that in the treatment of borderline personality disorder, medication should be for short term crisis use only, favouring psychological treatments, although calling for more research into the efficacy of various psychological approaches (NICE 2009). A recovery ethos finds little mention in the 500 pages of these new guidelines.

So, where does this leave the person who has attracted a diagnosis of personality disorder? Are their *achievements* built on psychological progress or do they stem from hope and self-belief, or both? The disenchanted words of one research respondent follow:

> **Stony:** *The Haven as a community isn't that good really, to be honest, because people are, like I said over again, focusing on the actual illness rather than trying to move forward with everything, and everybody's competing on how ill they are rather than trying to be better.*

Stony decided not to dwell on the past and resented those who seemed to be doing so. With this person's permission, I have included some details of their story and progress. After a number of years in secure hospitals, due to life-threatening self-harm, *Stony* started to attend Haven groups and was then discharged from hospital. Independent living followed and a reuniting with siblings, then a fiancé emerged, however, *Stony* still struggled with agoraphobia but maintained a cheerful outlook on life. Then came a break up with the fiancé and *Stony* experienced a re-emergence of untenable feelings and difficult behaviour. After swallowing a razor blade *Stony* fortunately came straight to The Haven, was assessed by the mental health team, and had a subsequent two week stay in the psychiatric acute inpatient ward. This was the first hospitalisation for almost four years. During the hospital admission *Stony* had leave and came to a Haven Life Skills session and said, for the first time, that psychological therapy was the way forward. Once discharged from hospital, therapy began at The Haven. However, feelings unearthed during the therapy proved too painful and *Stony* decided not to attend for more sessions at that time. Bearing in mind that *Stony's* history includes, while in care, being chained to a radiator with a sibling and being systematically sexually abused, it is not difficult to appreciate how untenable those emotions proved to be. But what courage *Stony* has shown in pursuing life with hope and *achieving* some dreams. Physical appearance and presentation today is attractive and well-groomed and is an unrecognisable comparison to the *Stony* who was in a secure hospital. *Stony* continues to hope to *achieve* aspirations and dreams and whether this will include psychological therapy is a very personal choice. Bettleheim (1960) claims that psychological therapy is not the most effective way to change personality but that being placed in a particular environment can produce greater

changes in a shorter time. This gave rise to his experiments with milieu therapy, the creation of a total environment or therapeutic community, to achieve radical personality changes in those holocaust survivors who could not be reached by psychoanalysis.

Ben's quotation, two pages previously, claimed a fundamental defining of self by being labelled and stigmatised as personality disordered. *Ben* has now gone on to redefine the internal sense of self and external roles, by taking up paid employment and, at a recent presentation about *achievements*, told the audience the following:

> **Ben:** *Although there are still good days and bad days, if you learn to love yourself you can begin to help others.*

Recovery and Maintaining Healthy Attachment

Maslow's (1943) pyramid ends in achievements and self-actualisation, whereas the pinnacle of our pyramid is *Transitional Recovery*. As described in the last chapter, *Transitional Recovery* is a developmental and flexible concept which embraces the whole pyramid. The *Transitional Recovery* Group was described by respondents as a mutually empowering experience:

> *Boris: It helps build confidence and helps you build new friendships and support one another, and it's really productive and really positive. Last week was really good hearing people's goals and looking at what stopped us achieving them.*

The concept of *Transitional Recovery* was cited by participants as an approach that offers the layers of the pyramid, when needed, and they acknowledged this need for intermittent support:

> *Leska: I personally think recovery is still being able to ask for support and say you are struggling but also know that you are getting better and that you don't need the services as much as you did when you were ill.*

> *Cosmic: Well, if I saw a tortoise on its back I think recovery would be putting him the right way up, because that's something he can't do for himself. There's no way a tortoise wanted to get on its back and it was there for circumstances beyond its own control. So, if you help him by putting him back on his feet, and he goes plodding along at his own pace, as long as the Tortoise Rescue Centre is still there we'll be alright.*

One of the questions asked in our study represented fears about recovery and 43 client participants expressed such fears and highlighted significant barriers on the journey. These ranged from fear of failure; fear of the unknown or new; to fears about losing identity. Loss of security, sometimes linked to age, was also expressed:

> *Tiffany: I'm frightened of getting well then not being able to work. Like coming off benefits, that's what frightens me most.*

> *Cosmic: At fifty-one to say that I've recovered is putting a hell of a lot at risk. I'll have to be forced out of this safety net, not that I'm lazy. It's the Government want to get people back to work, and that's what this is, isn't it. I'm getting DLA (Disability Living Allowance), rent paid, but I've got a dread of going back to what it was like before. I would overwork, do all the hours under the sun, then come down with depression and alcoholism. I might self-harm then two weeks later get back on my feet and be able to do agency work, work myself to death again.*

> *Brunhilda: I think recovery is frightening because in my imagination it means losing security that I've now got, which I've wanted for so long. I am aware that for a lot of the time nowadays I feel like I am in a comfort zone, but that's such a novelty, something that I've never experienced before.*

Towards Implementation of Recovery Principles: Policy Intentions and Practice

New Horizons (HM Government 2009) was heralded as the government's plan for mental health in England over the next ten years. Unlike its predecessor, it includes this diagnosis and states that five percent of women and three percent of men are assessed as having a personality disorder, compared to point four percent who have a psychotic disorder such schizophrenia or bipolar disorder. New Horizons encompasses a response to complex cases. In light of the recent General Election, it remains to be seen whether this plan will be replaced. In this document the former Prime Minister talks of the prejudice and stigma that excludes people with mental health problems from those things that most of us cherish, 'family life, decent homes and careers'. The new NHS Performance Framework (Department of Health 2009), and its application to mental health trusts, includes two new and refreshing indicators, number in secondary mental health services in settled accommodation, and number in employment. Hot on the heels of these documents are the Perkins Review, Realising Ambitions (Perkins et al 2009), and Work Recovery and Inclusion (HM Government 2009a), outlining employment support for people in secondary mental health services. This leaves us in no doubt that the government's aim is to close the gap between the number of people in the country in employment and those using secondary mental health services in employment, currently standing at 72.5% to 3.4% (HM Government 2009a).

McGowan (2009) suggests that, in aiming for the best evidenced-based treatments, the guiding principle of the NHS during the last ten years has been flawed, in that the National Institute for Health and Clinical Excellence may be prescriptively stifling innovation by only reflecting research which is in vogue or shouts loudest. He highlights the fact that the huge complexity of getting people off welfare benefits, and back to work, needs comprehensive solutions and not a one-size-fits-all. For those in secondary care in the NHS little exists between hospital admissions and the workplace. Repper and Perkins (2003) stress the importance of integrating social inclusion efforts with the clinical work of a team rather than creating distinctly separate services and Community Mental Health Teams have now begun to introduce Employment Advisors. For those in tertiary care at

The Haven a Social Inclusion Unit exists. However, as reflected in The Haven Lifepaths to Social Inclusion Manual (Davies et al 2009), lessons of the past three years have shown that a range of leisure and vocational pursuits are needed as building blocks to employment and that even then Haven clients in paid employment, although much higher than the national average of 3.4%, is as yet only 15%.

The Perkins Review (Perkins et al 2009) is overt about its optimism in a recessionary climate where the country is contending with a huge national debt. It claims that reconfiguration of existing investment may yield more fruitful outcomes. The review highlights the undesirable consequences of enforced inactivity which robs people of valued roles and networks. It proposes a system of Individual Placement and Support, a well-researched and successful model of support carried out in the USA and six European countries including England (Bond et al 2008). The review also defines employment as ranging from open employment; supported employment; sheltered employment; sheltered work; to time-limited internships; and voluntary work, and looks at the value of work as measured against welfare benefit rates. In addition to support for employees it also addresses employer support in terms of education about mental health 'first-aid'. This, however, is where I believe the Perkins Review falls short. It talks a great deal about the rights of employees with mental health problems under the Disability Discrimination Act, and the right to reasonable adjustments in working conditions to accommodate mental health difficulties. It makes one small recommendation about funding for small organisations to cover extended sick leave absences for employees with mental health problems by using the Access to Work initiative to fund temporary cover for condition-related absences. I would like to suggest that some employers may be afraid to employ those with a mental health history because they fear being sued under the Disability Discrimination Act. Even if an organisation is too small to be expected to make reasonable adjustments a case can still be brought under the Disability Discrimination Act, and there is a cost, in terms of both legal fees and stress, in fighting this at an Employment Tribunal. No matter how caring an employer is, financial viability remains a crucial and necessary concern that is likely to remain hidden, because any concern is currently seen as discriminatory. Therefore, a system is needed, with clear definitions

under each section or type of employment, be it open employment, supported employment, internships or other types of employment. Safeguards need to work both for the employee *and the employer*, and be clearly enshrined within the law. If not, I predict that a sufficient number of employers will not become available to employ those with mental health problems. Adding this situation to an already weak employment market due to the recession means that few opportunities may present themselves for those with mental health problems wishing to return to employment, not to mention those who have never been in the employment market because of ill health from an early age. Despite promising new work initiatives outlined in the Perkins Review, a recent study about supported employment for people with mental health problems in the UK (Howard et al 2010) found that the effectiveness of IPS (Individual Placement and Support) was much lower than the success achieved in the US. Results showed that, in those aspiring to employment, there was a 13% success rate, compared to 60% in the US. The study cited differences in the way IPS has been implemented in the UK, and suggests that the disincentives of the UK welfare benefits system, and high unemployment rates in this country, have affected implementation.

Paid employment is cited as the epitome of *recovery*; however, respondents in our study clearly defined what recovery meant to them. Repper and Perkins (2003) suggest that *recovery* is a process rather than a goal. Twenty-five percent of participants in our study defined *recovery* as a journey that is taken step by step:

> **Jonny:** *I think recovery is part of the journey and it's like change in anybody's life, it's scary unless you continue with the journey. That's probably the most positive thing that The Haven has given us, the chance to continue our journey and to progress, and that's the most important thing, the journey.*

> **Elise:** *It's an ongoing process, you never actually get there. You are always recovering.*

As those likely to be closest to people with a personality disorder diagnosis, family members and carers in the study also clearly defined recovery as a realistic journey:

Sammy: It is not necessarily, as a lot of professionals will lead you to believe, about getting a job. At the end of the day, for some people, it might just be getting out of the house for the first time in five years. It's not about government targets of getting a million people off of incapacity benefit. It's about a journey that somebody takes.

Dinah: She's never going to hold a job down in a million years. I think my partner's always going to be happy to do a bit of farming, or looking after animals, a much easier life, where the demands are there but in a different way. I think that will be recovery.

Rob: While they are moving forward they're in a state of recovery. If they keep moving that's good.

Participants also defined *recovery* as having hope and a concept of the future:

Emily: I define my recovery, I've got hope now.

Rose: I'm looking to the future, which I would never have done, and I'm hopeful.

Others defined *recovery* as gaining control and independence:

Sheila: Being able to stand on my own two feet, without calling for help every five minutes.

Ross: To regain control.

Natasha: Freedom to do what you want without being stopped by disability, getting on with your life in a productive way.

One little explored aspect of *recovery* is the development of the ability to enjoy the here and now. Western ways of thinking are usually about planning ahead and the future dimension. With the exception of the DBT Programme (Dialectical Behaviour Therapy),

with its emphasis on mindfulness techniques, little exists within psychological therapies to help us encompass the concept of simply being and being able to enjoy things. Some respondents in the study did, however, clearly define this sense of now-ness and contentment:

> *Chloe: I'm talking about success as in how happy and content you are as a person. Success in life rather than qualifications and a good job. It's very individual for each of us.*

> *Brunhilda: The whole point is to live in the present. My vision of the future has changed since coming to The Haven because, when I first came, I thought I had absolutely no future except endurance. So I feel more positive about the future but I don't really have many goals or dreams. I'm much more able to live in the present and to enjoy the present as well sometimes. I quite often enjoy the present.*

Wallcraft (2010) discusses the difficulties surrounding outcome or quality of life measures for those using mental health services. This highlights questions about what is important to service users in their journey of recovery. She cites the current use of instruments such as the Health of the Nation Outcome Scale (HoNOS), which measures clinical problems and social dysfunctions, as being observed by professionals rather than being experienced by service users. Seen by professionals as a necessary structure used to influence expenditure patterns for health interventions, she questions what is being measured, by whom and for whom. Issues raised by Wallcraft include the condition-specific measures that may be needed for different psychiatric diagnoses. Methodological problems have caused complications in interpreting results for quality of life measures because of difficulties in reaching a consensus regarding definitions of the concept. I question the suitability of traditional instruments, in terms of their ability to measure recovery, compared to the value of subjective instruments based on service user stories. Wallcraft advocates a bottom up approach to the development of more sensitive measures, which will involve service users in their creation. She quotes one service user who tells how no-one had ever asked her about her journey. When she became the only member of the family who was able to help her dying father this represented a contribution which affected her position in life, her role and her citizenship to a much

greater degree than getting a job in the local supermarket. However, she considered that the latter would be deemed a more valid outcome by mental health professionals. Quality of life outcomes, and significances in the journey of recovery, are uniquely individual and concern a personal interpretation regarding wellbeing and the ability to think, dream and act.

Transitional Recovery Revisited

The concept of *Transitional Recovery*, and the reason for its introduction at The Haven, is described in the previous chapter. It was vital that the concept of *recovery* would not become associated with loss, and that progress would not be penalised with discharge from the service. *Transitional Recovery* means that progress is defined as a journey of small steps and progression is rewarded by being able to remain registered at The Haven as a safety net. The original concept of capacity at the service was 100 to 110 clients. Today The Haven has 142 registered clients. It has been possible to continue to register new people because, for *Transitional Recovery* clients, the choice to remain registered at The Haven is contingent on using the service less, but knowing it still exists as a firm base:

> **Pablo:** *One of my first questions when I very first came here, I said, is this a conveyor belt to chuck us in and chuck us out, get us well, I said, or is this a firm base that stays here forever? Just hold my hand on my bad days. I hope that's not too much to ask.*

> **Charles:** *I don't think we should clip our wings, we just need a nest to come back to.*

Historically, recovery for people with mental health difficulties has followed a sequential path of treatment, recovery and rehabilitation. *Transitional Recovery* offers a new way of working with people who have a personality disorder diagnosis. The pyramid of the journey of recovery in personality disorder addresses attachment issues, offers optional treatment, fosters hope and the regaining of control, and is embraced by the concept of *Transitional Recovery* where people can choose to retain a haven in which they may continue to develop and progress on their chosen path. This journey has also had implications for organisational learning and change, which are described in the following chapter.

ORGANISATIONAL LEARNING AND CHANGE

This chapter examines the elements that constitute a *Learning Organisation* and how a participatory action research approach impacts on organisational change. It outlines the process of *Change* related to the collective action research nature of our study and the increasingly participatory nature of stakeholder involvement. The Haven is a service which was created with some distinctly new and different features. It espoused aspects of the therapeutic community model where members would come together to explore emotional and psychological issues and exercise their decision making and personal responsibility while taking advantage of peer accountability. The setting for such organisations was usually residential and not based in the geographic area of participants, meaning they would take up residence at a service elsewhere in the country for a period of time (Hinshelwood 1999; Warren and Dolan 2001). Although the original concept of the therapeutic community suggested a retreat, over time the ethos of such communities embraced different models, some created as therapeutic community day units where participants could attend the programme whilst retaining links to their home area (Rawlinson 1999). In the 1990's Crisis Houses began to appear in different parts of the country, offering short respite at difficult times. Not specialising in personality disorder, they were represented as a kind of asylum in the community; an alternative to psychiatric hospital (Tomlinson and Carrier 1996). Wallcraft (in Faulkner et al 2002) championed the efficacy of the crisis house model, highlighting the user-led nature of such services and the emphasis on human interaction rather than drug treatments. Uniquely, The Haven was created as a blend of models combining a therapeutic community with a crisis house element. Therefore, participants could remain in their own geographic area, but also have the benefit of a short stay residential component within the service.

The Conception of a New Service

The concept of The Haven began essentially as dissolution of earlier models and responses to care and treatment for personality disorder in our area. It sprang from a shared vision and creativity which, from the outset, aimed to be proactive and responsive to lessons and the need for change. This was not a service model imposed on an area but

one coming out of previous user involved research (Castillo 2000; Castillo 2003; Ramon et al 2001). It arose in a climate where pilot services for personality disorder were being proposed nationally by the Department of Health. As a daring response to the disappointment of previous service models, we were being given carte blanche and, if our proposals for a service were agreed upon, we would receive the funding to pursue a pilot to test and develop our ideas for the care and treatment of personality disorder.

Kofman and Senge (2001) speak of learning organisations being an exercise in personal commitment and community building. They suggest that this type of organisation requires a re-definition of leadership to *Servant Leaders*. Such leaders are those who are walking ahead, and this is not necessarily dependent on management hierarchy. They propose that such leadership is intrinsically collective. Waiting for a leader to decide the way forward is a surrender of the power necessary to create a learning organisation. This does not necessarily preclude management positions such as Chief Executive but, in order to reconcile potential dilemmas for learning organisations, this requires a value system that embraces leadership as a decision to serve. Servant leaders choose to serve one another and a higher purpose. That higher purpose could be helping each other to excel and achieve personal transformation.

On completion of earlier research (Castillo 2003), outlined in the Context Chapter, the service users involved in our journey found themselves, in the early 2000s, aggrieved and offended at the notion of untreatability in relation to personality disorder. From this sprang the hope for recovery. An important factor was the convergence of climates which existed in the new millennium. Not only was there a national focus on finding new ways forward for the support and treatment of personality disorder, the concept of *Recovery* had also emerged in the mental health arena. This concept was led by service users in the USA, the UK and other countries.

As outlined earlier in the thesis, the first seeds for The Haven were sown during the research conducted in the late 1990s (Ramon et al 2001). This was an emancipatory study carried out with service users who had a diagnosis of personality disorder. These

seeds were nurtured during the discussions with service users, from 2001 to 2003, which resulted in the proposal submitted to the Department of Health to set up The Haven as a pilot service. The hope for recovery underpinned our efforts. In the planning of the service due consideration was given to evidence based treatments which already existed, especially therapeutic community models, which had an inherent flattened hierarchy, allowing staff and service users to 'walk ahead' together, as servant leaders.

The Structure of The Haven

As a context for this chapter, the structure of The Haven is now revisited. The service was planned around the views and needs of the service users with the diagnosis. A proposal emerged which incorporated both a 24/7 crisis service and a therapies service with a tiered approach to group support and one-to-one work. The Haven Community Advisory Group was formed, with a democratically elected leader and deputy from amongst the client group. The Acceptable Behaviour Policy was formulated with the clients and was administered by them. From the outset, structures were created that would allow service users to continue to drive developments at the service. Structures also ensured that clients would watch over and control behaviour, ensuring that the culture of the community was not eroded, thereby instigating an ongoing learning process about self and others. Clinical matters were negotiated on an individual basis, between clients and staff, and confidentiality was preserved to the degree that the client would wish. That is, unless they decided to share their personal, emotional and psychological matters with their peers, at groups or in community discussion, those matters would be entrusted only to the staff team. However, the shape of the services within The Haven, their efficacy, ideas for new developments, and many other matters regarding the day to day running of the service were, and continue to be, client-led. For example, during a recent visit by three clients from another personality disorder service elsewhere in the country, we discovered that they had wanted a greenhouse in their grounds but had not been allowed to have one because this was deemed to be a self-harm risk. They also had a desire to hang pictures on their walls and to make their centre warm, welcoming and homely. They expressed their admiration for The Haven and compared the shortfalls in their own service. Many rules and policies were imposed from the top down in their area,

whereas The Haven's bottom-up approach gave the clients the decision about whether we should have a greenhouse in the garden, which we do, and about painting and decoration at the service. Our visitors said that when they asked about pictures they had been told that blue tack could not be used as it was damaging and picture hooks were a suicide risk as people could hang themselves. Interestingly, The Haven Health and Safety Policy requires that sharp objects are kept in the staff office and requested when needed. But this policy was approved by clients, as are all Haven policies. This issue was revisited recently when some clients said they felt it was no longer necessary to have sharp knives locked away from them and that there had never been an incident of sharps being misused at the service. This was discussed by the community and, because two clients said they would still feel disturbed in relation to self-harm if sharp knives were left out in the kitchen, the community requested that the sharps remain available only on request and that the policy is not changed at this time. These types of decisions, which fundamentally characterise the atmosphere of an environment, are made by clients at The Haven.

Cycles of Change

Action research is closely bound to practical action in an organisation or social context. Main (1967) developed principles for a therapeutic organisation that include, 'The State of the organisation is kept under continual examination and renewal', presenting the organisation as a learning system. Organisational learning is about the capacity and processes within an organisation which can be used to improve performance (Nevis et al 1995). Learning does not always occur in a linear way and can take place formally, informally and in unplanned ways. Checkland (1999) discovered that management education occurred, to a large degree, by making mistakes and watching others. In the development of his Soft Systems methodology he examined the non-linear, complex networks of interrelationships and interdependence, within organisational elements, which produce negative and positive feedback. Checkland concluded that organisational systems should be viewed in a systemic rather than a systematic way. A soft systems approach will encompass many perspectives of perceived reality, making comparisons of

the whole in order to learn. Senge (1990:3) characterises learning organisations as places where …

… people continually expand their capacity to create the results they truly desire, where new and expansive patterns of thinking are nurtured, where collective aspiration is set free, and where people are actually learning to see the whole together.

The participatory action research nature of this endeavour has proved itself to be a vehicle for learning, creation and change. One of the main vehicles which has created a feedback loop at The Haven has been this research and, as a result of issues raised by participants, at the various research events, a series of changes were put into operation. These issues and changes are reflected in Table 21:

Table 21

Organisational Changes				
Issue Raised	**Research Event**	**Date**	**Modification/ Introduction**	**Date**
Crisis telephone use	Service Evaluation Groups 1 and 2	Feb 2005 May 2005	1.New phone system 2.Support calls in diary	April 2005 June 2005
Support for Carers	Service Evaluation Groups 1 and 6 Carers Focus Groups 1 and 2	Feb 2005 May 2006 Mar 2007 Aug 2007	1.Educational Workshop 2.Carer Focus Groups 3.Families&Carers Group	Sept 2005 March to Aug 2007 Aug 2007
Outreach	Service Evaluation Groups 3, 4 and 5 Interviews and Focus Group 4	Aug 2005 Nov 2005 Feb 2006 April 2007 May 2007	1.Student Outreach 2.Student & Staff Outreach 3.Established Outreach	Sept 2005 March 2006 Sept 2006
Staff overload on crisis shifts	Service Evaluation Group 4 Focus Group 1	Nov 2005 Aug 2006	1.Introduction of students & volunteers	Sept 2006
Life Skills	Interviews Focus Group 2	Oct 2005 Nov 2006	1. Life Skills Course expanded	Feb 2007
Care Planning	Service Evaluation Group 4 Focus Group 2	Nov 2005 Oct 2006	1. Progress Planning and Long Term Care Plans/Lifeplans	Nov 2006
Rewarding positive progress	Interviews	Aug 2006 Oct 2006 Nov 2006	1.Transitional Recovery Group 2. Social Inclusion Unit	Nov 2006 July 2007

An array of potential stakeholders existed in relation to the creation of the service at The Haven, including policy makers, commissioners, external mental health professionals and

the general public. The wishes of various stakeholders were likely to be different, for example, ranging from cost savings achieved by a reduction in psychiatric hospital admissions to fewer disturbances from the range of symptomatology employed as coping strategies by clients with this diagnosis. However, the internal stakeholders involved in our journey of organisational change were the service users and the staff at The Haven. A transparency about information, and the dialogue that had been set up with our clients, were essential, and transcripts of research events with clients were made available to the staff. The clients' monthly Community Advisory Group was also attended by staff and minutes distributed widely, meaning that clients and staff not present at the meetings would be made aware of the dialogue and the issues. Similarly, minutes of all Community Discussions regarding unacceptable behaviour were distributed. Others closely associated, such as the Steering Group and the Board, included a number of service users in their membership and all were apparently in accord with how the service had been set up, in relation to its recovery ethos, and the fact that this would be a bottom-up structure where clients were able to drive developments. Nevertheless, although the staff team was committed to being responsive to the decisions of clients, this was a new and radical way of working for most of them. Also, recovery has many different meanings and, for many clients coming to this new service, it initially meant the right kind of support at critical times.

Crisis Telephone Use in 2005

Therefore, the first change occurred as follows. During the planning of the service the high level of use of the crisis telephone line was underestimated. Participants soon made it clear, at the first research event in this study, in February 2005, that the tension between support for crises in the building and *Crisis telephone use* from outside the building was impacting detrimentally:

> *Chloe: But, if you're seeing someone in a one to one you can't have them constantly jumping up to answer the phone because it just doesn't work, you know, like there's no continuity. You're made to feel unimportant and the phone takes priority and that's not good enough. (Service Evaluation Group Feb 05)*

> *Collie: I was supposed to get a support call and it didn't come at all yesterday and I've got no answer to why it didn't come. I just thought that I 'aint worth nothing. It feels like I don't belong here. (Service Evaluation Group May 05)*

It was difficult for staff to hear these criticisms, especially as they were coming to grips with running a crisis service in a hectic climate and were, consequently, working very hard. It would have been easy to decide that the staff can't do everything; this client group is endlessly needy; they are projecting their earlier unmet needs onto the staff; and so forth. However, client comments were taken very seriously and it was decided that there was indeed a flaw in the system and, during the Spring of 2005, a new phone system was installed where, in addition to the mobile number for sending texts, the new system gave a dedicated crisis number, with a message saying that calls, if not answered immediately, should be responded to within 30 minutes. Additionally, short-term care plans now included support calls, booked in the diary. The care plan forms were also created with a checklist on the back where staff could double check that all entries had been made in the diary before the plan was signed off, ensuring calls were not missed and opportunities for clients to feel rejected were reduced.

Support for Carers and Family Members 2005 to 2007

Setting up the new service had been a monumental effort in itself and no initial structures were created to include family members and carers. Therefore, a crucial group of stakeholders had been excluded. Clients began to call for ***Support for Carers*** during the first research event in February 2005:

> *Harry: I'd like to see something for carers. Carers get forgotten and services don't really help carers at all and, quite often, when they attend CPAs, and things like that, they're totally ignored. (Service Evaluation Group Feb 05)*

In response, a Psycho-Educational Workshop was held at The Haven in September 2005, run by Kingsley Norton from the Henderson Hospital. Here, clients were able to bring their family members and carers for an afternoon of sharing problems and solutions. However, ongoing support for carers and family members was still not created at the service and, again, this was called for by clients at the research event held in May 2006.

The clients at The Haven Research Group also considered it was vital that some of the research focus groups should include family members and carers, and that research questions should also be included that would ask them about the kind of support they would like. The carer focus groups were held in March and August 2007. Here, our participatory action research process had led to a change in the research design itself and, as a result, family members and carers were enabled to express their views and ideas about what recovery meant for them and those they supported. Participants at those groups valued the support they gained from each other. In fact, during the first focus group it proved very difficult for the facilitator to keep the carers and family members to the agenda. There appeared to be so much pent up emotion on their part, and so much they wished to say, that their inclusion and support was observably long overdue:

> *Alex: The chats that we have as carers, I think we can learn a lot from each other because we are discussing something with somebody else who knows where you are coming from and that just makes a difference. It's good for us all to see a different side isn't it. (Carers Focus Group March 07)*

> *Sammy: I would like to see some kind of informal Carers Group run through The Haven. (Carers Focus Group Aug 07)*

In response a Family and Carers Group is now held at The Haven each month.

Outreach Work 2005 to 2007

Adopting a philosophy of 'if it ain't broke don't fix it', research feedback provided a very positive percentage of responses about what was working at the service and this is outlined in detail in the Findings Chapter and in the appendices. We kept doing what was working, however, the concept of *Outreach* work became a frequent theme at service evaluation groups, client focus groups and interviews, throughout the course of the research. As the initial needs of clients began to be met, in terms of crisis work and therapy, the need for outreach in the community was expressed. This included the desire for a range of help, from support in the home to support with children or in attending college:

Elise: It's kind of a tentative suggestion, I haven't really thought it through but it strikes me that there's an awful lot going on here in this building and on a one to one basis with clients, but there's nothing that I'm aware of that happens outside in the community. I really feel that one of the ways that recovery can be supported is if people are actually helping you to live lives in the actual community, outside of the four walls that are The Haven, and that goes along with what was mentioned previously about helping people maybe have new flat starts and that kind of thing. (Service Evaluation Group Aug 05)

Jonny: Support on public transport as well, because I don't have a problem with it at all, but I know people do. (Service Evaluation Group Nov 05)

Poppy: I do feel I need outreach work for when I'm at home. (Client Focus Group Aug 06)

Fred: I need a little bit of help with moving. (Individual Interview April 07)

Leska: I have had a baby and I am feeling quite isolated and it's so hard to kind of still stay positive when you haven't got the support that helps you along with that and keeps you afloat. (Individual Interview July 07)

This began as a particularly challenging feedback because staff were already stretched in their efforts to maintain successful actions in crisis and therapeutic work. As a way of addressing this need, student social workers were introduced to the service in September 2005 and, each year since, a minimum of two students have been on placement at The Haven:

Daniel: I think an important thing we do need to do is invite more student workers that are coming up to the finishing of their courses, to educate them in the mental health side, and not just letting them do the course and then letting their peers turn around to them and saying this is the way it should be done. (Service Evaluation Group Nov 05)

Students have been used for a range of outreach work, including supporting parents in the home:

Leska: One of The Haven social work students comes out most weeks to give us support and comes to any meetings I have. Because of this I don't feel secluded and I can still be part of The Haven. It's really nice to have someone to talk to, even if she is a chatterbox! But that's good distraction too. This has given me real practical and emotional support and I'm very grateful. (Individual Interview July 07)

Using students to help with core services within The Haven has enabled both staff and students to become engaged in outreach work to help clients move home, attend meetings at college, negotiate public transport, and practice life skills such as shopping and looking after themselves in the home:

Natasha: Self-esteem and confidence, it's quite a major issue, I am getting some one-to-one support in going to college, someone's going to college with me. Going to college is quite a big deal. (Client Focus Group Nov 06)

Outreach statistics began to be kept in 2006 where they were averaging 20 hours a month. They now average 40 hours a month and outreach is a consistent part of the service provided at The Haven.

Staff Overload on Crisis Shifts 2005 to 2006

As the client base at the service grew new clients presented in crisis at the beginning of their journey. At service evaluation groups and client focus groups, participants highlighted the fact that they were aware of *Staff overload on crisis shifts*, because of the need to respond to the many crises being presented by clients:

Abigail: I think the staff sometimes cut themselves into lots and lots of pieces but I actually phoned in early in the morning, and my brain was telling me to do one thing and I thought I'll phone up and speak to somebody and unfortunately the staff were probably busy dealing with somebody else and it was too late when they did find me. When they rang me, the situation had happened. But I don't think it's an easy thing to overcome. I just don't think that the staff even carrying the phone around with them can be everywhere at once. I don't know how we can get around it. (Service Evaluation Group Nov 05)

This issue was born out by feedback from staff so, in addition to the compliment of social work students which were added to the team, by September 2006, the situation was

addressed by the introduction of volunteers, not just to help with group work, but also to help with specific shifts where crisis contacts were proving most prolific.

Life Skills 2005 to 2007

Positive feedback also concerned therapies and group work. Early in 2005, as evidence based therapy, the DBT Skills Group (Dialectical Behaviour Therapy) was introduced to the group programme.   As a structured group, requiring good commitment to sessions, not all clients were ready or able to access the DBT Skills programme.   However, participants felt it was important to learn *Life Skills* that would help them to understand and control their anxieties, and they began to express this need at research events during 2005:

> **Abigail:** *I don't know whether it's possible within the budget, the groups we have so far are very good, but I think anxiety management and I noticed you'd put a note on the board about anger management. Personally, anxiety management, if there was a group to do that I would appreciate it. (Service Evaluation Group Aug 05)*

In 2005 the Life Skills Programme was developed. It runs weekly to encompass anxiety management, anger management, assertiveness and confidence building and addresses common difficulties associated with personality disorder such as self-harm, eating distress and substance misuse. The programme was appreciated; however, help with such skills continued to be called for at research events during 2006:

> **Elise:** *The programme of activities that runs needs to be constantly developed towards developing life skills for people so that, at the end of the day, they can actually go out and live that life. (Individual Interview Oct 06)*

In response to this, by 2007 the Life Skills Programme had been expanded to include 18 weeks of sessions, now encompassing managing finances, managing time and routines, sleeping difficulties and WRAP sessions (Wellness Recovery Action Plan).   This continues as a rolling programme of sessions that begin again once the course is completed.

Care Planning 2005 to 2006

As mentioned earlier in this chapter, short term care plans were introduced soon after the service opened, as a proactive response to crisis support and ***Care Planning***. This was an effort to work preventatively with clients by pre-booking support calls and one-to-one work each week. During the service evaluation groups and client focus groups in 2005 participants began to talk about the need to be supported to plan and look ahead:

> ***Cosmic:*** *For me it's, I spent so many years just trying to get through the day that I've never actually had any long term plans. I wouldn't know how to start. (Service Evaluation Group Nov 05)*

Some also spoke of being caught in a comfort zone. Staff responded by agreeing that they did not want to collude with that comfort zone and concluded that we needed to work with clients in a more in-depth way, looking at longer term issues and what would help each individual to move forward:

> ***Jonny****: Well that's going from short-term care plans to long-term care plans, isn't it? (Service Evaluation Group Feb 06)*

Long Term Care Plans began to be introduced and, by 2006, a weekly clinical meeting was formed, called Progress Planning, where staff would discuss one client each week, in a more in-depth way. Preliminary ideas for the Long Term Care Plan were formulated at the meeting and taken to the client, to enable staff member and client to work on the plan together. In more recent years, at the suggestion of clients at the monthly Advisory Group meeting, many of whom felt the word 'care' felt medicalised, Short Term Care Plans have been renamed Support Plans and Long Term Care Plans are now called Lifeplans. Today, the feedback loop has come full circle in that an annual review, or re-registration, takes place for each client who wishes to remain registered at the service. A section of the Annual Review Form includes the pyramid of our journey of recovery in personality disorder, where clients are given time to reflect on their progress on the pyramid to see, from their own individual perspective, how the layers relate to each other, and to pinpoint where they may be stuck and where they may be progressing. The

Annual Review Form ends with a Lifeplan or an update of that person's Lifeplan if one already exists.

It is difficult to evaluate whether some of the changes described above would have occurred despite the research. I would argue that they occurred substantially because of it, due to the feedback loop established by the ongoing dialogue that had been opened with clients. One change that did occur was not connected directly to research feedback. It was, however, related to the proactive ethos adopted at the service in terms of care planning and a preventative approach. This concerned the use of the crisis beds. Four beds exist at the service and a stay may be anything from one night up to three weeks.

Nomenclature was an important factor here because the term 'crisis' bed suggested that someone had to be in crisis to obtain one. This had the potential to provoke a competition of crises to see who might be most deserving of a bed. It was also noted by staff that, in our early days, clients would not infrequently overdose on discharge from a crisis bed stay. This occurred despite the 24/7 nature of the service, which was geared for contact on discharge from a bed and which would even ensure transport to the service at critical times of the day or night. Thought and discussion from the staff team yielded ideas about using the four beds in a different way. These changes were taken to the client group and agreed with them. Respite stays began to be planned ahead. They were contingent on good engagement. It was also important to agree with clients whether the bed stay had been beneficial. One of the ways formulated to do this was to see how that client coped in the week after discharge from a bed before booking in their next respite stay. Overdoses after discharge from a bed stopped. Although there are times when a client is admitted to a bed at The Haven when they are in crisis, especially to avoid a psychiatric hospital admission, the majority of bed stays are now pre-booked as respite stays, for example, a week every two months or two weeks every three months. This has proved to be a way to encourage progress and to give clients the hope of planned respite to enable them to manage their recovery. Clients use beds in different ways. Some book a stay during difficult anniversaries, others plan challenging therapeutic work during a

stay so they know they will be safe during that time, others use the stay as a kind of holiday and a break from day to day pressures.

A Need for Change which Clients Found Hard to Articulate 2005 to 2006

The following section is included here as important background data regarding organisational change. It concerns an issue, which resulted in an important change, not included in Table 21, shown earlier in this chapter. The reasons why, I believe, will become very clear as it is explained. Because they have often experienced early traumatic events, and overwhelmingly unmet needs in early and later life, people diagnosed with personality disorder may have little sense of boundaries (Mahari 2004). An individual needs to have a sense of their own identity and space, and the space and identity of another, in order to have an awareness of boundaries. Someone with a personality disorder diagnosis may not be aware of where they end and you begin. Demands placed on professionals and others can be experienced by them as a violation of boundaries and limits and may cause a mental health worker to either become over involved or to distance themselves from someone with this diagnosis.

Hinshelwood (1998) suggests that difficult patients create reactions in those who try to care for and treat them. Kerr (2001) speaks about the idea of *'the ailment as ignorance'*, that is, a lack of understanding may cause others to respond either by becoming too closely associated with a client, or by regarding that individual as too difficult a patient to work with. Both approaches further affect that person's mental health in an adverse way. He explains that behaviour is also a form of communication, and that the way in which a system responds to this behaviour may also be dysfunctional. He urges us to see things in a *systemic* way, as a series of dynamics being enacted around that person. Services and people around the client may be reacting in a variety of ways; identifying, sympathising and becoming inappropriately involved; getting angry with and rejecting them; feeling guilty or burnt out; a variety of responses which fall short of actually understanding how it is for that individual. This can be experienced as a mine-field which presents a significant challenge to any staff team who may be subject to extreme boundary testing. Confronted with a therapeutic community environment, such as The

Haven, staff and clients co-existing in a close atmosphere are sometimes exposed to a hazardous excess of emotions. For this reason boundaries must be negotiated, drawn, and clearly understood by clients and staff alike. Boundaries must be consistent and allow clients to take stock of thoughts and feelings and learn to take responsibility for how their actions impact on themselves and others, and staff must understand clearly how this works.

In earlier years at the service, personnel difficulties were experienced in terms of boundary breaking. It is not possible to discuss the details of these issues here. They were also not disclosed in any research event, including individual client interviews. Staff felt the need to discuss the boundary issues with certain clients who had been affected but were reticent to do so because they felt clients should not be burdened and involved. This, however, presented a deadlocked situation with insufficient information. The Vulnerable Adults Lead from the local Mental Health Trust was consulted and pointed out that many in this client group were used to keeping secrets within the family and it would be a great disservice not to help them bring matters out into the open because, by not doing so, we could be replicating patterns of early abuse. We were urged to at least give the clients involved an opportunity to do so. As a result, not only was it necessary to create The Acceptable Behaviour Policy for clients at the project, which had been written at the outset, it now became necessary to create policies for staff which spelled out and made boundaries very explicit.

However, retaining humanity while holding firm boundaries, sometimes requires flexibility and can leave grey areas that we believe will always exist with this client group. Opportunities at staff meetings, individual supervision and teambuilding need to be safe enough, and to occur often enough, for a culture of openness to thrive. If someone is drawn into a compelling situation it can be much easier for colleagues to see what is happening. Our procedure at The Haven is to bring all issues to the staff team, bring them to supervision, write them in client notes, and discuss them openly and in an authentic way with the client. Boundary issues are always up for debate at the project. Where we have run into difficulties in the past is when issues have become hidden. Key

learning has included the fact that where a staff member has unresolved personal difficulties, and un-drawn boundaries, working with this client group can become untenable. Working with personality disorder is not for everyone and requires a truly honest and fairly constant examination of working practices for a staff member, and support systems that allow that person to do so (Castillo 2009).

During the National Evaluation of the 11 community personality disorder pilots, of which The Haven is one, part of the study concerned burnout rates for staff (Crawford et al 2010). The study cited prevalence of aggression and suicidal behaviour as high risk factors for staff burnout, and noted that such behaviours are common amongst those with a personality disorder diagnosis. However, the study found that burnout rates were lower amongst the staff group at the personality disorder pilots. The recruitment of reflective and resilient personnel; an emphasis on teamwork and mutual support; reflective practice involving forums where staff could regularly come together were all factors which were highlighted as reducing work-related anxiety and burnout. Many staff involved in the study emphasised the positive aspects of working with this client group and reported a sense of achievement in their work.

At a Teambuilding meeting in March 2010, staff at The Haven discussed this recently published study and added their thoughts. Some talked of the team being the best they had ever worked with. They valued team interdependence and the fact that colleagues looked after each other. They discussed how support was enhanced in service structures from handovers, to teambuilding, to clinical supervision. Some spoke of their commitment to working with this client group because they had struggled to support them in other service settings. Many staff spoke of The Haven as a unique service and that they felt part of something challenging and different and how there was both a sense of freedom to be oneself but also firm structures and boundaries. Some staff spoke of not being drained at work for the first time ever and about feeling glad to walk through the door to work. Mirroring the views of clients, some spoke of it being a safe place to work with a sense of belonging and being part of a family. One said *it's like coming home.*

Rewarding Positive Progress 2006 to 2007

Returning to Table 21, although feedback about the services provided continued to indicate that they were successful and supportive, some respondents, in the privacy of individual interviews rather than focus groups, began to make powerful statements about recovery and the importance of ***Rewarding positive progress***:

> ***Elise:*** *I think, fundamentally, people with PD need a certain amount of love and care and TLC and pampering and I think The Haven's taken that well on board and has supplied that, where other statutory units have failed dismally. I do think it's very easy to pour out the love and concern and that's so important because so many people haven't had that, but then I think there's a danger that that then becomes an emotional crutch and people don't particularly want to move on. That dependency shouldn't be fostered; it should be actively discouraged in a very gentle way. (Individual Interview Oct 06)*

> ***Cosmic:*** *The staff could be more accessible and stop spending all their time on attention seekers and people that just go home, get wrecked and come back, and are on that cycle. (Individual Interview Nov 06)*

However, others spoke of the need for continued healthy attachment and support:

> ***Pablo:*** *One of my first questions when I very first came here, I said, is this a conveyor belt to chuck us in and chuck us out, get us well, I said, or is this a firm base that stays here forever? Just hold my hand on my bad days. I hope that's not too much to ask. (Individual Interview Aug 06)*

The concept of Transitional Recovery was adopted in late 2006, as an effort to address both needs expressed above, by allowing clients to stay registered at The Haven as a safety net whilst making positive progress. The Haven had been planned primarily around its service users' views and ideas. They had asked for a 24 hour crisis service, and this had been refined over time in accordance with their views. Similarly, therapy services had been set up in accordance with clients' ideas, providing one-to-one support and group work, which were also refined over time in response to views and ideas expressed at research events. The concept of Transitional Recovery and the desire for social inclusion were not something envisioned by clients during their original planning

of the service. The degree of crises and the need for care, support and therapeutic work, obscured the arena of the outside world. One of the first accessories acquired at the service, in 2004, was a board for 'Blue Sky Thinking', where clients could take a white dove and write their dream for recovery and then pin it on the board. What was written on the doves was humbling and included needs such as, *'just to be listened to'; 'someone to understand'; 'I just want to feel safe'*. Two years later, although the need for support and care was still apparent, a different kind of need began to be expressed:

> **Harry***: For those that are further along in their recovery, interview techniques would be handy, to help get there, practice role play and get them used to the process with college and employment. (Service Evaluation Group May 06)*

> **Rose:** *My goal is to go to university to get my MA and then take it further. (Service Evaluation Group May 06)*

> **Tiffany:** *The Haven should help us get voluntary work. (Client Focus Group Nov 06)*

> **Jenny:** *I now want to do my Access Course and I want to work in care. (Individual Interview Feb 07)*

This heralded the most fundamental shift in the shape of Haven services. Now our participatory learning and change process led to proposing role transition. By the end of 2006 the Transitional Recovery Group began to be held weekly in an effort to support clients to work towards such goals. Eight months later, in July 2007, we were able to open a Social Inclusion Unit at The Haven with a full-time coordinator, teaching a range of personal development skills, and a part-time assistant to help her to support clients in fulfilling their hopes, dreams and goals in their journey of recovery. This was an organisational change, and fundamental augmentation of The Haven model, that we had never envisioned at the outset. It had not been factored into our original funding proposal. The financing of the new unit came from HM Cabinet Office Social Exclusion Task Force. The Task Force offered start-up funding only but we believed our successful efforts, in terms of maintained client stability and achievements in the outside world,

would encourage local commissioners to take over the funding for this newer part of the service once the initial two years were complete. In a difficult financial climate, and despite a third year's funding from the Cabinet Office, local commissioners felt unable to fund the unit further. Because the Social Inclusion Unit was set up with temporary funding this made it more susceptible to rejection in the current economic climate, especially when medical rather than social interventions for mental health problems have traditionally received more investment. The news about this decision came just three months before the original set-up funding was due to cease.

During discussions with service users and other stakeholders, in the days after we had received the news, it became clear that there was a will to raise the funds necessary to continue and a determination not to lose this part of the service. The Social Inclusion Unit at The Haven had emerged as a product of organisational change and its stakeholders were not about to stand back and see it disappear. In the first week of 2010 the snow fell heavily and the buses were cancelled. However, many service users walked to The Haven in the snow to attend a special meeting to plan what should be done. A campaign was launched and the servant leaders of the organisation have 'walked ahead', both staff and service users together, taking the lead on raising funds. This began with a media campaign:

> **Boris:** *It's about supporting someone through troubled times; encouraging them to college; giving something back; being part of a bigger picture; improving someone's quality of life; and feeling safe.*
> BBC TV Look East - Jan 10

> **Doris:** *The Haven has helped me to get on an even keel and addressed stuff that's happened in the past. Since the Social Inclusion Unit started it's helped me realise the person I can be. I want to be the best (me) in the world. I had the devil on my back in the form of a Math's GCSE. It took me seven attempts and, last year, with the help of the Social Inclusion Department I finally obtained it.*
>
> Local Gazette – Vital Project's Funding Plea – Jan 10

> **Emily:** *By the time I was thirty-five I was an alcoholic. I was self-harming, having flash back of sexual abuse when I was a kid and I was suicidal. I was on*

life support about five times. Since I've been at The Haven I haven't been back in hospital for four years. I haven't had a drink in twenty-six months. With the support of the Social Inclusion Unit I have two NVQs for English and Volunteering. I now do voluntary work.

<div align="center">Local Gazette – Vital Project's Funding Plea – Jan 10</div>

Lesley, the first service user to make her views known in 1998, during our original research endeavour (Castillo 2003), was out of the area during the time Haven research took place. However, she had now returned to the area and was receiving support from the Social Inclusion Unit at The Haven in seeking employment. In a full circle return to campaigning, Lesley took the lead in a letter which was sent out nationally:

> **Excerpt from Lesley's letter:** *Twelve years ago, in 1998, as a service user with this diagnosis I became part of the original campaign to highlight the plight of those with personality disorder and, from the efforts of service users with the diagnosis in North East Essex, I have seen The Haven come into being from a dream to an embryo; to being the current flourishing service. It is with real sadness that I write to confirm that, as some of you already know, funding has not been able to be agreed to continue The Haven's Social Inclusion Unit. This is a vital part of our service and we are now trying to find alternative funds to retain two valued and knowledgeable members of staff and keep the other activities in the unit going. It seems ironic that, just as national guidance such as 'New Horizons' and 'Realising Ambitions' is hot off the press, aiming for social inclusion and work opportunities for people with mental health problems; this is the very part of The Haven service that has come under threat. (Jan 10)*

Finally, one of our research respondents wrote a testimonial and wished to have this circulated widely so it was sent out nationally, as part of Lesley's letter:

> **Ben:** *I heard with dismay that funding for this vital work at The Haven will not be continued and I would like to make my views known. I have Personality Disorder and was referred to this service by my Psychiatric Consultant several years ago. At that time I recognised that I was very ill indeed and again, at that time, few professionals thought that Personality Disorder was a treatable condition. It was, in effect, a dustbin diagnosis and marked the end-of-the-line of hope for recovery. The success of the care, (or treatment, for want of a better word) at The Haven is nothing short of astonishing. Over a period of time I have changed from an emotional cripple with no self-esteem and certainly no future in society, to a working professional, with a strong network of friends and a fully-functioning family. This situation was created in no small part with the full*

assistance of the social inclusion team at The Haven. Despite my years of self-loathing, this unit gave me every skill and confidence to fight my way back into society. And they remain there for me, if I need their support again. I am far from alone with my experience of this team. Not everyone is able to recover to my extent but everyone has something to give back to their environment. I don't believe that there is any such similar specialist support throughout Essex for those in the community with a personality disorder diagnosis and to lose their skills would be devastating for many sufferers. The cost-benefit analysis bears testimony to the success of this project. Before engaging with these wonderful people I was admitted to acute psychiatry services several times every year, often for weeks on end. I haven't had a hospital admission for two years now and only come to The Haven for four nights rest every few months. Without the support of The Haven and its Social Inclusion work I very much doubt I would be in this privileged position. There must be a huge saving to the NHS as a direct result of successful support from this service. The cost saving will be replicated for every client who makes a full or partial recovery. I can see that short-term savings can be made by not continuing funding for this service. Times are hard for all of us. But I beg everyone to reconsider. The savings accrued would soon be swallowed up by the increasing costs to statutory services. And this takes no account of the cost in terms of human suffering. (Jan 10)

True to their word that the Social Inclusion Unit would not close, by June 2010 stakeholders had managed to secure most of the required funding for the current financial year and remained resolved to continue to fundraise for the following financial year. I believe that this later development is an expansion of participatory action research in a true Frierian (1970) sense. The group as a whole has been an agent for change in that it has sought solutions that are shaping their lives and, in doing so, it has engaged a wider, often passive public. The Haven is now even more connected to the non-NHS world, through involving people from the media, and in reaching so many others who have given donations who are now legitimate stakeholders of the service.

Shared Power and Participatory Action

Kofman and Senge (2001) propose that organisational learning is engendered by groups who espouse capabilities beyond the traditional; empathy, compassion, even love they would say; practices that generate conversation, dialogue and collaborative action; and which have the capacity to see work as a system which is a flow of life. The values of an organisation are its life blood and service users as stakeholders are setting forth on a life journey that circumstances may have previously robbed them of, or perhaps never

allowed them to develop. Such organisations necessarily attract staff and other stakeholders who have compassion and flexibility of thought. The Haven research did not seek the views of its staff members during the course of this study, however, the way the organisation has adapted and changed suggests that, after some initial difficulties, the service has chosen well in its staff team and other major stakeholders, such as its Board of Directors.

Ramon (2010) highlights a multiplicity of cycles of imposed change in NHS organisations. Disempowering change can result in attempts to secure power for one's faction and in magnifying the fear of change. Why is change feared and why do people cling to a comfort zone? Perhaps because change represents something that is out of that individual's control; imposed from above or outside.

This chapter proposes that recovery led services require an adjustment at the power base of any organisation and shows how the use of a PAR approach has led to fruitful changes. A learning organisation is a collective action (Kofman and Senge 2001) and requires a shift that changes the core of how we work. The Haven, as an organisation, has attempted to espouse such principles and remains a living, learning and changing community.

THE CONCLUSIONS OF THIS STUDY

This final chapter re-examines the reasons for undertaking the study and reflects on the main questions the research has asked. The findings are reviewed and any original contributions to knowledge are discussed in conjunction with the implications for practice. I will also reflect on what I have learned personally from the process and outcomes of this thesis. The limitations of the study are considered and desirable future research is suggested.

The Reasons for Undertaking the Study

The earlier inquiry about personality disorder (Castillo 2003) yielded a new understanding of the diagnosis, defined by service users. This contributed to a change in the national agenda when the Department of Health (2003a) responded by providing national guidance and funding for pilot projects throughout the country, resulting in the creation of The Haven as a new service which was ideally poised to act as the service context for further inquiry. There was an opportunity to build research structures into the developing service from its inception. The service was created around the views of its users and they would continue to guide its development, suggesting fertile ground for a participatory study which, again, would be an inquiry with findings defined by service users.

During the course of our study, the National Evaluation for the 11 community-based personality disorder services took place (Crawford 2007). The evaluation spanned only the first two years the pilots were in operation. Part of the National Evaluation was a Delphi study aimed at seeking consensus about how community-based personality disorder services should be configured. Only a 39% consensus was reached (Crawford et al 2008). The study revealed that, as yet, a limited evidence base existed, reflected in the rudimentary experience of service provision at the pilot projects. Although the findings of the Delphi study highlighted good practice, they indicated the need for further research.

Thus, the reasons for conducting this research are re-enforced by the need for a more in-depth study of developments over time. Internationally, there is no agreed rationale of recovery for those diagnosed with personality disorder and the views of service users regarding this have not usually been researched. Therefore, the underpinning motive for this study has been the need to examine the psychotherapeutic, social and material aspects of the process of recovery, from the perspective of those with a diagnosis of personality disorder and their carers. It constitutes the first ever research study about personality disorder and recovery.

The Research Questions Asked

The Haven, as the service context, was the backdrop to the whole study and many questions in the research events related back to this context.

During the study it was essential to examine service user perceptions of recovery. The concept of recovery had different meanings, at different times, for participants. These ranged from the right kind of support in times of crisis, to social inclusion and ideas about what would make life meaningful. Therefore, it was important to first ask client participants if The Haven had helped them and, if so, in what ways it had helped them. Later questions directly asked for participant definitions of recovery.

The perspectives of carers and family members were also an important comparison with the views of clients and, again, questions to carers were designed to elicit responses about if and how their family member had been helped by The Haven, as well as directly asking for carer perspectives about recovery.

Questions to clients concerning therapeutic interventions, and about The Haven as a community, aimed to examine the efficacy of various interventions, and the relationship between clients and the community and any correlation between this and the development of healthy attachment. An examination of coping skills, and the development of more positive skills, was also an important focus for client questions. The disturbed self-image and chronic sense of emptiness ascribed to those with a personality disorder diagnosis led

to a question regarding participant perception of the internal sense of self and if and how this had changed over time.

It was important that questions to both clients and carers ascertained to what degree hope was present. The Research Group members also considered that barriers to recovery might be drawn out by explicitly asking if recovery was frightening. Both clients and carers were asked, in different ways, about dreams, goals and progress, in order to draw out perspectives regarding internal and external accomplishments and achievements. The research design aimed to find answers to the following questions:

- How do those with a personality disorder diagnosis define recovery?
- What factors are important in taking control over one's life for those diagnosed with personality disorder?
- Does The Haven, as a project, contribute to this process, and if so how?

The Methodology and Methods Used in the Study

The methodological approach to the study was non-positivistic and hermeneutic. This involved an interpretive analysis, which was a process of double hermeneutics where I attempted to make sense of the participants making sense of their world (Smith 2003).

The research approach was empancipatory where the study of a problematic or oppressive reality is not carried out by experts but primarily by those experiencing the oppression (Freire 1970). A process of mutual learning was achieved through the creative dialogue which was facilitated between me as the initiating researcher, the service users as co-researchers and other participants. This necessitated both reflection and action in interaction which sought meaning and change.

Qualitative methods, employing a participatory action research (PAR) approach, were selected for the study. This was a way of carrying out research designed by all participants. It focused on concerns highlighted by the reflections of those involved

(Winter and Munn-Giddings 2001). The core value underpinning PAR is empowerment and its goal is democratic as well as collaborative. It challenges inequality and establishes the right of people to actively participate in processes that affect their lives (Gorman 1999; Stanton 1989). Here, service users became researchers in the study with control over the selection of issues to be researched, data collection, analysis and dissemination (Evans and Fisher 1999). The core issue underpinning the action research nature of the study was to bring about change in the direction chosen by participants, as described in the preceding chapter.

The study relied on the participation of *Experts by Experience* in the form of a large number of people with a personality disorder diagnosis, 60, and a smaller number of carers and family members, six, who were involved in the day to day living of some of our clients. The Research Group, with a membership of nine Haven clients and me, was a primary vehicle in this process and methods employed for data collection included focus groups and individual interviews. Background data was used to inform and illustrate results. This included numerical data that had been recorded and statistically presented at The Haven, for all clients. Service evaluation groups, minutes of the service user advisory group, community discussions, service reports and newsletters were also employed, combining data streams representing a rich amount of information.

The potential sample for the study was 166 clients who had registered at the service by the time data collection was complete, and any associated family members and carers. The 66 participants involved in the study began to be identified by self-selection followed by a degree of purposive and theoretical sampling.

Thematic analysis was the method used for data analysis. This was a way of identifying, analysing and reporting patterns within data rich in detail and searching for themes across the entire data set (Braun and Clarke 2006). A six-stage method of conducting the thematic analysis was used (Whittaker 2009) and the Nvivo[7] computer software package was employed as a way to respond to the large quantities of data the study had yielded.

The Main Findings of the Research

Whatever we may call the difficulties experienced by those who have attracted a diagnosis of personality disorder, be it disrupted attachment experiences or unresolved trauma, they have come to The Haven robbed of central aspects of identity, memory and feelings, sometimes resulting in widely swinging emotions, chronic hyper-arousal, terror, rage, despair, hopelessness, guilt and shame. Thoughts can be incomprehensible and overwhelming and the need for physical and psychological *safety* has been palpable. The first lesson in our study was that respondents were able to define the component parts of a *safe* place and how this related to an increased ability to protect them from the harm they might do to themselves. The 24 hour nature of the service emerged as a crucial factor that could be internalised, even if one were not physically present at the service. It existed and it could be conceived of. Feeling *safe* was related to learning to *trust*, and *trusting* meant that it was *safe* to show one's pain and talk about difficult emotions and experiences.

The study also revealed the importance of *feeling cared for* as a finding and participants described a component of *care* in terms of first contact and acceptance; acceptance no matter what. They knew about the affection that can exude from a smile and the warmth than can be felt from a hug or simply being made a cup of tea. They spoke of being listened to and treated as if they were important, and the touch of pampering and complementary therapies, and of interconnectedness and humanness.

Our families are supposed to provide a place in which we feel safe and learn to trust, where we feel cared for and where we develop and learn to be spontaneous and creative. Clients at The Haven had often found this not to be the case and they came to us instead with a legacy of abuse, neglect, abandonment or a lack of emotional responsiveness. The next finding to emerge from the study was about the *sense of belonging* that the *community* generated. This was experienced as a reciprocal relationship where common ground was identified. You are broken like me. Where decision making was shared, bonds of friendship were made, where there was fun, where shared realities were

negotiated, where there were experiences of uniting in a common purpose, and where, ultimately, clients began to regain, or gain for the first time, a sense of home and family.

The findings that were emerging represented the re-creation of secure attachment (Bowlby 1969; Haigh 1999). The next finding concerned the limits of acceptable behaviour. If The Haven is likened to an exercise in re-parenting, in addition to nurturing and love, this needed to include firm *boundaries* which imposed limits on unacceptable behaviour. The findings revealed that *boundaries* needed to be known and democratically negotiated and administered. This finding also represented a learning process which addresses respect, not just for the reality of self, but also the reality of others, enabling an individual to ultimately find the self as the seat of agency and to begin to take control and responsibility. Concurrently, the staff team was also engaged in a process of *learning the boundaries*. Gutheil and Gabbard (1993), who are international experts in the field of boundaries in clinical practice, suggest that both complex and lesser *boundaries* pose significant challenges for clinicians. Sometimes clearly delineated but often amorphous, certainly at the outset, the response to *boundary* issues for the staff team required not just the creation of clear policy, but also the espousing of openness and systems where staff could share and receive peer perspectives. The democratic institution of *boundaries* had a great bearing on behaviour at The Haven and 76% of client participants answering the question about coping skills reported a reduction in their use of negative strategies during the course of the study.

The first four findings concerned developing healthy attachment in terms of safety and trust; feeling cared for, a sense of belonging and learning acceptable boundaries, limits and behaviour. The next finding revealed that only when these were in place did respondents begin to learn to *contain* their past experiences and build necessary *skills* to progress. Meaningful therapy can not take place, no matter how desperately it is needed, if trust does not exist and if behaviour is chaotic, risky and destructive. Healing is about integrating experience by making sense of what has happened. Prior to this stage, reality often proved to be unbearable and making sense out of traumatic experiences and child

abuse is a difficult thing to do. This finding marked the long process of beginning to reframe traumatic experience.

Although dealing with symptoms and developing skills had an important place in the journey, they were not an underpinning principle in the user defined concept of recovery. Waiting until all symptoms have subsided, before trying to discover and use one's abilities, could take a very long time and hope for a cure can overtake other ambitions (Repper and Perkins 2003).   A focus on a deficit in skills can create a sense of hopelessness which is a feeling easily triggered in the face of past trauma.   Deegan (1990) characterises this 'giving-up', indifference and apathy as a way of surviving and protecting the last vestiges of the wounded self. A sense of *hope* and realistic, attainable *dreams and goals* emerged as the next finding. *Hope* is a mysterious thing in that it can transcend life's catastrophes. Here some participants said they had begun to conceive of *dreams and goals* for the first time. Others began to link *hope* to a concept of the future and a range of specific *dreams and goals* began to be envisaged by participants.

What respondents felt they had accomplished emerged as a finding about *achievements*. This included both internal and external *achievements*.   This interplay between the development of personal qualities, such as confidence and self-esteem, and their external expression, characterised their responses. Beginning from what was usually a high degree of self-loathing, during the course of the study 75% of client participants answering a question about their internal sense of self reported positively regarding disliking oneself less. The majority who answered positively had been attending The Haven for two to three years, suggesting that building self-esteem, even in a hope-inspiring environment, takes time. Identity and valued roles are central to *achievements* and to giving meaning to life. Supporting recovery is about helping people to build self-esteem and identity and finding valued roles in society (Allott et al 2003). Participants spoke of external *achievements* in terms of homemaking, parenting, leisure activities, education, voluntary work and employment, and how these *achievements* had contributed to growing confidence, gaining a sense of purpose and being able to separate out from the identity of their diagnosis.

Liberman and Kopelowicz (2005) have provided an operational definition of *recovery* and they discuss its outcomes. They make a distinction between *recovery* and *recovering* and show that it is not easy to separate the process from the outcome. Repper and Perkins (2003) speak of *recovery* being a process rather than a goal and represent it as a journey of *recovery*. Davidson (2003), within his definition of recovery, makes a distinction between living well with the illness and living beyond the illness. This concept suggests that the journey of *recovery* requires that the person does something rather than having something done to him or her by others. Such constructs are consistent with the last finding in this study. *Transitional Recovery* emerged as both a concept and a vehicle. It embraces all other findings in that clients can continue their journey of *recovery* by defining and pursuing their unique goals and dreams, whilst still having a choice about whether to remain registered at The Haven or not. Participants feared losing their base and sense of home if they *recovered*. Many of the respondents had not developed a safe base in life and had no family or wider network of support to turn to if necessary. Some had achieved this at The Haven for the first time in their lives. Because the word *recovery* could potentially become synonymous with the idea of loss, and the pursuit of *recovery* could lead to the withdrawal of crucial support, due to policy makers' narrowness of approach, it became vital to define what came next in a way that was going to work. As a result, the concept of *Transitional Recovery* was born, meaning that progress would be defined as a journey of small steps and that progression would not be penalised by discharge but rather rewarded by continued support, resulting in less use of the service over time but a choice about whether to remain part of it.

Original Contributions to Knowledge and Implications for Practice

Implications for practice are inherent in the service model of The Haven as the context for this study. The Haven is a therapeutic community but it is neither a residential therapeutic community nor a day service community. It has emerged as a unique model where therapeutic community principles have been combined with those of a crisis house. The 24/7 nature of the service has been cited by respondents as a vitally important dimension. Service users asked for this during the planning of the service and

participants highlighted its effectiveness during the course of the study. The entire structure of the service at The Haven had been suggested and refined by its service users. Their unique knowledge about what would best support them and help them to progress has shown that crisis support, therapy services and social inclusion development can all co-exist in a very effective way, as a continuum of support under one roof. The type of service model and the lessons on the journey of recovery highlighted below, represent a finding that it is possible to work effectively with a relatively large number of people with personality disorder, well in excess of a hundred at one time, many of whom had not made progress in other service settings. Additionally, therapies and services which exist for people with personality disorder often require that the person meets certain criteria which represent 'readiness' to work therapeutically. However, The Haven is able to hold and support many clients who do not yet meet such criteria.

The first four findings in this study concern the creation of 'readiness'. The concept of re-creating healthy attachment in those with damaged attachment experiences is not something new in the world of therapeutic community services and other psychodynamic approaches. What is new in this study is that the processes and significances of this re-creation have been defined by service users. For example, the importance of feeling cared for is unlikely to have been stressed to the same degree in research that was not user-focused. Here, service users came to feel safe, learned to trust, feel cared for and belong. The process of learning the boundaries has also been explained from the perspective of those who had started from a point of confused identity and a lack of awareness of space and the boundaries between themselves and others. The study has begun to create a synthesis of human development and recovery theory, which is new and important for people with a personality disorder diagnosis.

The finding that second-stage progress for clients relies on the 'pillars' of the first four lessons, emerged in this study (see Diagram 2 page 103). I believe this provides answers to why someone with a personality disorder diagnosis may be progressing, or why someone may not. The service users have described in great detail the developmental journey of re-creating healthy attachment and their views have been reinforced by family

members and carers. The insight gained from this description has implications for practice in that it gives guidance about what will be most effective in this process.

The involvement of service users as co-researchers was crucial to this study. This is not the first study to include service users in an emancipatory way, but it is the first one about personality disorder in which the service user participants have made most of the research decisions. Participatory action research (PAR) is still relatively new and transparency about how this study was conducted, reflected in the Methodology Chapter and the Research Diary, has implications for practice for those who wish to carry out research in this way. The inclusion of family members and carers, in a study that also had service user participants, adds a valuable dimension to potential research design. Although many in this client group are estranged from their family or, for obvious reasons, may not have wished them to be involved, we were still able to find some relevant participants. This indicates that it is possible to include family members and carers in a study about personality disorder. Family members and carers, understandably, more readily observed outward manifestations of recovery, rather than changes in the internal sense of self which were perceived by our service user participants. However, the views of family members and carers about the importance of safety, trust and belonging, and the importance of retaining healthy attachment, concurred with those of service user participants.

The link between research and action can be a characteristic feature in a PAR approach, where the cycles of action and reflection are a participatory encounter eliciting moments of realisation or changed consciousness. Such cycles may help to make sense of one's life, transforming perspectives on past experiences and influencing action in future situations. In this study the action in the PAR cycle was made explicit. Action research occurs in repetitive cycles of planning, action, observation, reflection and revised planning. The action stemming from this study was carried out in a concrete way in the world, as reflected by organisational learning and change described in the previous chapter. This indicates that a PAR approach can be used not just to raise consciousness but equally effectively to bring about rapid concrete change.

In relation to the remaining four findings, once someone with this diagnosis is able to work therapeutically, the process may continue to be long. However, findings show that a service with a recovery ethos fosters hopes, dreams and goals. This has valuable implications for practice in that it moves away from a focus on skills deficit and the need for cure, which can create a sense of hopelessness. Here, participants showed that they could progress in their journey and embrace both internal and external achievements, in terms of empowerment and self esteem, and in terms of role transition and moving away from the identification of self as a diagnosis.

The finding about the significance of Transitional Recovery is an original contribution to knowledge in that it provides a new construct for personality disorder, with important implications for practice. Transitional Recovery re-enforces The Haven ethos of reward for progress rather than a response to illness and dysfunction which characterises mainstream services. Related to the construct of recovery as a journey of small steps, namely a process rather than a goal, the *concept* of Transitional Recovery also addresses the issue of attachment. In psychological terms, healthy attachment ideally becomes internalised. However, for those of us who have been lucky enough to have grown up with a safe base, this does not necessarily disappear in adulthood. We are still able, in many cases, to have our family in our lives. If we have developed healthy attachment in our earlier years we are not hampered by difficulties in relating to others as we grow up. We have been able to form relationships and build networks anew. This is often not true for someone with a personality disorder diagnosis. At The Haven, if a healthy attachment has been formed, the concept of Transitional Recovery means it will not be taken away.

The *vehicle* of implementing Transitional Recovery became the Social Inclusion Unit at the service, where clients are able to work specifically on personal development skills related to their aspirations and achievements outside of The Haven. Participants who had embraced the concept and structures of Transitional Recovery began to use the service less, while remaining registered at The Haven. It is likely that, over further time, and as outside networks are developed, as self-esteem continues to increase, and as

achievements accrue, more may decide not to stay registered at the service, or may decide to offer peer support or contribute in other ways to The Haven. However, control over this decision rests with the individual. As an alternative to the historically sequential path of treatment and proposed recovery and rehabilitation, Transitional Recovery offers a new way of working with people who have a personality disorder diagnosis where they may choose to retain a haven in which they can continue to develop and progress on their chosen path in the wider world.

Personal Reflections About This Study

As I embarked on my involvement with The Haven I embraced the dual roles of Chief Executive and initiating researcher for this study. The latter role sat more easily than the former. As we established the Research Group and began to collect data at service evaluation groups, I re-experienced the rhythm and joy of opening an exciting dialogue with service users. Prior to this time I had managed advocacy services for many years. Working as a mental health advocate I was used to being on the service users' side of what they often saw as a 'divide'. Now, as Chief Executive, I was a service provider and in the novel, and sometimes uncomfortable, position of accepting criticism about the service that was being provided. I also became aware of projective identification. Those who have been abused can internalise the abuser and sometimes project this onto those who try to care for them. This is not an uncommon feature of those with a personality disorder diagnosis (Fonagy and Bateman 2008). What could be constructive criticism about The Haven was sometimes made known with projective identification attached. As clients began to trust The Haven, a perceived imperfection might be experienced as a deep betrayal of initial idealisation (Hillman 1992). While trying so hard to help, being cast as an abuser was difficult to experience. As time progressed, both I and the staff team learned to understand such projections and worked at not taking them personally. Criticisms and suggestions were given very constructively by some participants. When they were not, it was very important to examine our personal defensiveness and separate out the projections from the issues, to ensure valuable feedback was not lost.

At many times during the study my workload was close to untenable. The sheer volume of work connected to setting up a new service was exacerbated by the fact that we were a new organisation positioned in the voluntary sector. This meant it was not possible to take advantage of policies and structures that would already have been in existence if we had been part of a larger organisation. These had to be newly created. Conversely, the advantage of this meant that policies and structures could be informed by service users' and research participants' views. But the workload remained immense and finding sufficient time to continue the study was hard. There were many times that I felt exhausted and deprived of time for leisure and family. I believe few people realised how hard it was, with the exception perhaps of my clinical supervisor and my husband. However, 'poor me' is rarely an attractive presentation and I will now move on from this particular personal reflection with the words of one of my managers: *I sense the smell of burning martyrs.*

As Chief Executive it was vital to me that the service would succeed. A potential bias could be construed from this, in relation to my role as initiating researcher. I believe that my quest to reveal the truth about this client group, and my personal integrity, meant that I strove to put the truth of the study before other considerations. When the facilitation of research events was taken over by a client participant-researcher I was not present at individual interviews and I endeavoured to keep quiet at focus groups and simply listen. This was not always easy because I often wanted to contribute to the dialogue that was taking place, but I did not do so. Aspects of being Chief Executive were also of great value to the study. I had an ongoing overview of the organisation and I was ideally placed to disseminate learning and institute suggested changes that the emerging findings revealed.

As this study has drawn to a close I have been asked questions about ownership of the research. In truth, this has not emerged as a problematic issue. As a participatory study this is *our* research and the essence of a PAR approach is shared endeavour. However, the understanding from the outset, amongst the Research Group and other participants, is that this thesis is mine, along with all the hard work of writing it up. The study, as

distinct from the thesis, belongs to The Haven as a collective. Continued activities of other participants in the study include one member of the Research Group who is now co-ordinating a Department of Health Personality Disorder training initiative for the East of England. Two members have aspirations to set up service user groups in other parts of our County, to enable grass roots support and to help people with this diagnosis to inform the development of services for personality disorder in their respective areas. In the final pages of the Research Diary, Appendix II, one participant reflects on her involvement in further research and dissemination of the study. Another speaks of embarking on a book about her experiences of the last five years at The Haven. The data and the understanding and changes this study has brought belong to all of us and it is envisioned that dissemination of the study, both orally and in writing, will continue in a participatory way.

The Limitations of the Study

There was a limitation in the study which, I believe, also constitutes a limitation in The Haven service. The National Evaluation (Crawford 2007) spoke of the reluctance of some of the community-based personality disorder pilots to take on people with a forensic history or a dissocial/anti-social personality disorder diagnosis. This has not been the case at The Haven and, while we have judged it important to glean sufficient information about index offences, the vital issue has not been past offences but whether the person can be helped to build up trust and learn to adhere to the boundaries of the service now. Table 18 page 77, in the Findings Chapter, shows that 19 of our client participants had a forensic history; this is almost a third of the client sample of this study. Histories have ranged from very serious offences to more minor transgressions of the law. During the course of the study a few participants effectively de-registered themselves from the service due to multiple transgressions against The Haven's Acceptable Behaviour Policy. However, the door was left open, with an opportunity to re-register at the service in the future. Most did re-register, one being a member of the Research Group, who we lost for a while but who came back to us before the end of the study. However, two or three clients with a forensic history, who caused untold disturbance at The Haven, are not reflected in research responses because they never

became part of the study. In terms of methodological limitations, this was a sampling issue. Ramon et al (2007) stress the importance of personal stories and qualitative approaches to research about recovery, rather than drawing on the 'gold standard' of randomized controlled trials. Therefore, rather than sampling in a randomised way, the need to allow people to choose to participate was most important in this study, which was exploratory in nature. This means that data about the small number of disturbing clients, who we were unable to help, is not directly available from the research. However, it is important to include observations about their differences.

Men are often given a dissocial/anti-social personality disorder diagnosis if they have offended, whilst women tend to retain a borderline categorisation (Castillo 2003). Again, whether someone at the service was diagnosed with antisocial/dissocial personality disorder was not the issue because a number who were categorised in this way progressed well. This highlights that it is possible to work well with clients who have been written off by other services or who may have otherwise returned to the criminal justice system. Some clients at the service had a history of violence in other settings but had never been violent at The Haven and began to make significant progress in their journey of recovery. But the small number of clients under discussion did have a violent forensic history and one was diagnosed as dissocial/anti-social. I believe they did not choose to join the research endeavour because their trust was too low to do so. Their sense of betrayal ran so deep that efforts to help them were interpreted as harm and eventually we saw that their fundamental lack of trust gave little chance of them being able to learn the boundaries. Behaviour for these clients was also exacerbated by substance misuse; alcohol or opiate use. But, many others at the project had similarly engaged in substance misuse so, again, this was not a factor but rather an exacerbation. Others at the service had displayed damaged aspects of their personality in a dissocial/anti-social way. However, other parts of their personality seemed to be more integrated, meaning that a positive side could be appealed to, could learn and could gain dominance over the damaged part for some of the time. Those we were not able to help appeared to display the damaged aspect of their personality as the dominant side. Although we understood the concept of projective identification, when someone is threatening to kill you, in

realistic terms, or appears determined to destroy the service, it is hard not to take this personally, or not to be disturbed by such behaviour.

It was the service users who insisted on de-registration of these clients. In one case, while I was contacting mental health services and the police, they convened a very large Community Discussion and insisted I attend until they had reached consensus about de-registration, for they also had been subject to threats and could see clearly how their open community could be damaged by such behaviour. Although this kind of maladaptive behaviour can be understood as a re-enactment of earlier rejection and abuse (Van der Kolk 1989) and what happened was a further rejection and termination of care, I believe a service must know its limits and protect the greater number of vulnerable people within its walls.

Issues for Future Research

When someone, who poses a potential risk to others, is de-registered from The Haven this does not absolve us of responsibility for what happens next. On the rare occasions this has happened we have requested a Professionals Meeting. This might result in someone being placed on MAPPA (Multi-Agency Public Protection Arrangements). It might result in no further action. This begs a question about what happens to the person and the society they are living in. The Henderson Hospital Therapeutic Community, a Tier 4 Service which served the south and south east of the country, was closed down in recent years. If it had been open we would have attempted to refer such clients to this service. In the consultation which occurred after the closure of the Henderson we responded by saying that we would be likely to refer one person a year to such a service. There are questions about whether the clients concerned would have been willing to be referred to a Tier 4 Service, whether they would have been accepted, and whether they would have stayed for the required timescale.

The DSPD (Dangerous Severe Personality Disorder) Programme (HO and DoH 2002) provides treatment for approximately three hundred men, half in high secure hospitals and half in prisons. Quinn (2010) highlights the escalation of behaviour that can occur

with inmates in the personality disorder unit at Whitemoor Prison when therapy attempts to expose vulnerability. A prison or secure hospital provides the boundary of detention in response to such risk. Service users at a Tier 4 Service are more likely to be willing participants. A new Tier 4 Service is now planned to encompass the former geographic catchment area of the Henderson Hospital. As yet, no service model has been decided upon.

The National Institute for Health and Clinical Excellence has issued new Guidelines for antisocial personality disorder (NICE 2010). The Guidelines state that the evidence base for successful psychological treatments is limited (Duggan et al 2007) and that much more emphasis has been placed on psychological interventions for borderline personality disorder. There is a gap in provision between those who can benefit from community-based personality disorder services and those who are considered dangerous enough to be detained in secure hospitals or prison. I believe that the model for the new Tier 4 Service should be addressing this gap in provision. This suggests the need for further research into the management and treatment of those who fall into the gap between successful treatment at community-based services and the need for secure or penal provision.

A second area proposed for further research is the concept of Transitional Recovery. With its emphasis on reward for progress, Transitional Recovery represents a departure from traditional service provision, resulting in a personal choice about whether to remain registered at The Haven. The complexity that can be encountered, in relation to resistance to recovery, offers challenges to the concept of Transitional Recovery (see Discussion Chapter, pages 150 to 153). Rather than engendering independence and rewarding achievements, Transitional Recovery may be perceived as pandering to dependency because time-scales can become protracted for some in relation to their progress on the pyramid of the journey of recovery. For this reason further research is suggested into the concept of Transitional Recovery. At The Haven we continue to collect background data and we have reinstituted SEGs (service evaluation groups), which now occur every six months, in order to continue to examine progress in the longer term.

A final area suggested for further research concerns the need to develop effective quality of life or outcome measures for this client group which are disorder-specific. Such an instrument, if it is to reflect both subjective and objective domains, and longitudinal changes, requires service consumers to be involved as equal partners in its development (Wallcraft 2010). The inclusion of semi-structured interviews, which seek personal perspectives on quality of life and which encompass people's concerns, in their own language, suggests a more effective augmentation of traditional measures.

Conclusion

This study provides new contributions to knowledge in that it offers a synthesis of human development reflected in the recovery journey for people with personality disorder. Here, the recreation of healthy attachment is combined with the principles of recovery, defined rather as *recovering*, representing a journey consisting of small steps. The service model at The Haven also proposes implications for practice in terms of a continuum of support, for relatively large numbers of people with this diagnosis, who are at different stages in their journey.

The study demonstrates amply the value of service provision for personality disorder being informed by its users. It shows that participatory action research (PAR) can be an exciting and fruitful adventure. When systems are informed by service users they often have a kind of simplicity and logic, as is the case in WRAP, Wellness Action Recovery Plan, created by Copeland (2001). Similarly, I believe that the answers the service users and the family members closely involved with them have revealed in this study are recognisable and once reflected upon seem obvious as solutions. In the spirit of giving the service users the last word, I would like to end this thesis with the reflections of two members of our Research Group:

> **Helen:** *It's not rocket science … KISS … keep it simple stupid.*

> **Jeff:** *I think we should call this 'Personality Disorder for Dummies'.*

References:

Adshed, G. and Jacob, C. (2009) *Personality Disorder: The Definitive Reader.* London: Jessica Kingsley.

Aiyegbusi, A. and Norton, K. (2009) *Modern Milieus: Psychiatric inpatient treatment in the twenty-first century* (in Norman, I., and Ryrie, I., 2009, *The Art and Science of Mental Health Nursing, Second Edition.* Maidenhead: Open University Press.)

Allen, J.G., Fonagy, P. and Bateman, A. (2006) *Mentalizing in Clinical Practice.* Arlington: American Psychiatric Publishing.

Allen, L. (1997) Letter to North Essex Health Authority published in *Linking Hands: North Essex Service User Journal 8.*

Allott, P., Loganathan, L and Fulford, K.W.M. (2003) Discovering hope for recovery from a British perspective. *Canadian Journal of Community Mental Health, p21.*

Alwin, N., Blackburn, R., Davidson, K., Hilton, M., Logan, C. and Shine, J. (2006) *Understanding Personality Disorder: A Report by the British Psychological Society.* London: British Psychological Society.

Anthony, W.A. (1993) Recovery from mental illness: the guiding vision of the mental health service system in the 1990's: *Psychosocial Rehabilitation Journal, 16, pp11-23.*

ARU (2006) *UREC Request for Ethical Approval.* Anglia Ruskin University: Aug 06.

Aymer, C. (2001) *Researching the Experiences of Black Professionals in White Organisations:* (In Winter, R. and Munn-Giddings, C. A Handbook for Action Research in Health and Social Care. London: Routledge.)

Bagge, C., Nickell, A., Stepp, S., Durrett, C., Jackson, K. and Trull, T.J. (2004) Borderline Personality Disorder Features Predict Negative Outcomes 2 Years Later. *Journal of Abnormal Psychology, 103, 2, pp279-288.* The American Psychological Society.

Bannister, P., Burman, E., Parker, I., Taylor, M. and Tindall, C. (1994) *Qualitative Methods in Psychology: A Research Guide.* Buckingham: Open University Press.

Barker, P. and Buchanan-Barker, P. (2005) *The Tidal Model: A Guide for Mental Health Professionals.* London and New York: Brunner-Routledge.

Bartlett, F. (1932) *Remembering*: Cambridge, Cambridge University Press.

Bateman, A. and Tyrer, P. (2004) Psychological treatment for personality disorders. *Advances in Psychiatric Treatment, 10, pp378-388.* The Royal College of Psychiatrists.

Bateman, A. and Fonagy, P. (2008) 8-Year Follow-Up of Patients Treated for Borderline Personality Disorder: Mentalization-Based Treatment Versus Treatment as Usual. *American Journal of Psychiatry in Advance, March, pp1-7.*

Beresford, P and Wallcraft, J. (1997) *Psychiatric System Survivors and Emancipatory Research: Issues, Overlaps and Differences.* (In *Doing Disability Research*, C. Barnes and G. Mercer, eds. Leeds: The Disability Press.)

Bettleheim, B. (1950) *Love is Not Enough*. New York: The Free Press.

Bettleheim, B. (1960) *The Informed Heart*. New York: The Free Press.

Black, D., Blum, N., Pfol, B. and St. John, D. (2004) The Stepps Group Treatment Programme for Outpatients with Borderline Personality Disorder. *Journal of Contemporary Psychotherapy, 34, 3, pp193-210.*

Bloom, S. (1997) *Creating Sanctuary: Towards the evolution of sane societies.* New York: Routledge.

Blum, N., Allen, J., McCormich, B. and Black, D. (2008) Letter regarding Randomised Control Trial. *The American Journal of Psychiatry, 165, 10, p1354*

Bond, G.R., Drake, R.E. and Becker, D.R. (2008) An update on randomized controlled trials of evidence-based supported employment. *Psychiatric Rehabilitation Journal, 31, pp208-289.*

Bowlby, J. (1969) *Attachment and Loss.* London: Hogarth Press.

Bowlby, J. (1988) *A Secure Base*. London: Routledge.

Braun, V. and Clarke, V. (2006) Using thematic analysis in psychology. *Qualitative Research in Psychology, 3, pp77-101.*

British Psychological Society Division of Clinical Psychology (2000) *Recent Advances in Understanding Mental Illness and Psychotic Experiences*. Leicester: British Psychological Society.

Brower, L.A. (2003) The Ohio Mental Health Consumer Outcomes System: Reflections on a Major Policy Initiative in the US. *Clinical Psychology and Psychotherapy, 10, pp400-406.*

Burman, E. (1994) *Feminist Research:* (In Banister, P., Burman, E., Parker, I. Taylor, M. and Tindall, C. 1994 Qualitative Methods in Psychology. Buckingham: Open University Press.)

Cambell, D.T. and Fiske, D. (1959) Convergent and discriminant validation by the multitrait-multimethod matrix. *Psychological Bulletin, 56, pp 81-105.*

Campling, P. and Haigh, R. (1999) *Therapeutic Communities: Past, Present and Future.* London: Jessica Kingsley.

Campling, P. (1999) *Chaotic Personalities: Maintaining the Therapeutic Alliance* (in Campling, P. and Haigh, R., 1999, *Therapeutic Communities: Past, Present and Future.* London: Jessica Kingsley.)

Campling, P. (2001) Therapeutic Communities. *Advances in Psychiatric Treatment, 7, pp365-372.* The Royal College of Psychiatrists.

Care Services Improvement Partnership, Royal College of Psychiatrists and Social Care Institute for Excellence (2007) *A Common Purpose: Recovery in Future Mental Health Services*. Leeds: CSIP.

Castillo, H. (2000) *Personality Disorder: Temperament or Trauma?* Masters Dissertation, Anglia Polytechnic University.

Castillo, H. (2003) *Personality Disorder: Temperament or Trauma?* London: Jessica Kingsley Publishers.

Castillo, H. and Allen, L (2006) What is community? *Personality Disorder, North Essex News, issue 40, pp3-4.* Colchester: The Haven.

Castillo, H. (2009) *The Person with a Personality Disorder.* (in Norman, I., and Ryrie, I., 2009, *The Art and Science of Mental Health Nursing, Second Edition.* Maidenhead: Open University Press.)

Chamberlin, J. (1988) *On our own*. London: Mind Publications.

Checkland, P. (1999) *Systems Thinking, Systems Practice: includes a 30 year retrospective.* Chichester: Wiley.

Chiesa, M., Bateman, A., Wilberg, T. and Friss, S. (2002) Patients' characteristics, outcome and cost-benefit of hospital-based-treatment for patients with a personality disorder: A comparison of three difference programmes. *Psychology and Psychotherapy: Theory, Research and Practice, 75, pp381-392:* The British Psychological Society.

Coid, J., Yang, M., Tyrer, P., Roberts, A. and Ulrich, S. (2006) Prevalence and correlates of personality disorder in Great Britain. *British Journal of Psychiatry, 188, pp423-431.*

Coleman, R. (1999) *Recovery: An Alien Concept?* Gloucester: Handsell.

College of Occupational Therapists (2006) *Recovering Ordinary Lives: The Strategy for Occupational Therapy in Mental Health Services 2007-2017*. London: College of Occupational Therapists.

Copeland, M.E. (2001) *The Depression Workbook.* New York: Barnes and Noble.

Crawford, M.J. (2007) *Learning the lessons: a multimethod evaluation of dedicated community-based services for people with personality disorder.* London: HMSO.

Crawford, M.J., Price, K., Rutter, D., Moran, P., Tyrer, P., Bateman, A., Fonagy, P., Gibson, S and Weaver, T. (2008) Dedicated community-based services for adults with personality disorder: Delphi study. *The British Journal of Psychiatry, 193, pp342–343.*

Crawford, M.J., Adedeji, T., Price, K. and Rutter, D. (2010) Job satisfaction and burnout among staff working in community-based personality disorder services. *International Journal of Social Psychiatry, 56, pp196-206.*

Creswell, J.W. (2003) *Research Design, Qualitative, Quantitative, and Mixed Methods Approaches, Second Edition.* London: Sage.

Davidson, L. (2003) *Living Outside Mental Illness: Qualitative Studies in Schizophrenia.* New York and London: New York University Press.

Davies, I., Beacham, C. and Castillo, H. (2009) *Lifepaths to Social Inclusion Manual.* Colchester, The Haven.

Daw, R., Spencer-Lane, T., Cobb, A. and Bell, A. (2007) *The Mental Health Act 2007: the final report.* The Mental Health Alliance.

Deegan, P. (1988) Recovery: the lived experience of rehabilitation. *Psychosocial Rehabilitation Journal, 11, pp11-19.*

Deegan, P. (1990) How recovery begins. *The Centre for Community Change Through Housing and Support: VT, CI 25:* Burlington: Trinity College.

Deegan, P. (1993) Recovering our sense of value after being labeled mentally ill. *Journal of Psychosocial Nursing and Mental Health Services, 31, pp7-11.*

Denman, C. (2001) Cognitive-analytic therapy. *Advances in Psychiatric Treatment, 7, pp243-252.*

Denzin, N.K. (2009) *The Research Act: A Theoretical Introduction to Sociological Methods.* New Jersey: Transaction Publishers.

Department of Health (1999a) *The National Service Framework for Mental Health:* London: HMSO.

Department of Health (1999b) *Managing Dangerous People with Severe Personality Disorder*. London: HMSO.

Department of Health (2003a) *Personality Disorder: No Longer a Diagnosis of Exclusion. Policy Implementation Guidance for the Development of Services for People with Personality Disorder.* London: HMSO.

Department of Health (2003b) *Personality Disorder Capabilities Framework: Breaking the Cycle of Rejection.* London: HMSO.

Department of Health (2006) *From Values to Action: The Chief Nursing Officer's Review of Mental Health Nursing.* London: HMSO.

Department of Health (2009) *Implementing the NHS Performance Framework: Application to mental health trusts*. November 09.

Droysden, J.G. (1858) *Gundriss der Historik* (In Creswell, J.W. 2003 Research Design, Qualitative, Quantitative, and Mixed Methods Approaches, Second Edition. London: Sage.)

DSM 1 (1952) *Diagnostic and Statistical Manual of Mental Disorders 1st Edition*. Washington DC: American Psychiatric Association.

DSM IV (1994) *Diagnostic and Statistical Manual of Mental Disorders 4th Edition*. Washington DC: American Psychiatric Association.

DSM IV TR (2000) *Diagnostic and Statistical Manual of Mental Disorders 4th Edition Revised*. Washington DC: American Psychiatric Association.

Duggan, C., Adams, C. and McCarthy, L.(2007) *Systematic review of the effectiveness of pharmacological and psychological strategies for the management of people with personality disorder.* NHS National R&D Programme in Forensic Mental Health.

Edwards, A. and Tabot, R. (1994) *The Hard-pressed Researcher: A Handbook for the Caring Professions.* New York: Longman.

Evans, C. and Fisher, F, (1999) *Collaborative Evaluation with Service Users: Moving Towards User Controlled Research:* (In Shaw, I. and Lishman, T. eds Evaluation and Social Work Practice. London: Sage.)

Fahy, T. (2003) Speech at the Launch Conference for National Guidance: *Personality Disorder – No longer a Diagnosis of Exclusion:* by Professor of Forensic Psychiatry at Institute of Psychiatry. Harrogate 23/1/03.

Faulkner, A., Petit-Zeman, S., Sherlock, J. and Wallcraft, J. (2002) *Being There in a Crisis.* Mental Health Foundation and Sainsbury Centre for Mental Health.

Feigenbaum, J. (2007) Dialectical behaviour therapy: An increasing evidence base. *Journal of Mental Health, 16,1, pp51-68.*

Fonagy, P. (1997) When Cure is Inconceivable: The Aims of Psychoanalysis with Borderline Patients. *Paper to New York Freudian Society 4/4/97.*

Fonagy, P. and Bateman, A. (2008) The Development of Borderline Personality Disorder: A Mentalizing Model. *Journal of Personality Disorders, 22, 1, pp4-21.*

Foucault, M. (1972) *The Archaeology of Knowledge.* London: Tavistock.

Freire, P. (1970) *Pedagogy of the Oppressed.* New York: Herder and Herder.

French, G.D. and Harris C.J. (1998) *Traumatic Incident Reduction.* London and New York: Taylor and Francis.

Fuller, R. and Petch, A. (1995) *Practitioner Research.* Buckingham: Open University Press.

Gans, S. and Grohol, J.M. (2010) Transference-focused therapy, Dialectical behaviour therapy, Schema Therapy and Mentalization-based therapy. Adapted from articles by *The American Psychiatric Association: www.bpdresources.net/top_articles/bpd_therapy.htm.*

Glaser, B.G. and Strauss, A.L. (1968) *The Discovery of Grounded Theory: Strategies for Qualitative Research.* London: Weidenfield and Nicholson.

Goffman, E. (1963) *Stigma: Notes on the Management of Spoiled Identity.* London: Penguin.

Gordon, W., Morton, T. and Brooks, G. (2005) Launching the Tidal Model; evaluating the evidence. *Journal of Psychiatric and Mental Health Nursing, 12, pp703-712.*

Gorman, H. (1999) *Practitioner Research in Community Care: Personalising the Political* (In Broad, B. ed The Politics of Social Work Research and Evaluation. Birmingham: Ventura Press).

Gray, D.E. (2004) *Doing Research in the Real World.* London: Sage.

Gregory, R. J. (2004) Thematic Stages of Recovery in the Treatment of Borderline Personality Disorder. *American Journal of Psychotherapy, 58, 3, pp335-348.*

Guba, E.G. and Lincoln, Y.S. (1985) *Effective Evaluation: Improving the Usefulness of Evaluation Results through Responsive and Naturalistic Approaches.* San Francisco: Jossey-Bass.

Gutheil, T. and Gabbard, G.O. (1993) *The Concept of Boundaries in Clinical Practice; Theoretical and Risk-management Dimensions* (in Adshed, G. and Jacob, C., 2009, *Personality Disorder: The Definitive Reader.* London: Jessica Kingsley.)

Haigh, R. (1996) *The matrix in the milieu: the ghost in the machine* (in eds. Georgas, J. and Manthouli, M., et al, 1996, *Contemporary Psychology in Europe: Theory, Research and Application.* Gottingen: Hogrefe and Huber.)

Haigh, R. (1999) *The Quintessence of a Therapeutic Environment: Five Universal Qualities* (in Campling, P. and Haigh, R., 1999, *Therapeutic Communities: Past, Present and Future.* London: Jessica Kingsley.)

Haigh, R. (2003) *Services for People with Personality Disorder: The Thoughts of Service Users:* Personality Disorder: No Longer a Diagnosis of Exclusion. Policy Implementation Guidance for the Development of Services for People with Personality Disorder. London: HMSO.

Haigh, R. and Lees, J. (2008) 'Fusion TCs': Divergent Histories, Converging Challenges. *International Journal of therapeutic communities, 29, 4, pp347-374.*

Hammersley, M. (1989) *The Dilemma of Qualitative Method: Herbert Bulmer and the Chicago Tradition.* London: Routledge.

Harding, C.M., Brooks, G.W., Asologa, Y.S.J.S. and Brier, A. (1987) The Vermont Lognitudinal Studies of Persons with Severe Mental Illness. *American Journal of Psychiatry, 144, pp718-726.*

Harvey, R. (2009) Stepps Programme. *Presentation to Haven Staff 8/7/09.*

Henderson, D. (1939) *Psychopathic States.* New York: W.E. Norton.

Henwood, K.L. and Pidgeon, N.F. (1994) *Qualitative Research and Psychological Theorising:* (In Hammersley, M. 1994 Social Research: Philosophy, Politics and Practice. London: Sage.)

Herman, J. and Van der Kolk, B. (1987) *Traumatic Origins of Borderline Personality Disorder in Psychological Trauma.* Washington DC: American Psychiatric Press.

Heron, J. and Reason, P. (1997) A Participatory Inquiry Paradigm: *Qualitative Inquiry 3, 3, pp274-294.*

Heron, J. and Reason, P. (2001) *The Practice of Co-operative Inquiry: Research "with" rather than "on" people:* (In Reason, P. and Bradbury, H. (eds) *Handbook of Action Research: Participative Inquiry and Practice.* London: Sage.)

Hillman, J. (1992) *Archetypal Psychology:* Prague, Fortuna.

Hinshelwood, R. D. (1996) Communities and their health. *Therapeutic Communities, 17, pp173-182.*

Hinshelwood, R. (1998) The difficult patient: The role of "scientific psychiatry" in understanding patients with chronic schizophrenia or severe personality disorder. *British Journal of Psychotherapy, Nov, pp187-190.*

Hinshelwood, R.D. (1999) *Psychoanalytic Origins and Today's Work; The Cassel Heritage* (in Campling, P. and Haigh, R., 1999, *Therapeutic Communities: Past, Present and Future.* London: Jessica Kingsley.)

HM Government (2009) *New Horizons: A shared vision for mental health* (Superseding the National Service Framework for Mental Health from January 2010)

HM Government (2009a) *Work Recovery and Inclusion*: Employment support for people in contact with secondary mental health services.

Hogan, M.F. (2001) *Vital Signs: A Statewide Approach to Measuring Consumer Outcomes in Ohio's Publicly-Supported Community Mental Health System.* Final Report of the Ohio Mental Health Outcomes Task Force.

Home Office and Department of Health (2002) *The Dangerous and Severe Personality Disorder Programme:* London. Home Office and Department of Health.

Howard, L.M., Heslin, M., Leese, M., McCrone, P., Rice, C., Jarrett, M., Spokes, T., Huxley, P. and Thornicroft, G. (2010) Supported employment: randomized controlled trial. *The British Journal of Psychiatry, 196, pp404-411.*

ICD 10 (1992) *Classification of Mental and Behavioural Disorders*. Geneva: World Health Organization.

Jick, T.D. (1979) Mixing qualitative and quantitative methods: Triangulation in action: *Administrative Science Quarterly, 24, pp602-611.*

Kabat-Zinn, J. (2001) *Full Catastrophe Living: Using the Wisdom of your Body and Mind to Face Stress and Illness.* London: Piatkus Books.

Kemmis, S. and McTaggart, R. (1988) *The Action Research Planner, Third Edition.* Geelong: Deakin University.

Kernberg, O. (1984) *Severe Personality Disorders: Psychotherapeutic Strategies.* London: Yale University Press.

Kerr, I.B. (2001) Presentation at South London and Maudsley Mental Health NHS Trust Conference on Personality Disorder (in Castillo, H. (2003) *Personality Disorder: Temperament or Trauma?* London: Jessica Kingsley.)

Kerr, I.B. (2006) Cognitive-Analytic Therapy for Borderline Personality Disorder in the Context of a Community Mental Health Team: Individual and Organisational Psychodynamic Implications. *British Journal of Psychotherapy, 5, 4, pp425-438.*

Koch, J.L.A. (1891) *Die Psychopathischen Minderwertigkeiten.* Ravensburg, Germany: Maier.

Koch, T. (1996) Implementation of a hermeneutic inquiry in nursing: Philosophy, rigour and representation. *Journal of Advanced Nursing, 24, pp174-184.*

Koch, T. (2006) Establishing rigour in qualitative research: The decision trail. *Journal of Advanced Nursing, 53, 1, pp 91-100 (10).*

Kofman, F. and Senge, P. (2001) Communities of commitment; the heart of learning organisations. *Organisational Learning Centre,* Massachusetts Institute of Technology, Cambridge USA.

Kolakowski, L. (1995) *An Overall View of Positivism.* (In Reason, P. 1995 Human Inquiry in Action. London: Sage.)

Kraepelin (1905) In Gelder, Gath and Mayou (eds) 'Personality Disorder'. In *Oxford Text Book of Psychiatry 2nd Edition.* Oxford: Oxford Medical Publications.

Kuhn, T. (1972) *The Structure of Scientific Revolutions* (2nd edition). Chicago: University of Chicago Press.

Lees, J., Manning, N. and Rawlings, B. (1999) *Therapeutic Community Effectiveness. A Systematic International Review of Therapeutic Community Treatment for People with Personality Disorders and Mentally Disordered Offenders:* CRD Report 17: York: NHS Centre for Reviews and Dissemination.

Leete, E. (1989) How I perceive and manage my illness. *Schizophrenia Bulletin 15, pp197-200*

Leistyna, P. (2004) Presence of mind in the process of learning and knowing: A dialogue with Paulo Freire. *Teacher Education Quarterly, Winter 2004.*

Lewis, G. and Appleby, L. (1988) Personality Disorder: The Patients Psychiatrists Dislike. *British Journal of Psychiatry, 153, pp44-49.*

Liberman, R.P. and Kopelowicz, A. (2005) Recovery from Schizophrenia: A Concept in Search of Research. *Psychiatric Services: ps.psychiatryonline.org, 56, 6, pp735-742.*

Lincoln, Y. and Guba, E. (1985) *Naturalistic inquiry.* Beverly Hills, CA: Sage.

Linehan, M.M., Armstrong, H.E., Suarez, A., Allmon, D. and Heard, H.L. (1991) Cognitive-behavioural treatment of chronically parasuicidal borderline patients. *Archives of General Psychiatry, 50, pp971-974.*

Linehan, M.M. (1993) *Skills Training Manual for Treating Borderline Personality Disorder.* New York and London: Guilford Press.

Mahari, A.J. (2004) BPD from the inside out: Why Boundaries? : *www.borderlinepersonality.ca.borderlinewhyboundaries.htm*

Main, T.F. (1967) Knowledge, learning and freedom from thought. *Australia and New Zealand Journal of Psychiatry, 1, p64-67.* Re-printed in *Psychoanalytic Psychotherapy, 5, pp49-78.*

Marshall, M.N. (1996) Sampling for Qualitative Research: *Family Practice, 13, 6, Oxford University Press.*

Maslow, A.H. (1943) A Theory of Human Motivation. *Psychological Review 50, 4, pp370-96.*

Maudsley, H. (1984) In Kutchins, H. and Kirk, S.A. eds (1999) *Making us Crazy: DSM The Psychiatric Bible and the Creation of Mental Disorders.* London: Constable.

McGowan, J. (2009) Use your loaf: Open up choice. *Health Service Journal 2/7/09, p15.*

McGowan, J. (2010) It's time we shattered a great NHS myth and said that service-user involvement if often of little or no use. *Health Service Journal 27/5/10, pp14-15.*

Menzies, D., Dolan, B. and Norton, K. (1993) Funding treatment for personality disorders: are short term savings worth long term costs? *Psychiatric Bulletin 7, pp517-519.*

Moran, P. (2007) Psychotherapy for BPD Gets Growing Evidence Base. *Psychiatric News, 42, 2, p26.* American Psychiatric Association.

Nehls, N. (2000) Recovering: A Process of empowerment. *Advanced Nursing Science, 22, 4, pp62-70.* Aspen Publishers.

Nevis, E.C., DiBella, A.J. and Gould, J.M. (1995) Understanding organisations as learning systems. *MIT Sloan Management Review: Winter 1995, p3626.*

NICE (2009) *Borderline Personality Disorder: treatment and management.* Nice Clinical Guideline 78. National Institute for Health and Clinical Excellence. NHS.

NICE (2010) *Antisocial Personality Disorder: treatment and management.* Nice Clinical Guideline 77. National Institute for Health and Clinical Excellence. NHS.

NIMHE (2005) *NIMHE Guiding Statement on Mental Health Recovery*. National Institute for Mental Health England.

NIMHE (2006) *Reaching Out: Evaluation of three mental health promotion pilots.* 1/6/06 National Institute for Mental Health in England.

Norton, K. and Bloom, S.L. (2004) The Art and Challenges of Long-Term and Short-Term Democratic Therapeutic Communities. *Psychiatric Quarterly, 75, 3, pp249-261.* Netherlands: Springer.

O'Connar, J. (2001) *NLP Workbook.* London and New York: Harper Collins.

Oliver, M. (1996) *Understanding Disability: From Therapy to Practice.* Basingstoke: Macmillan.

Oliver, P. (2004) *Writing Your Thesis.* London: Sage.

Onken, S.J. (2004) *User Perspectives on Mental Health Recovery Facilitating and Hindering Factors.* The Fourth International Conference on Social Work in Health and Mental Health, Quebec City, Canada, May 23-27.

Ooi, R. (1997) *Everyone's Life Has a Price*. The Guardian: 22/7/97.

Padilla, R.V. (1993) *Using Dialogical Research Methods in Group Interviews* (In Morgan, D.L. ed 1993 Successful Focus Groups: Advancing the State of the Art. London: Sage.)

Paris, J. (2004) Half in love with easeful death: the meaning of chronic suicidality in borderline personality disorder. *Harvard Review of Psychiatry, 12, pp42-48.*

Parker, I. (1994) *Qualitative Research* (In Banister, P., Burman, E., Parker, I. Taylor, M. and Tindall, C. 1994 Qualitative Methods in Psychology. Buckingham: Open University Press.)

Payne, J. (2003) *Researching Oneself Through Reflective Writing* (In Ramon, S. ed Users Researching Health and Social Care: An Empowering Agenda? Birmingham: Ventura Press.)

Percival, W. (1961) *A Patient's Account of his Psychosis.* Stanford, California: Stanford University Press.

Perkins, R. (1999) The Individual's Journey: Recovery and Service Provision. *Psychological News (2) 1.* Bromley Psychosocial Rehabilitation Forum.

Perkins, R., Farmer, P. and Litchfield, P (2009) *Realising ambitions: Better employment support for people with a mental health condition.* November 09. Department of Work and Pensions.

Perry, J.C., Banon, E. and Ianni, F. (1999) Effectiveness of psychotherapy for personality disorders. *American Journal of Psychiatry, 156, pp1312-1321.* American Psychiatric Association.

Pilgrim, D. (1991) *British Special Hospitals:* (in Ramon, S. ed. *British Special Hospitals in Psychiatry in Transition.*) London, Pluto.

Pilgrim, D. (2000) *Construct Validity in Personality Trait Theory:* Seminar presented in relation to the results of dissertation by Castillo, H. *Personality Disorder, Temperament or Trauma?* Anglia Polytechnic University.

Pinel, P. (1801) In Gelder, Gath and Mayou (eds) 'Personality Disorder' (Ref. Kauka,1949, for translation) In *Oxford Text Book of Psychiatry 2ⁿᵈ Edition.* Oxford: Oxford Medical Publications.

Pope, C., Ziebland, S. and Mays, N. (2000) Qualitative Research in Health Care: Analysing qualitative data. *British Medical Journal, 320, pp114-116.*

Popper, K.R. (1980) *The Logic of Scientific Discovery.* London: Hutchinson.

Price, K., Gillespie, S., Rutter, D., Dhillon, K., Gibson, S., Faulkner, A., Weaver, T. and Crawford, M.J. (2009) Dedicated personality disorder services: A qualitative analysis of service structure and treatment process. *Journal of Mental Health, 18, 6, pp467-475.*

Pritchard (1835) In Gelder, Gath and Mayou (eds) 'Personality Disorder'. In *Oxford Text Book of Psychiatry 2ⁿᵈ Edition.* Oxford: Oxford Medical Publications.

Quinn, D. (2010) *Treatment Model for the Fens Unit*: Presentation to the Eastern Region Personality Disorder Reference Group, Fulbourne, Cambridge, March 2010.

Ramon, S., Castillo, H. and Morant, N. (2001) Experiencing Personality Disorder: *International Journal of Social Psychiatry, 47, 4, pp1-15.*

Ramon, S., Healey, B. and Renouf, N. (2007) Recovery from mental illness as an emergent concept and practice in Australia and the UK. *International Journal of Social Psychiatry, 53, 2, pp108-122.*

Ramon, S. (2010) Organizational change in the context of recovery oriented services. *Journal of Mental Health Workforce:* Forthcoming, March 2011.

Rapaport, R.N. (1960) *Community as Doctor*. London: Tavistock

Rawlinson, D.. (1999) *Group Analytic Ideas; Extending the Group Matrix into TCs* (in Campling, P. and Haigh, R., 1999, *Therapeutic Communities: Past, Present and Future.* London: Jessica Kingsley.)

Reason, P. (1994) *Three Approaches to Participatory Inquiry* (In Denzin, N.K. and Lincoln, Y.S. eds 1994 Handbook of Qualitative Research. London: Sage.)

Reason, P. (1995) *Human Inquiry in Action.* London: Sage.

Reeves, A. (1999) *Recovery: A holistic approach*. Gloucester: Handsell Publishing.

Rendu, A., Moran, P., Patel, A., Knapp, M. and Mann, A. (2002) Economic impact of personality disorders in UK primary care attenders. *British Journal of Psychiatry, 181, pp62-66.*

Repper, J. and Perkins, R. (2003) *Social Inclusion and Recovery: A Model for Mental Health Practice.* London and New York: Bailliere Tindall.

Roberts, G. and Wolfson, P. (2004) The rediscovery of recovery: open to all: *Advances in Psychiatric Treatment, Vol 10, pp37-49.*

Roberts, G. and Wolfson, P. (2006) New directions in rehabilitation: learning from the recovery movement (in G. Roberts, S. Davenport, F. Holloway and T. Tattan eds *Enabling Recovery: The principles and practice of rehabilitation psychiatry*. London: Gaskell.)

Robson, C. (1997) *Real World Research: A Resource for Social Scientists and Practitioner Researchers.* Oxford: Blackwell.

Rollnick, S., Miller, W.R. and Butler, C.C. (1995) *Motivational Interviewing in Healthcare.* New York and London: Guildford Press.

Roth, M.A., Crane-Ross, D., Hannon, M.J. and Cusick, G.M. (2000) A Longitudinal Study of Mental Health Services and Consumer Outcomes in a Changing System: Time 5 Results. *New Research in Mental Health, 14, 159-176.* Columbus, Ohio: The Ohio Department of Mental Health.

Rowan, J. and Reason, P. (1981) *Human Inquiry a Source Book of New Paradigm Research.* Chichester: Wiley.

Russinova, Z. (1999) Providers' Hope-Inspiring Competence as a Facto Optimising Psychiatric Rehabilitation Outcomes. *Journal of Rehabilitation, Oct-Dec pp50-57*

Ryle, A. (1997) *Cognitive Analytic Therapy: The Model and the Method*. Chichester: Wiley.

Sandelowski, M. (1994) *The proof is in the pottery: Towards a poetic for qualitative inquiry*. (In J. Morse (Ed.): *Critical issues in qualitative research methods pp46-63*. Thousand Oaks, CA: Sage.)

Schneider, K. (1923) *Psychopathic Personalities*. London: Cassell.

Schofield, J. (1995) *Increasing the Generalisability of Qualitative Research:* (In Hammersley, M. 1994 Social Research: Philosophy, Politics and Practice. London: Sage.)

Senge, P.M. (1990) *The Fifth Discipline: The Art and Practice of the Learning Organisation.* New York: Doubleday.

Slade, M., Amering, M. and Oades, L. (2008) Recovery: an international perspective. *Epidemiolofia e Psychatria Sociale, 17, 2, pp128-137.*

Smith, J.A. (2003) *Qualitative Psychology.* London: Sage.

Smith, K., Shah, A., Wright, K. and Lewis, G. (1995) The prevalence and costs of psychiatric disorders and learning disabilities. *British Journal of Psychiatry, 166, pp18-19.*

Sperry, L. (2003) *Handbook of Diagnosis and Treatment of DSM IV TR Personality Disorders: Second Edition.* New York: Routledge.

Stalker, K., Ferguson, I. and Barclay, A. (2005) 'It is a Horrible Term for Someone'. Service User and Provider Perspectives on 'Personality Disorder': *Disability and Society, 20, 4, pp359-373.*

Stanton, A. (1989) *Invitation to Self-Management.* Ruislip: Dab Hand Press.

Straughan, H. (2006) *The effectiveness of "In-Sight": a user-led lifestyle development group training for people with bipolar disorder.* University of Hertfordshire: PhD Thesis.

Tait, L., Birchwood, M. and Trower, P. (2003) Predicting engagement with services for psychosis: insight, symptoms and recovery style. *British Journal of Psychiatry, 182, pp123-128.*

Tallis, D. (1997) *A Criminal Waste of Life and Time*. The Guardian: 5/2/97.

Tashakkori, A. and Teddlie, C. (1998) *Mixed Methodology: Combining Qualitative and Quantitative Approaches.* London: Sage.

Tesch, R. (1990) *Qualitative Research: analysis types and software tools.* London: Falmer.

The Disability Discrimination Act (2005) London. HMSO.

The Mental Deficiency Act (1913) London: HMSO.

The Mental Health Act (1959) London: HMSO

The Mental Health Act (1983) London: HMSO.

The Mental Health Act (2007) London: HMSO.

Tindall, C. (1994) *Issues in Evaluation:* (In Banister, P., Burman, E., Parker, I. Taylor, M. and Tindall, C. 1994 Qualitative Methods in Psychology. Buckingham: Open University Press.)

Tomlinson, D. and Carrier, J. (1996) *Asylum in the Community.* London and New York: Routledge.

Topor, A**.** (2004) *What Helps People Recover?* Keynote Speech to the Annual NIMHE Eastern Conference 23/9/04.

Tucker, S. (1999) *The Therapeutic Approach and Learning to Care* (in Campling, P. and Haigh, R., 1999, *Therapeutic Communities: Past, Present and Future.* London: Jessica Kingsley.)

Turner-Crowson, J and Wallcraft, J. (2002) The Recovery Vision for Mental Health Services and Research: A British Perspective. *Psychiatric Rehabilitation Journal, 25,3, pp245-254*

Tyrer, P. (1988) *Personality Disorder, Management and Care.* London: Wright.

Unzicker, R. (1989) On my own: a personal journey through madness and re-emergence. *Psychosocial Rehabilitation Journal, 13 ,1, pp71-77.*

Van der Kolk (1989) The compulsion to repeat trauma: re-enactment, revictimisation and masochism: *Psychiatric Clinics of North America, 12, pp389-411.*

Van der Kolk, B. (1996) *Traumatic Stress.* London and New York: Guilford Press.

Von Wright, G.H. (1995) *Two Traditions:* (In Reason, P. 1995 Human Inquiry in Action. London: Sage.)

Wallcraft, J. (2005) *The Place of Recovery:* (In *Mental Health at the Crossroads: The Promise of the Psychological Approach:* Editors Ramon S. and Williams, J: Abingdon: Ashgate.)

Wallcraft, J. (2010) Service Users' Perceptions of Quality of Life Measurement in Psychiatry. *Advances in Psychiatric Treatment.* Forthcoming.

Warren, F. and Dolan B. (2001) *Perspectives on Henderson Hospital.* Sutton: Henderson Hospital.

Whittaker, A. (2009) *Research Skills for Social Work.* Exeter: Learning Matters.

Wicks, P.G. and Reason, P. (2009) Initiating Action Research: Challenges and paradoxes of opening communicative space. *Action Research, 7,3, pp243-262.*

Widiger, T.A. (1998) Invited Essay: Sex Biases in the Diagnosis of Personality Disorder, *Journal of Personality Disorders 12, 2, pp95-118.*

Wilkinson, S. (1999) *How Useful are Focus Groups in Feminist Research* (In Barbour, S. and Kitzinger, J. eds 1999 Developing Focus Group Research: Politics, Theory and Practice. London: Sage.)

Winnicott, D. (1965) *The Maturational Process and the Facilitating Environment.* London: Hogarth

Winnicott, D. (1971) *Playing and Reality.* London: Tavistock

Winter, R. and Munn-Giddings, C. (2001) *A Handbook for Action Research in Health and Social Care.* London: Routledge.

Young, J.E., Klosko, J.S. and Weishaar, M.E. (2003) *Schema Therapy A Practitioner's Guide.* New York and London: Guilford Press.

Zeller, R.A. (1993) *Focus Group Research on Sensitive Topics* (In Morgan, D.L. ed 1993 Successful Focus Groups: Advancing the State of the Art. London: Sage.)

T I M E L I N E

Date	Method	Duration of Data Analysis	Duration of Formal Data Collection	Duration of S.E.G.s	Duration of Other Background Data/Minutes	Duration of Numerical Data Collection	Duration of Research Group
June 04	Creation of the Research Group						▓
July 04	Collection of Numerical Data				▓	▓	▓
July 04	Other Background data						
Feb 05	Service Evaluation Group (S.E.G.)			▓	▓	▓	▓
May 05	Service Evaluation Group (S.E.G.)						
Aug 05	Service Evaluation Group (S.E.G.)						
Nov 05	Service Evaluation Group (S.E.G.)						
Feb 06	Service Evaluation Group (S.E.G.)						
May 06	Service Evaluation Group (S.E.G.)						
Aug 06	First Client Focus Group		▓		▓	▓	▓
Aug 06	First of twenty Client Interviews						
Nov 06	Second Client Focus Group						
Feb 07	Third Client Focus Group						
Mar 07	First Carer Focus Group						
May 07	Fourth Client Focus Group						
July 07	Last of twenty Client Interviews						
Aug 07	Second Carer Focus Group						
Aug 07	Service Evaluation Group (S.E.G.)			▓	▓		▓
Nov 07	Service Evaluation Group (S.E.G.)						
Nov 07	Data Analysis Begins	▓			▓		▓
June 09	Data Analysis Ends						
Sept 09	Last Meeting of the Research Group						▓

APPENDIX I

RESEARCH GROUP

DIARY

A précis of research group minutes from June 2004 to September 2009

RESEARCH GROUP DIARY 2004 – 2009

Friday 25th June 2004

At the very first research group there were nine people present and we began with an introduction to the aims of The Haven. We have started at temporary premises at the Northgate Centre and we're looking for a permanent home. Meantime we're only open during the day. Heather explained that the aim of the research is to look at how and why The Haven Project is effective over the two years of the pilot. It will be a follow-on from previous local research. There will be training for service user researchers and payment will be made within the confines of the therapeutic earnings limits as set by the DWP, this will ensure that user researchers benefit entitlements are not compromised, whilst ensuring fair recompense for work carried out.

The group talked about a couple of papers that had been written concerning recovery within mental health and discussed the concept of recovery, with recovery being a journey, not an imposed pressure to get well. Most members of the group agreed that recovery is not the word that they would choose to use. Those who are moving out of mental illness, particularly those with a PD diagnosis do not want to recover who they were, they want to get to a future that they want and what they think everyone else has. They want to disregard all the pain and problems of the past and all that happened to them and to become new, maybe to be reborn, not to go back to all that was wrong in the first place. We discussed the term iatrogenic i.e. harm caused by something that is supposed to do good, in this case the health care services and it was agreed that psychiatric services can be iatrogenic. We looked at methods to recover and some of the ones brought up were: hope, independence and empowerment (medical treatments e.g. drugs can impede recovery)

People at the group felt the need to feel safe and discussed what makes us feel safe? Quality of life is important, as is restoring the ability to cope with life; positive coping strategies would be very useful. Independence is a goal but remembering that interdependence is also important, we all need to depend on others. It is part of the human condition, and so it is unreasonable to expect someone to be totally independent and, as such, an unrealistic goal. The idea of adult babysitting for people in crisis or those feeling particularly vulnerable was discussed. It was felt that therapeutic alliances are very important like consistent respectful relationships with staff. A national anti stigma campaign is needed.

We then looked at what sort of questions could be asked by researchers to determine whether The Haven Project has been successful, staying with the idea of recovery, the following points were raised:

- It's not getting back to the way you were
- It's about growing and overcoming challenges
- Hope, independence, empowerment

How does it feel for you?
- expectations
- What didn't work for before?
- Optimisms – where in 5 yrs
- What has worked?
- Inner progress?
- Scales – sliding
- Inner calm and anxieties
- Safety net
- Coping strategies
- What have you learnt
- Changed behaviour and reasons for behaviour
- Do you like yourself?
- Occupation
- Strengths – looking for positives and futures
- Qualities

Finally we looked at what support needs to be in place for people using The Haven Project, these are the ideas we had, although we welcome any new ones:

- Sweetie chute – candy
- Encouragement
- Staff that are different – non judgemental
- Part of community
- A quiet place – set it aside
- Comfort – calm décor
- Homely
- Normal
- Common ground
- Problem free room
- Golden phone call
- Bright room
- Activities – different to others already offered
- Support groups for those ready for them

Friday 31st July 2004

Four people attended the meeting. Some measures regarding outcomes were discussed including the Ohio study, as recommended by Piers Allott "NIMHE Recovery Fellow", this details a different concept of recovery.

Eight people have registered with The Haven Project so far and Heather said that she has started collecting baseline information from them.

Heather asked whether the next Haven leaflet to be produced should be on self-harm, and aimed at both self-harmers and those who don't understand it. It was suggested that it may be a good idea to give a supply of the leaflets to Colchester A & E Dept. The group is interested in working together to compile the self-harm leaflet. In the current draft of acceptable behaviour policy, self-harm will be classed as unacceptable while at the Haven. Obviously this is a very sensitive subject and is open to much discussion.

For the Questionnaire design for the research we discussed how we will measure improvement. It should be measured not just from the baseline data, but also from self-reporting and individually tailored care plans. We need to try to capture the identified reasons why; the safety of the atmosphere – how safe is it, what is the continuity doing, how well do the long term individual tailored care plans work? We agreed that we will need to find a way to measure the tiniest of shifts in changes in each person's life. A possible problem that we may encounter could be the sense of identity in the sickness role, the 'fear of being well'. We talked about identifying the journey of response to inadequate caregivers, i.e. has the perception changed towards the caregiver in terms of less expectation and more balanced perceptions? The questions that we will be using in the questionnaire will need to be with the ethics committee by November/December of this year. This means that we need to start putting the questions together at the next meeting. The questionnaire needs to encompass many aspects of the inner and outer world of the individual and will hopefully measure the spectrum from small shifts to significant changes.

Friday 8th October 2004

We are meeting after a three month break during summer holidays and while setting up the service and four people attended. The project has been extremely busy what with the impending visit from the Department of Health and the Guardian newspaper both coming up next week. There have also been some problems with planning issues around our proposed permanent accommodation at Glen Avenue. As a result of this the leaflet concerning self harm has not been prepared. Heather will draft something up and bring it to the next meeting for discussion.

Heather also mentioned that recruitment for the crisis service is now complete and that we have some really good people coming on board. Fifty clients who have already registered and it feels like more people are needed to attend the research meetings. We need to approach more people to see if they would be interested in coming on board. Client researchers will be paid for every questionnaire that they complete, the amount to fall within the therapeutic earnings limit. Becky was concerned that the groups and activities should also be available in the evenings and at weekends to enable clients who work to have access.

The research questionnaire will not be ready for the ethics committee until January or February of next year now. It has been agreed by the research group that the project needs to have been up and running for many months before the questionnaire can be

implemented. This will also allow for things to settle a little after the upheaval of moving premises and all of the new staff coming on board. The group agreed to start to consider questions for the questionnaire to bring to next month's meeting.

Tuesday 9th November 2004

There are six people attending today with some new members joining the group. The group worked on the draft of the self-harm leaflet which will now be sent out to the whole mailing list for comment.

The safe centre opened yesterday and four people had used the service last night, all went well. The planning proposals for change of use of Glen Avenue are going to planning on 18th November, this means that The Haven Project won't be in the new premises until January 2005. This in turn has slowed down the questionnaire process as the whole service needs to be up and running before data can be collected. The purpose of the research questionnaire was revisited and the research group will help to formulate the questions. Both Dee and Heather L said have previous experience of research work. The questionnaire will need to be submitted to the ethics committee for approval before data collection can start. The group discussed the type of questions that it was felt would be useful to include, such as sense of self and coping strategies. It was suggested that the opening questions should be quite innocuous, followed by scaling and tick box questions. Finally it was felt that questions inviting individual comments and exploration should be included towards the end of the questionnaire.

Tuesday 14th December 2004

Five people attending today, with some new members joining the group. Hazel and Dee recently went down to Richmond for a couple of days to conduct interviews with the staff, clinical supervisors and course convenors involved in the Henderson/Cassel Hospital PD training course. Both enjoyed the experience immensely and we now have two interviewers for our research.

Baseline information is being collected on the registration forms and will be collected again at the annual re-registration. Hopefully we will then be able to see that money is being saved by less/more appropriate use of services by Haven clients.

On the subject of the questionnaire design and our own research, Heather said that we can already see that some people are feeling some improvement. However, the questionnaire is still some months down the line, as it was agreed that clients will need to access all of the upcoming services, such as reflexology, DBT etc. One idea is to have Recovery Service Evaluation groups every 2 or 3 months. This idea was well received by all present and it was agreed that the groups would be called Service Evaluation Groups (SEGs). Hopefully the first 'SEG' will be held in February and this is something we can keep doing until we gain ethical permission for our study.

At the last meeting it was agreed that all members would try to think of some possible questions to be used in the questionnaire. This is a list of questions which were brought to the meeting and agreed by all to be useful and relevant:

- *Can you say something about the kinds of responses you have received at The Haven when you have been feeling vulnerable or in crisis?*

- *What has been your experience of some of the groups, activities, one-to-ones and other therapies at The Haven? These therapies could be listed out for people to rate individually.*

- *How do you feel The Haven helps you personally?*

- *Are you learning new skills which are helping you to understand and cope better?*

- *Could you say something about the kind of coping strategies you have used and whether these have changed?*

- *Since coming to The Haven, do you feel you spend less time disliking yourself?*

- *In what ways, if any, do you feel you have changed as a person since attending The Haven?*

- *Can you say something about hopes, dreams, goals and the future and whether your vision of this has changed since coming to The Haven?*

Tuesday 11th January 2005

Seven present today and there seems to be a stable membership of the group occurring. Not everyone is present at every meeting, but it is a membership of 10: Heather C, Dee, Becky, Helen P, Hazel, Jeff, Cameron, Heather L and Helen S.

The project is due to move and open at Glen Avenue on 31st January, 2005. Again, it was agreed that carrying out full research questionnaires and interviews was still many months off because of the need to have the project fully up and running, with all parts of the service, before progress and recovery can be assessed in an in-depth way. Therefore, it was decided that the next meeting of the group on 11th February should be a SEG (Service Evaluation Group) and that a wider section of community members should be invited to attend. This group will be run over two hours, with a break, and will explore the questions formulated at the last meeting, as an interim service evaluation.

Tuesday 8th March 2005

Five present today. Last month, as planned, instead of the Research Group a SEG was held (Service Evaluation Group held on 8th February). It was very positive and offered a range of constructive criticism and highlighted help and improvements since The Haven opened. There was a lot of honesty and a lot of laughter and it was good that people felt so open about expressing things, despite the tape recorder, which people seemed to forget once the group got going. It was also agreed that this exercise should be repeated three-monthly, the next one being on Tuesday 10th May, and that an hour and a half, with a break, is a good length. The group reviewed the eight SEG questions and agreed that they should all remain the same for the next evaluation meeting, apart from number four which mentions coping skills and was similar to number five, a bit repetitive. It was agreed that this should be changed to:

Q4 Are you learning new skills which are helping you to understand yourself more?

The subject of being paid for participating in the SEG was discussed. Members of the group felt differently about this. It was felt that payment was about being valued, but others felt people might come just to be paid, and that plenty would come if not paid. It was agreed that travel expenses should still be available and that payment on an hourly basis, as therapeutic earnings, should be offered to those in attendance, but not until the end of the meeting. People could then refuse, accept or donate what was paid.

Heather said that one of her research supervisors from university, Dr. Nicola Morant, had suggested that pseudonyms be used at the SEG, so that progress for individual attendees might be seen more clearly over time. The group agreed and a variety of personal, and sometimes very novel, pseudonyms were suggested!

Hazel also suggested that it might be a good idea to include another question in the next SEG. This is about possible fears in relation to recover i.e. Is getting well scary? Why? In what ways? It would be really appreciated if group members could give this some thought before the next meeting and, if agreed, we can work out the wording.

Tuesday 12th April 2005

The next SEG will be held on the date of our next research meeting i.e. Tuesday 10th May, from 11am to 12.45pm, with a 15 minute break. Posters will be sent out and will go on display advertising this.

The suggestion from Hazel made at the last meeting was considered. This involved considering whether we should include an extra question at the SEG about recovery being frightening. Discussion occurred about the fact that it can be scary to think of getting well. There's no real safety net if difficulties return. One can have had difficulties for decades and have experienced, working, suffering, loss, ageing. Also, people get comfortable and changing this can be very scary because it's about the

unknown. It's not something you actively seek because of what might be lurking behind the big door. When you have mental health problems there's a real sense of losing time and that there is a big world outside with stigma and discrimination. In relation to recovery, people can feel rushed and have insufficient support. It has a lot to do with the way in which people are supported. It was agreed that a question in relation to this could yield valuable data. Helen suggested it should simply be:

Is recovery frightening?

This was agreed.

Tuesday 15th June 2005

Only three people at the meeting today but twelve people attended the first SEG in February and thirteen the second SEG in May. Although the whole community is invited, this was still considered a good turnout. It was felt that one client tended to dominate the last SEG, in places. It is hoped that we can have the same people, and more, attend the next SEG in August. It was felt that looking back at what was said, in the transcript, helps us to understand ourselves as a community. It's about ownership and having an input. The new question, about recovery being frightening, was felt to be fruitful. It was agreed that topics for the next meeting should be whether the SEG questions stand as they are or whether they should be amended and/or added to. Hopefully there will be more members at the next meeting at the new time of Wednesday afternoons.

Further discussion also occurred about what happens after The Haven, again relating to fears about recovery and the need for a continued safety net.

Wednesday 27th July 2005

A decision needed to be made about the format of the next SEG on 24th August. It was agreed that the same questions should be used and kept as a yardstick. One additional question was suggested:

"What else do you feel The Haven could do to support your recovery?"

It was agreed that this should be added. This will mean that five questions will have to be answered in the first half and five in the second half.

Invitations to several other clients had been given for the research group and it is hoped that they and existing members will be able to make our new time of the last Wednesday afternoon in the month. The next meeting is the SEG and a good attendance is anticipated.

Wednesday 27th September 2005

The last SEG was held on 24th August and it was agreed that this was a very good meeting, real positive movement and a marked difference between those who have been at The Haven for a while and those who have registered more recently. It was also noted that newer people still contributed well at the SEG. This was good because it can take a long time to speak up and trust. It was agreed that the questions for the next SEG on 23rd November should remain the same, but this decision has been kept open to research group members who are not present today. However, one reason it is probably good to keep questions the same is that consistent comparisons can be made over time.

The group was made aware of the collection of base line information for our first 25 clients who have been with us a year, showing big drops in annual use of many services including hospital admissions and Sec 136's.

The October meeting is due to fall during Heather C's next study leave week when she will be working on project research, Heather asked if the group would agree to cancel this meeting, but that members could get in touch about anything pertinent before the next SEG.

Tuesday 25th January 2006

We have a new member of the research group, Angie, as we have lost one member to an acceptable behaviour ban meantime.

The fourth SEG was held on 23rd November, 2005. The Group felt that, although it was challenging in parts, some very valuable data was captured in relation to recovery. This was around statements from attendees regarding wanting to be challenged in their comfort zone. This is being responded to by the new Progress Planning system at the project, where staff meet to work out a team formulation for individual clients then work with the client to create a long-term, recovery oriented care plan. The next SEG will be held in February this year.

Heather C informed the group that, at last, the research proposal for The Haven had now been submitted to Anglia Ruskin University and was also just about to go to the University Ethics Committee for approval. A copy of the final proposal was given out, together with copies of the Information Sheet and the Consent Form for the study. Discussion occurred about preliminary steps to ensure Haven clients are fully aware of the particular part of the study they are taking part in, including having help to read the Information Sheet if they have literacy or dyslexia problems and it also being made clear to such clients that they don't have to read anything as part of the study, questions will be asked rather than having to be read. Once approval has been gained, the SEGs will become Focus Groups throughout 2006. It was felt that, once the systematic part of the research has been competed, SEGs should still continue in future years, probably continuing every three months, because they have been so valuable to the development of

the project. A suggestion had been made by one of Heather C's supervisors, that we might add to or amend the questions developed. The group felt quite strongly that there are enough questions for an hour and a half and that they would like the same questions to remain as they will be consistent with the SEGs that have already taken place. Hazel emphasised the need to involve the carers and ideas for carers questions were discussed by the group. These will be suggested to, and refined by, a small number of carers so that they can be used for the two carers' focus groups to be held this year.

- *What should Carers be called? Clients don't always like the term Carers as it suggest dependency and something like Supporters might be better. This is a key question for the Carers to discuss we felt.*

- *How can Carers best be helped? Hazel said her husband favoured informal support when he needed it, rather than the idea of a Supporters Group. What support do they feel they personally need? The Henderson workshop for clients and their significant others had been a great success last year and perhaps these kinds of forums might be repeated. This was educational, which highlights the question of information and education and what do Carers feel they need in this respect?*

- *In what ways do Carers feel the Haven has helped?*

- *Is there any more The Haven can do to help?*

- *Issues around helplessness, especially at times of relapse. Do Carers feel hopeless/helpless? Do they have a sense of guilt and frustration? Sometimes overdoses occur when the Carer is asleep and it must be pretty awful to awake and find out what's happened. The Haven engenders hope for clients because of its underpinning recovery ethos. But Carers are not necessarily given this kind of hope and can feel quite excluded by The Haven. Although we are not always able to give a full picture, Carers need information about what we're doing here.*

- *Meetings with Clients and Carer should happen more often if the Client gives permission. Some of them haven't even been to The Haven and it was felt that Clients sometimes take home a very negative view of how they are and how they are progressing and the Carers need to hear more of the positive.*

- *What does a Carer feel recovery is? It might be a totally different concept from that of the Client. They might be expecting some magic wand cure. It was also felt that Client and Carer can become locked into a negative dynamic – dependent/helpless Client and rescuer Carer. If this is not clearly understood by both parties a Carer may unwittingly sabotage progress. Jeff suggested information from Eric Berne's "The Games People Play" and this could possibly be the subject of a workshop for both Clients and Carers and it would be about a new contract being negotiated between Client and Carer as recovery progresses.*

Individual interviews for clients have also been suggested by supervisors. The group felt that this could enable us to involve some clients who might not come to a focus group and that people might say things in an interview that they might not say at a group. Interviews would ideally be carried out by a client. It was agreed by all present that Dee should carry out the interviews to be done in the first part of 2006. Apart from being an experienced researcher, she has also never used Haven Crisis Services and this would, hopefully, present less of a boundary issue for clients. It may be that other members are further along in their progress and can become involved in the follow-up interviews which will occur at a later date. The importance of stressing that people should feel comfortable with the person interviewing them was discussed. This is covered in Information and Consent Forms, giving the right to withdraw at any stage.

The group questioned whether other information gathered from clients will be used, like base line information of use of services and other questionnaires for the national evaluation. Heather C felt that all this data could be used as background to the study.

Tuesday 26th April 2006

The February meeting was a SEG on 22nd February, and the next Research Meeting, due to be held on 22nd March was cancelled due to staffing shortages. The fifth SEG held in February was excellent with some real shifts apparent for some people.

The Haven internal research and Heather's PhD have fallen by the wayside this year, due to the staffing difficulties and pressures. The question this afternoon is can it be salvaged? Dee and Helen felt that it must be and Heather C said she had spoken to the Service Manager who says she is keen to cover study weeks for Heather C to enable this to happen.

Heather C said that her supervisors, Shula and Nicola, had both suggested that the SEG questions need some adjustment before focus groups can be held. Helen felt it was important not to lose the current questions but that we should be open to smaller tweaks and suggestions, especially in relation to recovery-type questions. A discussion occurred about the simplicities and the subtleties of recovery. i.e. being able to go into town is your short-term goal and you manage to go in and do your shopping – that's a first step – it's all about steps. Also, you can get to the finishing line and slip back. It's all about steps and reaching plateaus. Dee said one very notable thing was that when people at the project are going down now they are picking up a lot quicker.

Heather said there wouldn't be a research meeting before the next SEG and we probably wouldn't be at the stage of modifying the questions, and getting ethical approval, and being able to run it as a focus group. She also said that Shula had mentioned that external supervisors were talking about the possible need for independent facilitation of the focus groups. Dee and Helen agreed with Heather that this is collaborative research and that the clients don't hold back in relation to what they say at SEGs because Heather is

facilitating – quite the contrary sometimes! It was noted that clients involved in the national evaluation's individual interviews and focus group, in March, presented a glowing picture of the project all round and perhaps weren't as honest with outsiders as they are at the SEGs. However, discussion also occurred about it being important to prove a lack of bias in the study and it was agreed that Dee would facilitate the focus groups as well as the interviews. Heather said she hoped to talk to her supervisors to see what they were looking at in terms of question modifications but that she felt the research timetable realistically needed to be extended. It was agreed that this would make more sense if data collection took place until mid 2007, rather than stopping in February 2007.

It would be possible to carry out the proposed Carers' Focus Groups in this timescale and the research group had already begun suggestions for the carers at the last meeting. What Heather needs to do is to hold a meeting with some of the carers to also get their input regarding possible questions. This needs to be done soon.

The individual interviews pose a trickier problem. Now that we are only registering two clients a month it is much harder to get 20 interviews "before" and 20 interviews "after". It was felt that a much better idea would be to capture the before/after aspects within the interview questions themselves and look at a more comprehensive interview schedule than for the SEGs/Focus Groups i.e. mapping the journey of recovery. Dee is still keen to do the individual interviews and it would be ideal if these could begin in June and could target a range/variety of clients. The national evaluators also aimed at a variety of clients in terms of gender, circumstances, age, time at project, use of services etc. It was felt that the right interview schedule, for the individual interviews, could capture the journey in an exciting way with all its "speed bumps" and detours.

Heather said that, although her research proposal had been approved, the timescales are not as above and she wasn't sure how this would link up with the Ethics Committee application. She also said Shula had asked her to contact the National Evaluation to see how much of their data can be shared. Heather has done so and this will be possible and an interim report will be available in next couple of months.

Wednesday 28th June 2006

The May meeting was a SEG. The May SEG transcript has been ready for over two weeks but Heather C hasn't had an opportunity to check them. They should be distributed to the research group and SEG attendees very soon.

Near to final drafts of focus group questions and the interview questionnaire had been circulated in recent weeks. Heather C said she had reviewed the drafts with Shula and Nicola yesterday and the group now needed to make some final decisions to enable a submission to the University Ethics Committee for permission to carry out the research:

Carer Focus Group Questions: This had been circulated to five carers and concern was expressed about question four, ***"Do you experience personal difficulties regarding the***

person you support? If yes, can you say something about these difficulties." Even though results are anonymised, some carers felt that they would be reticent to say anything about who they support. Heather C had suggested making it more general like, *"Do you think carers experience….. etc".* Shula had alternatively suggested, *"Research shows that carers often experience difficulties in caring. Do you think this statement is correct and, if so, in what way do you think the role affects carers?"* This was unanimously agreed as the new question four. Shula had also suggested that every group and interview should end with, *"Have you got anything more to add?"* Again this was agreed for focus groups and the interview. Heather C said that Toni, who is a carer of a Haven client and a Haven director, had agreed to facilitate the carer focus groups and members agreed this was a good choice.

Client Focus Group Questions: The latest draft of the client focus group questions was discussed. The altered sequence of some of the questions, and the more open-ended wording was greed. The new question four about community was also agreed. Nicola's suggested amendment to question five i.e. *"…… what do you gain from these new skills?"* was agreed. However the suggestion that question six should change to, *"Since coming to The Haven have you changed the way you feel about yourself?"* was rejected and members still want to keep, *"Since coming to The Haven do you feel you spend less time disliking yourself?"* because somehow this way of phrasing seems to speak to PD.

Client Interview: The questions on page two will be consistent with the changes discussed for the client focus group questionnaire above. There are also an additional two questions, one about how The Haven compares with other services, and another one about community which asks about interaction and support between clients. Both additions were agreed and it was noted that there will be more time to ask questions during the individual interviews. Dee focussed our attention on getting the individual interviews started and felt there should be an introductory paragraph to guide her and the respondent into the interview. Nicola had suggested that actual age is included, not just age range. It was pointed out that marital status should also include *Civil Partnership* as well as *Married/Living as*. Additional questions at the end of page one were agreed i.e. *"how long have you been using the project"* and also additional boxes about which parts of the service are being used by the respondent.

Dee was asked to outline her research experience for the application form because she will be conducting the major part of groups and interviews. Apart from her involvement in the Henderson/Cassel PD course research last year, she has also carried out research in the past in education, social care, and animal behaviour and ecology. It looks like we are now ready to go to Ethics Committee and the next SEG will hopefully be a client focus group. It is hoped that the first carer focus group will happen in August, or soon after, and that the individual interviews will start soon after that.

Wednesday 27th September 2006

The last meeting in July was just Dee and Heather C and we discussed the application for ethical permission and the next stage of the research. No minutes were distributed.

The Research Proposal received permission from Anglia Ruskin University in March this year, and Ethical Permission to carry out the research was granted by the University Ethics Committee in August.

We have already held 6 SEGs with lots of relevant data. The first Client Focus Group was held in August and the transcript will be ready soon. Dee facilitated this and has also carried out the first Individual Client Interview. Her aim is to get something like 2 interviews done per month. The next Client Focus Group is on 22nd November. We are aiming to have the first Carer Focus Group in October or November, facilitated by Toni. This may have to be held during an evening. There were lots of suggestions for individual interviewees, most of who don't usually come to SEGs/Focus Groups. Twenty were suggested in all, 8 men and 12 women, with a good range including younger and older members, and single, divorced, parents etc.

The group discussed the idea of a Transitional Recovery category at The Haven which would be a category that people who were really making progress in their recovery could graduate to with pride. However, we looked at all the systems that will need to be in place to achieve this, in addition to the crisis and therapeutic input The Haven gives. The Study and Work Peer Support Group needs support and there is also a whole spectrum of educational needs from confidence to literacy. Voluntary work, as a good introduction to eventual paid work, was discussed, plus the idea of clients going in two's and three's initially. It was agreed that, in order to successfully map the Journey of Recovery in the research, it would be necessary for The Haven to have a full spectrum of support and skills available to its clients.

Wednesday 28th March 2007

We have two new members of the group, Laura and Belle, and a good turnout today. It was noted that this is the first meeting of the Research Group this year. The purpose of the meeting is to take stock of what data we have collected so far, and what data we still have to collect between now and July. It is also important to begin to think of categories, themes, or codes, for the research data, to enable it to be separated out for analysis.

Data collected so far:

SEGs (Service Evaluation Groups) - *informal data*	*Additional informal data*
6 groups 2005/2006 = approx 180 pages	Research Group Minutes
Client Focus Groups - *formal data*	Advisory Group Minutes
3 groups 2006/2007 = approx 100 pages	Minutes of Discussions
Care Focus Group - *formal data*	Newsletter
1 group 2007 = approx 40 pages	Creative Writing
Client Individual Interviews - *formal data*	
13 interviews 2006/2007 = approx 280 pages	

Total = approx **600 pages** of verbatim transcripts

Still to be collected

Client Focus Group - *formal data*
1 Group = approx 30 pages

Care Focus Group - *formal data*
1 Group = approx 30 pages

Client Individual Interviews - *formal data*
7 interviews = approx 140 pages

Grand total = approx **800 pages**

It was agreed that this is a vast amount of data and we need to begin thinking of ideas for categories and themes that seem to be emerging and that relate to recovery in personality disorder and The Haven. Following is a list of initial ideas from the group.

Initial ideas for Themes emerging:

Safety
Issues of trust
Boundaries and Boundary testing
Betrayals
Loss of trust
Misconceptions about recovery
What is recovery?
Hope
Fear of failure
The importance of peer support
What were the main coping strategies?
How did people feel about themselves to begin with?
Shedding old coping strategies
The pain of trying to move on
Split/dichotomy – their fault /my fault – blame
Letting go of the past
Losing idea of how family was, or even losing family
Loss and grieving process
Blips and relapses
Faster recovery from blips with insight
Changing sense of self
New messages about self from Haven community
Internalising new messages/good ideas about self
Being and feeling valued
Valuing self and others
The community as home and parent
Power sharing and feeling in control

Being trusted with responsibility
Being recognised for skills
Comparisons with other services
Recovery comes from person themselves
It's not all down to The Haven
The Haven is life saver vs. The Haven is too safe and holds you back
Stuck in learned helplessness
The response to learned helplessness is tough love
Rewarding constructiveness and progress
Small steps
Developmental process, learning to walk, leaving "parents"/Haven
Fear of loss of support
Fear of failure
Sense of identity when recovering – who am I, where am I, where do I fit in
The concept of Transitional Recovery/need for safety net/secure attachment
A new set of trust issues – with the outside world
Huge issue of benefits and money – basic survival
Wanting to work and being given a chance
Realising that recovery is an onward journey for everyone

Wednesday 25th April 2007

The fourth and last Client Focus Group will be next month, on 23rd May. The date for the second Carer Focus Group needs to be set for July. Thirteen individual Client Interviews are complete and there are seven still to do. A discussion occurred about who might be included in the seven and how we can keep a balance of gender and other factors. It was also agreed that two people who were no longer at the project, due to behaviour, should be approached as this could give an interesting dimension to the data being collected

Although the meeting next month will be a Client Focus Group, the next Research Group meeting will be on Wednesday 27th June from 2pm to 3pm. It is now very important that we have good attendance at Research Meetings to enable us to work together on analysis of the findings.

Wednesday 27th June 2007

We have now held the fourth and last Client Focus Group. A decision needs made on whether, in two month's time, to have a SEG in August. It was agreed, yes, because why change a successful action and it will also give more background data to the research. The Second and last Carer Focus Group will be in July (now 3rd Aug). Sixteen individual interviews have been done so far, 4 men and 12 women, which follows project ratio of clients. Consideration was also given to age and status in terms of children, married or single etc. and we have been fairly inclusive so far. Five names were suggested, 4 of whom will be selected to complete the 20.

It remains important that we have good attendance at Research Meetings to enable us to work together on analysis of the findings.

Wednesday 25th July 2007

Heather C had not had a chance to look at the transcript for the fourth, and last, client focus group, which will be sent out to everyone soon. The second and last carer focus group will be held on 3rd August, with time afterwards for carers to talk together informally – the first Families and Carers Group? Nineteen out of the twenty individual client interviews are done and discussion occurred about who the last participant should be. So far Dee has interviewed 14 women and 5 men. Age ranges are quite well spread over younger, middle, older. Home conditions in terms of having a partner, children, or not, are also quite well spread. Twelve clients were considered, with three being most desirable. One will be interviewed over the next week. This will be the end of data collection and Heather C thanked members of the group who have attended recently as we move into the phase of data analysis.

Wednesday 26th September 2007

Only three of us attending today, Dee, Belle and Heather C. All data is now collected, however, Heather C's next study leave is not until the end of October. This is when data analysis will begin. For this reason it was decided to cancel the October meeting until some preliminary data analysis has been completed to enable this to be brought back to the research group. The meeting took a look again at the categories that had been suggested at the March meeting, earlier this year, and this mapping of the recovery process will be taken into account when Heather C begins the analysis.

A SEG was held on 24th August and the transcript from this will be made available in coming weeks. The next Research Group meeting would fall during the Christmas holidays, therefore, it was decided that a meeting may need to be scheduled before then as initial comments will be needed on data analysis. Heather C will consult with members about this.

Wednesday 30th January 2008

A good turnout today with most members of the group here, including Cameron who is back. It is our first meeting since September and Toni has joined us in relation to the data from family members and carer focus groups and members were happy to have her present.

Belle and Jeff, although unable to make today's meeting, they have both agreed to help with data analysis, detailed below.

In November a SEG was held. Again, in December, it was agreed that data analysis needed to progress and Heather C had study leave in January and good progress is now been made on the analysis.

Originally we held SEGs (Service Evaluation Groups) every three months and six were held over a year and a half. These turned into four focus groups held over one year. Since then we have resumed the SEGs at three-monthly intervals and two have been held. Heather C said that, in research terms, she feels we have reached saturation point for data collection. However, the SEGs serve an important function in themselves in that they continue to give client feedback for monitoring project progress, and they give new clients an opportunity to feed back in a structured way. Hazel suggested that, once data analysis is complete, we resume the SEGs on a six-monthly basis. This was agreed. We also discussed the idea of follow-up feedback being invited from research participants. As we know, since focus groups and individual interviews took place, some clients have made significant further progress. Some may also have had setbacks and have bounced back from these. It was felt that it could be important to capture developments and progress for individuals as part of the findings. It was also suggested that Carers and Family members should be included in any invitations to send in more data.

Heather C said that we have 770 pages of data! It was agreed that it is a good thing that so many people want to help. It was also agreed that ten clients and a carer involved in data analysis will really be in the spirit of our research which is participatory action research. The data collected is as follows:

Data Collected

6 SEGs Feb 05 to May 06	- informal data
4 Client Focus Groups Aug 06 to May 07	- formal data
20 Client Individual Interviews Aug 06 to Aug 07	- formal data
2 Carer Focus Groups March 07 and Aug 07	- formal data
2 SEGs Aug 07 and Nov 07	- informal data

During her study leave this month Heather C had coded all 770 pages manually i.e. she had marked, with different coloured pens, fourteen categories detailed below which we will eventually narrow down to some of the themes discussed at our March meeting. She then used a computer programme called NVovo[7] to begin to put all the quotes she had coded together in one place. During study leave she had managed to do this only for the first category, Trust and Safety. She had spent 17 hours last weekend trying to complete the rest but had only managed to get two thirds done, but hoped to complete everything this weekend so that transcripts were available to the group. She said that, although there are 14 different categories so far, she suggested keep in mind three areas that seem to speak to respondents in terms of recovery i.e. dependence on psychiatric services, psychological changes, and social progress.

Three Recovery Issues

1.	Am able to cope with less support in terms of hospital admissions etc.
2.	Am I feeling better, symtomatology, able to see the future etc?
3.	Do I feel valued in terms of my contributions in life/social inclusion

It was decided that different group members would take responsibility for reading through different categories. Some transcripts are much larger than others and quotes collected for each category so far were given to the group. Below is each category and how many pages each transcript turned out to be:

Categories for Client Research Group Members to work on

Number	*Category*	*Pages*
1.	Trust : Safety : Consistency : Responsiveness	37
2.	The Community	51
3.	Empowerment : Confidence	18
4.	Service Savings : Changing Coping Strategies	79
5.	Feeling Cared For	9
6.	Non-judgement : Respect	9
7.	Self-worth	35
8.	Hope : Recovery : Social Inclusion	132
9.	Being Challenged	11
10.	Attachment	4

Categories for Toni to work on

11.	The Term Carer	4
12.	Burden : Guilt	20
13.	Involving and Supporting Carers and Family	9

Needs more work by Heather C

14.	Service Developments

This last category is about research affecting the development of The Haven and, although coding has been done through all 770 pages, this needs more reflection. Although quotes from the Carer Focus Groups are included in some of the first ten categories, identity is protected. However, it was felt that the more sensitive aspects of that data e.g. "Burden: Guilt", should be further analysed by Toni because of confidentiality issues.

The transcripts were assigned as follows:

Number	*Category*	*Primary*	*Secondary*
1.	Trust : Safety : Consistency : Responsiveness	Becky	Dee
2.	The Community	Helen P	
3.	Empowerment : Confidence	Hazel	
4.	Service Savings : Changing Coping Strategies	Helen S	

5.	Feeling Cared For	Belle	
6.	Non-judgement : Respect	Cameron	Heather L
7.	Self-worth	Heather L	Angie
8.	Hope : Recovery : Social Inclusion	Dee	Hazel
9.	Being Challenged	Jeff	Helen P
10.	Attachment	Angie	Becky
11.	The Term Carer	Toni	
12.	Burden : Guilt	Toni	
13.	Involving and Supporting Carers and Family	Toni	

Some people have agreed to read through a second category and comments on both your choices will be welcome. Comments will be needed from the primary list by the next Research Group Meeting, date below. Guidelines as follows:

1. Read through full transcript and note if anything is in there that you feel shouldn't be

2. Reflect on what this category is telling us

3. Are the further categories within this category i.e. can it be broken down further e.g. hope, recovery and social inclusion is huge and will definitely need to be broken down, as will some of the others

4. Are there categories that you feel should be in there that aren't

5. Anything else you would like to add.

It was noted that Heather C had spotted some mistakes in transcription which she had missed. In focus Group 3, in some place Norris should be Boris and this needs changing. In one transcript "Rose" says she's given up cannabis! This has definitely been changed to "Ruth" has given it up!! We also have two "Sallys" and the one from the individual client interview is shown as "Sally 2" in the categories. We also have "Emma" as a pseudonym and this will need to be changed in due course as it is the name of one of our clients.

What we are doing here is just a beginning in mapping the journey of recovery in PD from this data. It will need to be broken down and then refined during the year into the major themes. A full analysis of service developments, in relation to the research, will also need to be done. Further categorisation, by client, will also occur i.e. all the bits from "Harry", "Boris" etc. throughout the data, will be drawn together. This is where the invitation for follow-up data could be valuable, to complete any case history type results we want to present. Heather C said that research supervisors were also stressing that it will be important to show, in the results, the reflective journey of this group.

Wednesday February 27th 2008

Dee had taken on the largest category "Hope, Recovery and Social Inclusion" which is 132 pages and definitely needs broken down into smaller categories. She had managed to

get through 39 pages so far and felt that the further categories should break down into "Hope, "Recovery", "Changing Attitudes" and "Social Inclusion". She also suggested a further break down into negative and positive responses in categories. Heather C said that supervisors at university had also suggested this. Dee's notes on the first 39 pages also reflected other issues e.g. drawing out the spectrum of recovery and social inclusion issues – not just employment; issues about respect; being challenged; fear of change and its relationship to attachment; the strong link between recovery and trust, and perfectionism and its relationship to unrealistic goals and aims and how this is a hard nut to crack.

Helen P had looked at the category "Being Challenged" which is 11 pages, and felt this could be broken down into "Dealing with Challenging Behaviour" and "Being Challenged/Pushed". She felt that "Challenging Behaviour" might best be in the "Community" section. Heather C said that quotes about "Challenging Behaviour" had also been included in the "Community" category. Helen has "community" as her main category and hasn't made a start on this yet – it is another big one at 51 pages.

Angie had taken on "Attachment" which is 4 pages. Her analysis reflected on the sense of family at the Haven in relation to attachment; the fact that community is a safety net; the fear of losing The Haven being tied to the fear of recovery; the issue of learning to trust being related to being able to ask for help; non-judgement and acceptance as part of attachment that helped people to stand on their own two feet; the importance of nurturing attachment so that there is no pushing for discharge; the fact that the carers focus group also felt the staff were friends; that The Haven represented a home but that this was also hard for family to accept; that carers too wanted The Haven to be around forever and their biggest worry is loss of The Haven for their family member; carers also reflected on whether, if The Haven is working, their family member would have to move on and fears from the carer/family member that other people might think their family member didn't need The Haven; in relation to clients again there was a sense of being checked up on as being cared for and being able to come in at any time; that clients wondered how quickly you would get support back from The Haven if you made progress but then relapsed; and finally that for many clients the Haven becomes the family they have lost.

Belle had taken on "Feeling Cared for" which is 9 pages. She wanted to do more work on it but so far she felt that it was highlighting issues such as feeling wanted; belonging, how you are greeted at the door; whether you are let down; and the importance of pampering and complementary therapies which involve touch and are nurturing.

Toni had taken on the carer focus group categories of "The Term Carer" which is 4 pages, "Burden and Guilt" which is 20 pages, and "Involving and Supporting Carers and Family" which is 9 pages. She said that "The Term Carer" had shown that "carer" is a contentious issue and a double-edged term. In one way it is a known term that is recognised by statutory agencies including social services and benefits agencies but that family members can feel that it is patronising, not to mention the service user, and it doesn't really describe who they are, which may be husband or a wife etc. Toni said she needed to do more work on "Burden and Guilt" and didn't feed back at the meeting on

this category. On "Involving and supporting carers and family" it was interesting that some didn't want to be involved and definitely saw The Haven as their family member's place and did not want to destroy any trust between Haven and client, which was quite perceptive. The carers/family members seemed very aware of the delicate situation of whether they should ring and whether their significant-other would want them to have information.

Others hadn't done a lot as yet on their categories. Cameron is working on "Non-judgement and Respect" with Toni. Helen S needs to start on "Service Savings and Changing Coping Strategies". Heather C said that supervisors at university had pointed out that this category was wrongly named in that service users would not be focussing on "service savings". This is, however, relevant to funders and could be included in a chapter analysing results, but it should not be the name of a category. Everyone agreed with this and the name of the Category will be changed. Becky hadn't made a start on "Trust, Safety, Consistency and Responsiveness" yet. Hazel on "Empowerment and Confidence Building", Heather L on "Self-worth" and Jeff on "Being Challenged" weren't at the meeting today and there hasn't been any feedback from them yet.

Heather C said that supervisors had suggested that we might want to do some work as a group on analysing some of this so it was agreed to spend the second half of the meeting, the remaining half hour, analysing "Empowerment and Confidence" together. We did this but only got through 4½ pages out of 19 in the half hour. So, it is a very slow job. Issues we noted included the choice to attend is empowering; empowerment links to trust; empowerment links to caring and being able to give as well as take; setting goals can be empowering and even if you are feeling bad you can maintain some confidence; empowerment is learning from each other, the sense of ownership at The Haven is empowering and the fact that clients are able to affect and control things; learning to speak up in groups is both learning to trust and confidence building; being believed in and trusted can give you confidence outside and even to start work; insight and self-management is empowering; encouragement to reflect is empowering because it throws the issue back on self; helping others increased self-knowledge and self-worth; internalising positive comments from others can increase confidence; support without being taken over helps you to help yourself; pushing yourself even when you don't want to is a sign of confidence; being able to speak out at conferences shows a big leap in confidence; having people behind you gives you courage; having been brave enough to challenge staff and see that the relationship held increases trust and confidence; gaining confidence in groups at Haven gives confidence to join groups outside, confidence relates to non-judgement, acceptance and trust.

Wednesday 26th March 2008

Reflecting on data analysis, there was a discussion about the importance of a follow-up for certain clients who have been very involved in Haven research, especially if they are going to be sited as case studies. It was agreed that Heather C should code all data for each individual client involved in the research into individual transcripts.

Again, the importance of reinstituting the SEGs, once data analysis is complete, was agreed. Hazel and Dee stressed that this was important not just for ongoing service evaluation of the project, but also to give new clients the same sense of ownership and belonging that had been generated for clients who had been here longer.

The rest of the meeting was spent in a continued analysis of the category "Empowerment and Confidence".

Wednesday 30th April 2008

Heather C said she had used her last study leave week, earlier this month, to bring together individual data for the sixty clients involved in Haven Research. She brought the sixty transcripts to the meeting and group members now have a copy of their individual transcripts. Some Haven clients just attended one focus Group, SEG or individual interview, however, some people have data from many meetings and individual interviews and this represents two and a half years of data for that person. It is possible to see clear patterns of improvement, over time, for many people. Heather will be using her study leave week in August to analyse the transcripts further in terms of how many men and how many women, age groups, and responses to particular questions e.g. on a preliminary look at the data, for questions like *"Since coming to The Haven do you spend less time disliking yourself"*, it seems that there is a pattern of improvement to responses after a period of six months. These are the kinds of patterns and themes we'll be looking for in the individual data. Members agreed to read their own transcripts and feedback.

We are also continuing with analysis of themes as follows:

Dee and Becky – *"Trust"*
Hazel E to finish 2nd half of *"Confidence and Empowerment"*
Heather L is half way through *"Self-worth"*
Belle is part way through *"Feeling Cared for"*
Dee wants to look at breaking down *"Hope, Recovery and Social Inclusion"*
Angie will have a go at *"Non-judgement and Respect"*

Wednesday 28th May 2008

Incomplete tasks were reassigned as follows:

Dee and Heather L – *"Trust"*
Helen P to do *"Community"*
Heather L has finished *"Self-worth"*
Sacha will finish *"Feeling Cared for"*
Angie *"Non-judgement and Respect"*

Dee and Heather C *"Hope, Recovery and Social Inclusion"*

Otherwise, people agreed to read their own transcripts as most members of the group had not done so yet.

Wednesday 25th June 2008:

Angie gave notes on her analysis of *"Non-judgment and respect"*. Remaining tasks are in progress.

Some people had now read their own transcripts of all research events brought together and could really see progress over time.

Wednesday 27th August 2008

Hazel has resigned from the Research Group due to time commitments for her post-graduate course. Hazel was thanked for her valuable contributions to The Haven research over the past four years.

Heather C reported about her recent week's study leave. She said she had gone through all 60 individual interview transcripts again, to draw out responses to the various questions. This had taken some days and had caused her to come to the conclusion that we can't skip over a presentation of the data in terms of the individual research questions and concentrate only the analysis of themes. She felt that there had been a back-off from doing this, since data collected ended last November, not just because 60 clients were involved, but because many clients answered the questions more than once, multiple times for some, at different research events. The questions also changed sequence over time and some were only asked to those clients individually interviewed. It is simple a massive job, but it must be done. A lot of the week's study leave was spent working out a template for easier access to data on each question of each individual, and the first four questions are now done. A transcript was made available at the meeting, beginning with numerical tables, and data on the four questions which starts from page 7.

Heather C said she didn't want people to feel they had wasted time on the analysis of themes, because this crucial data comes later, and work should continue on it. However, there is no way that the questions-analysis can wait until Heather C's next study leave in December. She said that research supervisors had been saying, for some time, that the analysis needs more time, and she intends to work out with day staff a number of individual days, between now and December, to get the client-questions-analysis done.

A timetable was considered, as follows:

1) Research Group to read first draft of data analysis and give verbal feedback about credibility at the next meeting at the end of September.

2) Heather C to complete analysis for the remaining ten client questions between now and December.

3) Heather C to complete Carers Focus Group question analysis by the end of the year, which feels like a comparatively tenable task compared to client-question-analysis.

4) Thematic Analysis of the fourteen themes, including work from this group, to be carried forward in Heather C's December study leave.

5) Several case studies to be considered, as the final section of data, early next year.

There was a discussion about some of the findings in the first four questions e.g. negatives and the importance of The Haven having learned from this feedback. This is relevant in many ways, like "trust", what built up trust? What shattered trust etc.

Consideration was given to what remains on the analysis of themes:

"Trust" – Dee and Heather L will complete work on this
"Community" – Helen P would like to see the question-analysis on this first. This is the next question, No. 5, and should be done soon.
"Self-worth"- Heather L to complete
"Hope, Recovery and Social Inclusion" – Dee is half way through and will continue.

Wednesday 24th September 2008

The group looked through the timetable now formulated for data analysis:

1) Research group to read first draft of the data analysis and give verbal feedback about credibility at the next meeting.

2) Heather C to complete analysis for the remaining ten clients between now and December.

3) Heather C to complete question analysis be end of the year.

4) Thematic analysis of the themes, including work on the themes from this group, to be carried forward in Heather C's December study leave.

Wednesday 29th October 2008

Feedback from the group, regarding questions one to eight, was that they showed a real indication of progress – how far people have come – and how progress is different for

different people – continued movement. People felt that the analysis was definitely now on the right track.

Heather C said that she will be seeing research supervisors next week and hasn't yet had feedback from them. How she is feeling now is that the results should form three chapters:

1) **The Data** – which will be client questions 1 to 14 (and we are now past the half way mark) and carer questions from the two focus groups.
2) **Data Analysis** – which will include the thematic analysis of the stages of recovery mapped in our research e.g. Trust and Safety, The Community and Learning, Confidence and Self-esteem etc. etc. Dee is continuing to work on remaining transcripts with other group members, at the moment e.g. Heather L.
3) **Case Studies** – this will be a summation, and illustration, of progress from a few individual perspectives.

Heather C has 7 individual days booked for study between now and Christmas and feels she can complete all the question analysis, including carers, during this time. The next meeting of The Haven Research Group will be on Wednesday 28th January 2009 from 2am to 3pm. (If there is a need for a meeting before this date it will be called on an ad hoc basis.)

Wednesday 28th January 2009

It is October since our last meeting. The completed preliminary analysis of client questions had already been circulated to the sixty participants, however, since the last meeting the family and carer data has also been analysed. There were ethical considerations about distributing transcripts to the Research Group, because family members of some of the group took part, but the Group were very interested to hear about the kinds of responses there had been, and in what numbers. The family and Carer transcript has been sent out to the six participants, asking if they would like identity further protected in terms of identifying gender of family member and other factors. None have requested this as yet and, if none do, the group would feel comfortable about the data being shared more widely.

At the last meeting it had been decided that the data would be presented in three parts. However, supervisors felt that the transcripts of the question analysis were too long to include in the body of the research report and need to go into an appendix. On 6th February Heather C has to send Research Supervisors an outline about the next chapters regarding the data. It was agreed that this should be as follows:

1) **A précis of the questions analysis** which refers back to the appendices.

2) **Thematic analysis** of the stages of recovery drawing from the work we did last year, picking out the themes that map the process of recovery in PD i.e. a

conceptual map or framework about the logical steps enabling change, grounded into specifics.

3) **Case Studies** – a small number.

4) **Discussion** about the findings.

A lengthy discussion then took place about issues that had arisen at Heather C's recent tutorial. This included risks in the journey of recovery, current social factors i.e. learned helplessness, fear, and the welfare rights system, all against the background of the current economic crisis affecting employment opportunities. We discussed whether recovery does occur against the odds and it was agreed that they do – not just the poor odds of a difficult start. Biographical issues were also discussed and simple profiling has been built into the research in terms of age, how long at the project and other daily living data, however, it was felt that some might be willing to have biographical details of trauma included, and others not. There was also a discussion about "social capital" and the notion that those with better physical health, positive family ties, and better levels of education, might recovery more easily. The group did not feel this was the case with PD where some who fit this criteria were not progressing well at all, yet others who had been disadvantaged in so many ways continued to progress.

Wednesday 25th March 2009

The February meeting had to be cancelled as Heather C fractured her wrist on the way to a pick up Becky and Helen to speak at a conference in Suffolk about developing PD services. While Heather C went to hospital to get "plastered", Becky and Helen went to Suffolk and did the conference themselves, to rave reviews. Although she has been hampered by some left-handed typing, Heather C has been continuing on the data analysis.

Heather C had circulated the first two themes of the thematic analysis to the group:

A Sense of Safety and Building Trust

Feeling Cared for

And is currently working on the next theme:

A Sense of Community and Belonging

These analyses are coming from the themed transcripts compiled last year and the work individual group members carried out on those transcripts, together with work carried out at the group. Some group members had read the analysis so far and some had not. Those who had, felt it was building up in the right way.   Helen P made some interesting comments regarding the physical and mental aspects of being cared for i.e. physical being everything from a cuppa, to a hug, to pampering, and mental being greeting, listening, valuing etc. Then there was a discussion about the sequence of the remaining themes and the consensus is that themes involving sense of self/self-worth/self esteem/confidence should come before recovery and goal oriented themes. This is because the ability to formulate and pursue goals realistically comes from developing self-esteem and confidence, otherwise "fantasy goals" can present themselves i.e. unrealistic.   The sequence, after the first three themes above, might be – changing coping strategies, skills, then self-worth, esteem, confidence, and then recovery and goals. It was felt that a later theme should be about healthy attachment and the outside world as this is crucial to understanding recovery in PD. It was agreed that the thematic analysis should remain fluid and open to comment and amendment as we progress.

Heather C said that, last week, she had gone to spend the afternoon with staff from the Norvic Clinic in Norwich which was really fruitful. She had received an email from the team saying that they found The Haven inspirational and uplifting and that it was not all about schema this and schema that, but about real people and down to earth solutions. The group felt that this is what we want our research to be i.e. human – real language about real people. Jeff suggested this might be called "PD for Dummies"!

Heather C also made the revamped charts available at the meeting and Dee asked for a copy of these.

Wednesday 27th May 2009

Heather C had circulated a transcript of the first four themes and said she hoped to circulate the whole analysis of themes before the next meeting. Dee had read the first four, but Jeff said he hadn't received it and Heather C had no feedback from anyone else other than a valuable conversation with Helen P and Laura about barriers to recovery and people becoming defined by the diagnosis and the sick role, so we discussed what had been written up so far. Transitional recovery should be the final theme because it's the safety net for the whole journey.

There was a further discussion about the fact that later progress, like being able to be in therapy and contain experiences, and being able to have hope and develop realistic dreams and goals, and achieve things, depended on the earlier building blocks. This wasn't just about building trust and the nice things like being cared for and being part of something, it's also about being able to keep the boundaries or you just don't move forward.

Wednesday 24th June 2009

Heather C had circulated the analysis of themes to the research group and it will now be sent to all respondents quoted in it, clients, carers and family members, to share the analysis and ensure accuracy. The group had picked up a couple of typos which will be corrected. Group members thought the analysis was great and felt that the chart/pyramid was a really helpful way to illustrate themes at the beginning of the analysis and that it represents growth and progress. Incorporating the carers and families' data was also of great interest to the group as this had not been made available to them before. Heather C said that tutors had made suggestions but generally seemed pleased with progress. Also, Shula had stressed the importance of highlighting differences about people who are progressing and those who have not. This will be covered in the discussion chapter, which comes next. The group felt that statements were interesting from some clients, who are no longer at The Haven i.e. about it being too late for recovery. The fact that some become stuck in a sickness role was also discussed.

The next important task for the group is to help in the analysis of the Research Group's function in the research. This will be covered in the updated version of the Methodology Chapter, and the group's input and experiences will be central to this. Dee's experiences will be very important, as the principle interviewer. It was agreed that the group will not meet in July, due to the 5th Birthday Celebrations at The Haven on that day, but would meet for the August and September meetings. At these meetings the group will focus on its own processes during the course of the research.

A letter had been sent, before this meeting, to say that, if members did not give apologies about their non attendance we would assume that they did not wish to continue. It was agreed that this should be considered to be the case for Helen S who seems to have stopped coming for quite a while. In a few months a further decision will need to be made about whether the group continues in some form, or disbands i.e. whether further research will be considered, or not, in addition to re-introduction of the SEG every six months. Dee has been keen for a Twin Study to be carried out as a very high percentage of Haven clients appear to be one of a pair of twins.

Wednesday 26th August 2009

As agreed at the last meeting, the purpose of this meeting and our meeting in September will be to look at what it has meant for participants to be members of the Research Group.

> *Dee: Being involved in the Research Group has led to so much for me, including now doing research for other universities, even Greenwich University now. It's increased my confidence, sense of purpose and I have also been paid. The overall feeling of influencing the minds of professionals with the results our research has yielded. Also, the privilege of getting the vote of confidence from everyone to do the interviews and facilitate the focus groups, to be trusted was a privilege. This has led to other things and when I give input at talks and meetings it gets a really good response and I'm told, "we don't get this in other lectures".*

Angie: First of all, being part of the SEGs, I learned that we were really being listened to and I actually saw the changes being made in response to what we said. Being part of this research group and seeing it all come together and knowing I've been a part of it and that things have moved on in a measurable way. I'm beginning to get there with a bit more confidence and self esteem.

Cameron: People found their voices because of the research, where they hadn't found them before. Things have changed in the last ten years and that's been partially to do with this group and also to do with the earlier research group that I was involved in, before The Haven. Being part of these research groups is being actively involved in making changes, including when I was part of the National Group.

It was agreed that we need to try to get feedback from Becky, Helen P, Jeff, Belle and Heather L at the next and last meeting in September.

Wednesday 30th September 2009

Today is the last research group and everyone present had been with the group for five years. Our membership at the end has included Dee, Angie, Becky, Helen P, Jeff, Cameron, Belle, Laura, Heather L and Heather C – the intrepid 10! Heather C said she could not thank members enough for their huge commitment over these years. A bit of a feast had been provided, including favourites such as a very large chocolate cake, carrot cakes, donuts, and grapes and raspberries for Jeff of course! Those in attendance were also given therapeutic earnings/permitted work payment to say that extra thank you for all they have done. Heather C said she would like to continue to circulate drafts of the chapters being worked on. Currently it is the Discussion Chapter and she asked who would like to continue to receive information. Everyone said they would like to continue to receive, read and comment on them.

Last month we spent some time asking those present to reflect on what it has meant to be part of the research group. It was agreed to continue this process at the group today.

Dee, who had given feedback last month, said she wanted to say it had been fun, especially all the talks and conferences. Heather C said that these will continue and, in fact, they could increase.

Becky: It's been a learning curve. It's about believing in yourself and having other people believe in you. It's not just a learning curve about the research project, it's about how we've all changed and grown.

Heather L: I enjoyed every minute of it. It was about being understood and helping us to understand each other. I also felt it helped me to remember my BA and academic work. It helped me to think, but it has also helped me to stop

dwelling on bad things. I'm going to start a project, "Five Years at The Haven", starting at the beginning with my experiences and showing how far I have come. I want to interview other people at the project who have been here five years too and I want to keep my brain working.

Helen P: *If all the clients here were still stuck where they were five years ago, how awful would that be. It's not rocket science – KISS – Keep It Simple Stupid! What it's done for me personally, it's got me into reading more academic literature.   That can be quite a struggle when your head's like a washing machine, quite a test.*

Jeff: *It was a very productive time. I felt my opinions were really appreciated and that it was a very good project to have been part of, and to have been heard. It was all about self-worth. We could turn it all into a film. George Cluny could play Alan and Meryl Streep could play Heather!*

As agreed at earlier meetings, we will now resume the SEGs every six months. A date was fixed for the next one one. This will be advertised, run with the same questions, transcribed and distributed, just like it used to be. We will try to get some new people there.

Dee said, once Heather C has a bit of space in her head for more research, she would still like to see the Twin Study go ahead at The Haven.

Bye for now and see you later………………

<u>SEG Questions</u>

QUESTION 1: CAN YOU SAY SOMETHING ABOUT THE KINDS OF RESPONSES YOU HAVE RECEIVED AT THE HAVEN WHEN YOU HAVE BEEN FEELING VULNERABLE OR IN CRISIS?

QUESTION 2: WHAT HAS BEEN YOUR EXPERIENCE OF SOME OF THE GROUPS, ACTIVITIES AND ONE TO ONES AND OTHER THERAPIES AT THE HAVEN?

QUESTION 3: HOW DO YOU FEEL THE HAVEN HELPS YOU PERSONALLY?

QUESTION 4: ARE YOU LEARNING NEW SKILLS WHICH ARE HELPING YOU TO UNDERSTAND YOURSELF BETTER?

QUESTION 5: COULD YOU SAY SOMETHING ABOUT THE KINDS OF COPING STRATEGIES YOU HAVE USED AND WHETHER THESE HAVE CHANGED?

QUESTION 6: SINCE COMING TO THE HAVEN DO YOU FEEL YOU SPEND LESS TIME DISLIKING YOURSELF?

QUESTION 7: IN WHAT WAYS, IF ANY, DO YOU FEEL YOU HAVE CHANGED AS A PERSON SINCE ATTENDING THE HAVEN?

QUESTION 8: IS RECOVERY FRIGHTENING?

QUESTION 8: CAN YOU SAY SOMETHING ABOUT HOPES, DREAMS AND GOALS FOR THE FUTURE, AND WHETHER YOUR VISION OF THIS HAS CHANGED SINCE COMING TO THE HAVEN?

QUESTIONS 10: WHAT ELSE DO YOU FEEL THE HAVEN COULD DO TO SUPPORT YOUR RECOVERY?

<u>Client Focus Group Questions</u>

QUESTION 1: DO YOU FEEL THE HAVEN HELPS YOU PERSONALLY? IF YES, HOW? IF NO, WHAT WOULD YOU LIKE THE HAVEN TO DO FOR YOU?

QUESTION 2: CAN YOU SAY SOMETHING ABOUT THE KINDS OF RESPONSES YOU HAVE RECEIVED FROM THE HAVEN WHEN YOU HAVE BEEN FEELING VULNERABLE OR IN CRISIS?

QUESTION 3: WHAT HAS BEEN YOUR EXPERIENCE OF SOME OF THE GROUPS, ACTIVITIES AND ONE TO ONES AND OTHER THERAPIES AT THE HAVEN THAT YOU HAVE PARTICIPATED IN?

QUESTION 4: COULD YOU SAY SOMETHING ABOUT THE HAVEN AS A COMMUNITY AND WHAT THIS MEANS TO YOU?

QUESTION 5: ARE YOU LEARNING ANY NEW SKILLS AT THE HAVEN? IF SO, WHAT DO YOU GAIN FROM THESE NEW SKILLS?

QUESTION 6: COULD YOU SAY SOMETHING ABOUT THE KINDS OF COPING STRATEGIES YOU HAVE USED BEFORE COMING TO THE HAVEN AND WHETHER THESE HAVE CHANGED?

QUESTION 7: SINCE COMING TO THE HAVEN DO YOU FEEL YOU SPEND LESS TIME DISLIKING YOURSELF?

QUESTION 8: IN WHAT WAYS, IF ANY, DO YOU FEEL YOU HAVE CHANGED AS A PERSON SINCE ATTENDING THE HAVEN?

QUESTION 9: HOW WOULD YOU DEFINE RECOVERY?

QUESTION 10: DO YOU THINK RECOVERY IS FRIGHTENING?

QUESTION 11: CAN YOU SAY SOMETHING ABOUT HOPES, DREAMS AND GOALS FOR THE FUTURE, AND WHETHER YOUR VISION OF THIS HAS CHANGED SINCE COMING TO THE HAVEN?

QUESTION 12: WHAT ELSE DO YOU FEEL THE HAVEN COULD DO TO SUPPORT YOU IN RECOVERY?

HAVE YOU GOT ANYTHING MORE TO ADD?

<u>Client Interview Questionnaire</u>

Introduction: *Interviewer to introduce themselves and ask the interviewee if they would like to receive a copy of the final results. Assure of confidentiality and explain that the interviewee is free to stop the interview at any point or decline to answer any particular questions. Check that the interviewee is happy to have the interview taped and ask permission to additionally take notes during the interview.*

Gender: Male ☐ Female ☐

Ethnic Origin: _____

Age: ☐

Age range:

18-20	☐	35-44	☐
21-24	☐	45-54	☐
25-34	☐	55-65	☐

Marital Status:

Single ☐

Married/Living as ☐

Divorced/Separated ☐

Widowed ☐

Other ☐

Living with: **Alone** ☐

                         Partner ☐

                         Partner + children ☐

                         Single parent ☐

                         Parent ☐

                         Others/shared ☐

Housing: **Own house/flat** ☐

                         Rented house/flat ☐

                         Supported accommodation ☐

                         Hospital ☐

Time at the Haven: **Years** ☐   **Months** ☐

Haven Services Used: **Day Services** ☐

                         Crisis Line ☐

                         Safe Centre ☐

                         Crisis/Respite Bed ☐

QUESTION 1: Do you feel The Haven helps you personally? If yes, how? If no, what would you like The Haven to do for you?

QUESTION 2: How does The Haven compare with other services you have used?

QUESTION 3: Can you say something about the kinds of responses you have received from The Haven when you have been feeling vulnerable and in crisis?

QUESTION 4: What has been your experience of some of the groups, activities and one-to-ones and other therapies at The Haven, that you have participated in?

QUESTION 5: Could you say something about The Haven as a community and what this means to you?

QUESTION 6: Do the clients at The Haven interact with and support each other? If yes, how does this work for you?

QUESTION 7: Are you learning any new skills at The Haven? If so, what do you gain from these new skills?

QUESTION 8: Could you say something about the kinds of coping strategies you have used before coming to The Haven and whether these have changed?

QUESTION 9: Since coming to The Haven do you feel you spend less time disliking yourself?

QUESTION 10: In what ways, if any. Do you feel you have changed as a person since attending The Haven?

QUESTION 11: How would you define recovery?

QUESTION 12: Do you think recovery is frightening?

QUESTION 13: Can you say something about hopes, dreams and goals for the future, and whether you vision of this has changed since coming to The Haven?

QUESTION 14: What else do you feel The Haven could do to support you in recovery?

QUESTION 15: Have you got anything more to add?

<u>Carer Focus Group Questions</u>

QUESTION 1: DO YOU THINK THE TERM "CARER" IS APPROPRIATE? IF NOT, DO YOU FEEL ANOTHER TERM WOULD BE BETTER?

QUESTION 2: DO YOU FEEL THE HAVEN HAS HELPED THE PERSON YOU SUPPORT? IF YES, HOW? IF NO, WHAT WOULD YOU LIKE THE HAVEN TO DO FOR THEM?

QUESTION 3: DO YOU FEEL THE HAVEN INVOLVES YOU IN THE CARE OFFERED TO THE PERSON YOU SUPPORT. IF YES, HOW? IF NO, WHAT WOULD YOU LIKE THE HAVEN TO DO TO IMPROVE THIS?

QUESTION 4: RESEARCH SHOWS THAT CARERS OFTEN EXPERIENCE DIFFICULTIES IN CARING. DO YOU THINK THIS STATEMENT IS CORRECT AND IN WHICH WAY DO YOU THINK THE ROLE AFFECTS CARERS?

QUESTION 5: ARE THERE WAYS IN WHICH YOU FEEL YOU COULD BE SUPPORTED BY THE HAVEN IN YOUR ROLE?

QUESTION 6: DO YOU FEEL THAT THE PERSON YOU SUPPORT HAS CHANGED SINCE ATTENDING THE HAVEN?

QUESTION 7: DO YOU HAVE HOPE ABOUT THE FUTURE IN RELATION TO THE PERSON YOU SUPPORT?

QUESTION 8: HOW WOULD YOU DEFINE RECOVERY?

QUESTION 9: HOW WOULD YOU KNOW THAT THE PERSON YOU ARE SUPPORTING IS MAKING PROGRESS IN THEIR RECOVERY?

QUESTION 10: WHAT ELSE DO YOU FEEL THE HAVEN COULD DO TO HELP YOU, AND THE PERSON YOU SUPPORT, IN THEIR RECOVERY?

QUESTION 11: HAVE YOU GOT ANYTHING MORE TO ADD?

FINDINGS FROM

CLIENT QUESTIONS

FINDINGS FROM CLIENT QUESTIONS

DO YOU FEEL THE HAVEN HELPS YOU PERSONALLY? IF YES, HOW? IF NO, WHAT WOULD YOU LIKE THE HAVEN TO DO FOR YOU?

Eight of the sixty clients gave no response to this question.

Fifty clients responded positively and gave a range of ways in which The Haven helps them personally, many stating more than one way.

14 = It is the 24/7 accessibility of The Haven and the fact that there is always someone there who will give me a quick response.

Abigail: Its all round 24 hour support is something that I've really found helpful knowing that there's someone there, it gives you a sort of safety net.

Jenny: I can come in at any time, or pick up the phone, there's always someone on the other side of the phone.

May: In the hour of need I think, "The Haven is there".

11 = It is the caring nature of The Haven that helps me.

Ben: I have been met with universal kindness and support.

Gemma: The calmness, softness of the staff they make you feel …… they make you a cup of tea or coffee and they listen, they listen. They let you talk, they let you speak, they let you cry and they hand you tissues. You know I never …… care and genuine care. Absolutely wonderful.

Phoenix: The Haven provides like a huge big hug.

Norris: It's the sort of place you can get a hug or give one.

Chloe: I don't do hugs, but I do now.

9 = It is acceptance and not being judged at The Haven that helps me.

Leska: Being accepted for what I am, with no questions asked. It addresses my own issues and doesn't compare me to everybody else.

Donald: I can be myself without being judged.

Boris: Nobody's going to condemn you, you see the cuts on anyone, they're not going to condemn you.

Katy: In the past two and a quarter years The Haven has supported me, has been non-judgemental and has always been there for me, night or day.

9 = The Haven is somewhere where I am able to express emotions and be honest.

Harry: At The Haven I have permission to show emotion.

Cosmic: It's the only place I've found where I'm taken seriously as somebody with emotional problems.

Luckie: I can be me and express my emotions.

Rose: I find it difficult to show emotion and at The Haven I have permission to show emotion.

8 = The Haven has helped my confidence and self-esteem.

Elise: It's been the backbone to make life changes that I've needed to make for a long time.

Alexis: It's reduced the obsessional behaviour and encouraged me to mix with others and it has really boosted my self-esteem.

Ross: It gives me support, boosts confidence and gives me something to focus on. The Haven, for me, it's like having an extra backbone.

Charles: Crisis staff will always try to boost your confidence in some way, they will pull out all the stops to make you try to realise that, you know, your life isn't over and it's not the end of the world.

7 = It is the sense of safety at The Haven that helps me.

Harry: The Haven is my safe place.

Igor: It's a safe place. It helps you to be safe.

Katy: Sometimes just what I need at night time is to come in and know I'm safe and it stops me from doing anything at the moment.

Roosle: I'm new to The Haven so I'm just learning what it can do right now. I'm using it as a safe place from myself, because I'm in a very dangerous and unsafe state, and it's a place where I can go where I know I won't come to any harm.

5 = The Haven keeps me stable and able to cope.

Rose: It helps me to cope with ups and downs and gets me stabilised when I'm really losing it.

Daniel: It keeps me on an even keel and calms me down.

5 = The Haven helps me to socialise.

Alexis: I'm getting out and doing things and meeting people and learning new things. Before it was just vegetating at home.

Karen: If I didn't have the Haven to come to I'd be locked in my house most of the time.

Natasha: It gives me a reason to get up to something in the mornings. It helps me to get used to people in a sort of gentle way, you know, sort of like socially.

4 = The Haven has enabled me to trust.

Christine: The Haven has taught me to trust again and respect other people. It's through this place I've learnt that I don't have to hide my problems; I don't have to hide behind a smile anymore. I can come in and I can cry and I can be me for once.

Boris: It helps me trust other people and also helps me trust myself more and help myself more.

Anne: I don't have to pretend to be somebody else in front of people who come here because everybody accepts each other, whichever way we come in, happy, sad. I trust everybody here.

3 = The Haven helps me because it is like a family.

Pablo: The Haven provides for me a replacement role of my parental home.

Poppy: I'm now learning to use The Haven to help myself and it's like an extended family that I haven't got really.

Ben: It feels that you are a replacement Mum and Dad that I never had.

3 = The Haven helps me by offering practical support.

Charles: They helped me when I first came, with getting DLA and helping me to secure a flat so that I could be independent.

Jasmine: I've got in a lot of debts and the staff here help me with the paperwork, for which I'm very grateful.

2 = The Haven helps because it has kept me out of hospital.

Chloe: I've found The Haven's helped me, I haven't been in (psychiatric hospital) since I've been registered with you, and I haven't been 136'd either.

May: If it wasn't for the Haven I know I would be self harming. I would also be in hospital now if it wasn't for coming here.

Two clients responded negatively.

Kim: Sometimes I don't feel like I'm being taken seriously. Sometimes it feels like it's my paranoia.

Stony: There's people who are ill vying for attention. I feel the one who shouts the loudest gets heard.

HOW DOES THE HAVEN COMPARE WITH OTHER SERVICES YOU HAVE USED?

This question was asked only to the twenty clients who were individually interviewed. All responded to the question and nineteen responded by making a favourable comparison, most stating more than one point.

10 = The Haven is friendly, caring, welcoming, human and non-judgemental.

Doris: It basically knocks them all into a cocked hat …… more friendly, relaxed, supportive, and they are quite happy for you to wander off.   Whereas, at (another service), you have to sit there for the duration, which is a shame because, at the end of the day, you just turn out being disruptive because you end up annoying other people who want to get on and you don't.

Rose: There's no comparison. The Haven's way and above any of the hospital services I've used and, I'm glad to say I don't have to use inpatient facilities anymore. It's much more personal, and it's complete which helps the whole of you.

Sheila: It's a lot friendlier. It's a lot more caring and it's also trusting. It trusts me a lot more than other services, and you don't get talked down to and treated as though you are some kind of idiot.

Elise: It has a considerate and empathic approach to a situation and it attempts to understand the individual. It has a holistic approach to people's wellbeing and recovery.

Fred: They treat you like a human being for one and they get to know you as a person and keep up to date with your everyday life really. They are always welcoming.

Carl: They've had to achieve 120%, which no-one on this planet can do, but they're brilliant. They don't judge you and there's no bad feelings.

Brunhilda: It's ten thousand times better than any service I've ever used. In statutory services one definitely felt judged by people. Also, one of the most important things is the humanness of the staff and other clients, there's a kind of warmth and compassion plus The Haven understands the condition of borderline personality disorder.

3 = The Haven is a 24/7 service

Leska: The Haven gives you support 24/7 and you're always reassured that they are there and that you will be able to talk to someone and they care. They address your problems before they get to bad crisis point.

Poppy: It's 24 hours, there's always somebody to contact, whereas with other services they may be open during the day. The groups are much better, and some of the groups focus on specific problems that you have, and it's the only place that's got respite beds.

3 = The Haven is a Community

Meg: It compares highly. In fact it's number one. The two main things that stand out is allowing you to become a member of a community, and most organisations I've been to have always tried to reach a discharge date, which sometimes puts a lot of pressure.

Jenny: The community here is so supportive, there's always somebody to talk to and something to do, so you're not sitting and dwelling on how you're feeling. Whereas at (hospital,) and other hospitals I've been to, you do.

3 = The Haven is recovery oriented

Pablo: The Haven is consistent, it's been progressive and forward thinking, which is not a stale thing, it's not just something you go back to, it's something you go forward with. Anyone who tries to hold you back, they'll either be back at the (hospital), or back in the situation they were before. If you hang on to The Haven you go forward.

3 = The Haven gives us a voice and choices

Ian: It's a lot better because I feel I have choices. I don't feel like I'm being forced to do things and I come here of my own choice.

Boris: The Haven is completely different to any other service I have ever used. In every other service you don't actually have an opinion or your voice isn't heard. At The Haven your voice is heard and your opinions taken into consideration, and everyone is treated individually here and you're not a number anymore here, you're your own person.

1 = The Haven keeps me out of hospital

Curtis: Before The Haven I tended to be in and out of hospital and that wasn't a very positive experience for any of the time that I was in and out. Hospital is not the ideal place even when I'm not particularly well. The Haven kept me out of hospital, so I have nothing but praise.

One client did not make a favourable comparison.

Stony: It's the staff that I have found more helpful than the clients, it's vying for attention again.

> *CAN YOU SAY SOMETHING ABOUT THE KINDS OF RESPONSES YOU HAVE RECEIVED FROM THE HAVEN WHEN YOU HAVE BEEN FEELING VULNERABLE OR IN CRISIS?*

Of the sixty clients who were asked this question, fifty-two responded and eight did not. Of the fifty-two clients who answered this question, fifty had positive responses and two did not. Among the fifty who responded positively, nine also made negative comments or suggestions for improvement.

The fifty clients who responded positively gave a range of ways in which The Haven responds to them when they have been feeling vulnerable and in crisis, many stating more than one way.

26 = The Haven has met my needs when I have been feeling vulnerable or in crisis.

Katy: They've done exactly what I've needed when I've needed it.

Rose: I've always found the telephone responses very good when I'm in a crisis, they can usually talk me down.

Abigail: I had someone talk me through hyperventilation over the telephone and then talk me back to breathing properly.

Boris: The staff have been really fantastic, whether I've been in day or at night, and all the team have supported me and been there and talked to me if I needed it, or just given me space.

Elise: They've been very responsive. I haven't been pampered when I've been feeling low and vulnerable, or smothered in that sense, but actually people have helped me sit and think things through rationally.

Jasmine: When in crisis the staff go out of their way to see you as soon as they can and I find that really helpful and they help calm you down.

Ross: Good practical advice that puts things into perspective.

Luckie: I was understood and what they said would happen did happen.

19 = The Haven has given me a fast response/is always there when I have been feeling vulnerable or in crisis.

Sheila: I've come into the crisis centre someone's always been there immediately. Nobody seems to fob you off onto somebody else.

Ian: There's always been someone to talk to and help me see things differently.

Meg: I've always had immediate response when I've contacted The Haven, every time I've been in crisis, or phoned or texted, I have had a first class response from all members of staff.

Sally: Everybody's been so supportive, there's always somebody there for you.

Abigail: Early intervention, and in my case I was lucky and I had a weekend bed that I wasn't expecting which was very beneficial.

Katy: They have always been there, day or night, and I can rely on them to support when I need it in crisis.

Tiffany: They do respond to your phone calls and texts quickly to make sure that you don't go down even further. They have always got a friendly smiley face or a nice smiley voice at the end of the phone.

10 = The Haven has responded by getting me into the safe centre or a bed when I have been feeling vulnerable or in crisis.

Jenny: I've been in places where I've been feeling very vulnerable, a very bad situation, in crisis, and The Haven will always help me get in here, whether it's by taxi.

Eustace: You can stay overnight for a while under this fantastic roof. I feel everyone around me hated me, until I came here. There's always a smile and a kind word.

Fred: They say come in straight away, they've even booked me a taxi, it doesn't matter how I am, how I'm feeling or what I'm behaving like they still say come in.

Alexis: I've found it very helpful just to come in for a couple of hours and to be amongst people.

Rose: I've always had a good response, I find the calls very helpful and I've even had an admission once in crisis, very quickly arranged.

8 = The Haven has responded in a caring and kind way when I have been feeling vulnerable or in crisis.

Doris: It's been excellent, a kind ear, a cuddle, cup of tea, respite when I need it.

Sally: When I have been really down I have been taken into a room and they have made me a cup of coffee and they wouldn't let me out of the door until I have got myself together.

Cosmic: I couldn't wish for more help, more care.

Phoenix: They always look pleased to see you coming through the door.

Fred: I've phoned when I've been in crisis and I've always been welcomed no matter what my mood or what's going through my head.

7 = The Haven has saved my life/saved me from a hospital admission when I have been feeling vulnerable or in crisis.

Masie: Four weeks ago I would have ended up in hospital under Section 3 but, because there was intervention, it helped.

Emily: In the past The Haven have sent ambulances which have saved my life.

Crystal: I've had support and kindness, especially all the telephone calls that are regular. If it hadn't been for that I probably wouldn't be here now.

Katy: If it wasn't for The Haven I would have been sectioned, they're there 24/7 and understand.

5 = The Haven has kept me safe or made me feel safe when I have been feeling vulnerable or in crisis.

Pablo: You're always acknowledged. Iit creates security.

Harry: The Haven's my safe space when I get really panicky and, instead of running off and ending in the middle of nowhere, I'm more likely to come here now which actually helps my family a lot because they are not so stressed because they know I am somewhere safe.

Leska: When I've been feeling vulnerable I've always had someone come to talk to me, been reassured that I am safe, and that there are people here to support me and I'm not alone.

4 = The Haven has provided consistency when I have been feeling vulnerable or in crisis.

Calvin: There's been concrete, solid support and consistency.

Cosmic: The services here must be fantastic because I haven't been in crisis for ages and ages. It's all about continuity.

May: I think that the way things are handed-over, when you are in crisis you don't have to tell your story all over again from the beginning, because the people you speak to on the phone, or in a one to one, know enough about your symptoms and situation and that makes it much easier.

Eleven of the fifty clients also highlighted some occasions when they were not responded to adequately or made suggestions for improvement, and some answered in more than one way.

4 = The Haven did not respond quickly enough or missed calls when I have been feeling vulnerable or in crisis.

Christine: Well the only negative experience I've ever had which was a support call that was overlooked, and I was in crisis at the time, but you know, everyone makes mistakes.

Chloe: Down at the old building it seemed to me that the telephone was more important than me because I'd be sitting with somebody in a one to one and the minute the phone went they'd be off answering it. I can't compare it because I haven't been here in the new building yet.

Jonny: If there was somebody designated for the phone, you know that the person is designated and they will have to answer it, then you can respond better.

Abigail: I think the staff sometimes cut themselves into lots of little pieces. I actually phoned in the early morning and my brain was telling me to do one thing and I thought I'll phone up and speak to somebody and, unfortunately, the staff were probably busy with somebody else and it was too late when they did ring me, the situation had happened.

2 = I find it hard to pick up the phone and ask for help when I am feeling vulnerable or in crisis.

Sally: Sometimes you can see that staff are all busy, but you're too scared though, and you go home feeling worse, but it's too late. Then it's hard to pick up the phone.

Rose: Sometimes it is hard to pick up the phone so it is better that someone is phoning you.

2 = The Haven has not been caring when I have been feeling vulnerable or in crisis.

Harry: I've only had one negative experience, my first response when I got at the door was, "What time are you going home?"

Leska: Sometimes being let through the front door and nobody actually coming to speak to you for about an hour.

2 = The Haven did not meet my needs when I was feeling vulnerable or in crisis.

Boris: Most of the time positive, there are occasions when I talk to staff and I feel they don't actually hear what the problem is.

Gemma: I phoned during the night; I was really desperate and wanted to speak to (staff member). I was told she was busy on the other phone. She didn't offer anything else and I said I'll phone back later and she said okay and put the phone down. She didn't ask how I was. No support, nothing, she just fobbed me off.

1 = The Haven has not been consistent when I have been feeling vulnerable or in crisis.

Ben: I've felt a little bit lost because I've been speaking to new members of staff who don't know me and that's made me feel more vulnerable.

Two clients answered only negatively.

Kim: I feel I am not always taken seriously.

Norris: I texted in at 2.30pm in the afternoon and got a reply at 5.30pm in the evening.

> **WHAT HAS BEEN YOUR EXPERIENCE OF SOME OF THE GROUPS, ACTIVITIES AND ONE TO ONES AND OTHER THERAPIES AT THE HAVEN THAT YOU HAVE PARTICIPATED IN?**

Of the sixty clients who were asked this question, fifty-two answered and eight did not. All fifty-two responded positively but seven of these also commented negatively, or with comments or suggestions. Their comments are included within each category of activity. Most clients cited a number of activities at The Haven.

One to ones

18 = Responded positively about one-to-one work

Doris: They make you feel that, for half and hour, you are the sole focus of their attention. You're not just a number and you've got these issues and they are going to sit there and listen to you. Even if it goes over, they are not clock-watching. There's no "I'm going to get my lunch now". You are important.

Curtis: The one to ones I have, like focussed one to ones, I find really useful and also like sort of grounding yourself.

Abigail: They are quite inspirational and they make you come away and think. You might not always agree with what's been said at the time, but I have time to reflect and I think that's one of the benefits of having one to ones.

Boris: I like my one to ones because I have a chance to be me, I can let my barriers down, I can say how I am really feeling, I can vent myself when I am angry, and I can talk through every emotion that I am feeling and the troubles I am struggling with at the time.

Lara: I am really grateful for the one to ones so I can let it all out, and the staff that help me I can't give them enough credit because they really do help put you at ease.

Crystal: I find the one to ones very useful, although it can bring up the past and it's extremely painful, but is helping in the long-term.

Charles: I've been using the one to ones, it's a way forward for me if I'm feeling angry I vent my anger.

Brunhilda: I've felt the focussed one to ones very helpful because you can get to grips with something, a particular something, and there's continuity,

Poppy: The one to ones are extremely important.

Groups

18 = Responded

15 = Responded positively about the group programme in general

Brunhilda: There's such a nice wide variety of groups and activities and it feels as if there is something for everyone.

Natasha: It's just that there's something to do all the time. They encourage you to do things but there's no pressure.

Chloe: The comparison that springs to mind is with the groups that are run here, with the groups run in typical institutions and hospital settings that is, and it's just worlds apart and you don't feel like you're in a group. Well personally I don't feel I'm in a group just to pass the time, there's loads more to it than that. It's about social interaction, it's about learning, it's about all sorts of things, and you feel, you know, you do feel good afterwards.

Pablo: They have been educational and fun.

Rose: I'm talking more, getting more involved with groups and I've found this is helping me feel more part of the community.

Boris: What I like is when there isn't a member of staff available to run the group we are asked if we would like to do it.

Cosmic: The groups are excellent, the way you can just turn up for a group, I find that very supportive. I know that's in my diary, I like the group, and I turn up.

Phoenix: This is the first time in life I've felt safe in a group.

Katy: I think a lot of effort has gone into the groups and I think they are very beneficial to everybody.

3   = Responded negatively or with comments or suggestions about groups

Curtis: Groups stress me out.

Rose: I find groups overwhelming.

Christine: I find it very difficult to start in joining groups that have already been established for a while, so I might need some encouragement or a size 9 behind me to help me join in.

DBT (Dialectical Behaviour Therapy Skills Group)

13 = Responded

10 = Responded positively

Pablo: I'm learning to tolerate people, I'm not so judgemental of people. I know that's a DBT skill.

Harry: DBT has been teaching us mindfulness exercises, which I have got to say have helped me enormously, because I used to suffer from really bad road rage and generally I can control it now.

Lara: I attend DBT because I can see how much enjoyment people get out of it. I think it's helped me tremendously. I used to go off the handle at anything, now I stop to think of a different way of coping with it and a different way of speaking to people, and it's much more effective than just lashing out.

Natasha: I find DBT's been very helpful especially with negative thoughts and coping skills, mindfulness.

Charles: Mindfulness, to my knowledge, is about being mindful of others and say, for instance, someone is throwing a temper tantrum and acting aggressively, you have to think to yourself there's a reason. How would I feel if I was doing that, because I have thrown temper tantrums here. What I'm trying to say is the next time I throw a temper tantrum I should really and truly be thinking about how I am affecting other people.

Brunhilda: DBT I have found very interesting and helpful. It's a particularly difficult module at the moment that we are doing, called distress tolerance, and I think it's quite good that I've noticed that one or two members of staff know a little bit about it as well and that's helpful because I can discuss it in a one to one. But for other clients it could be quite helpful as well because I'm sure more people would be in DBT if it were possible, so some staff knowing about it passes on the benefits.

3 = Responded negatively or with comments or suggestions

Stony: I found that didn't help me because I looked too much in my past.

Doris: I started DBT, I didn't click with the group. There were some members of the group that seemed to consider it their group and they bullied and took over the place, so I wasn't prepared for it. I wasn't going to have that, and when I feel like doing DBT again it won't be when they are in the group.

Harry: It's the lack of reminders because when you do DBT anywhere else you have a one to one session during the week to help to remind you of your skills and you are supposed to be practicing and obviously here we haven't got that.

Reflexology

13 = Responded positively

Emily: I hate being touched and I actually let a member of staff do my feet.

Lucy: Reflexology I have also had and that's helped me to chill out, and unwind, it was nice.

Karen: Reflexology is brilliant, I never felt so calm.

Rose: Reflexology is good, I nearly fell asleep three times.

Cosmic: Reflexology, that was great, that was good, she's a brilliant listener too.

Carl: I've had reflexology and that's very good, it calms you down, makes you feel good, sometimes it helps with answers which has been related to the problem, to yourself, to your body, and then it can be washed away, or that's what I found.

Friendship Groups

12 = Responded

11 = Responded positively

Chloe: I think the Friendship Groups are the best groups. I think people tend to interact, peer support. I haven't laughed as much in years at the last Friendship Group I came to here. It was just hilarious.

Doris: Friendship Group I love, especially now it's more structured, like we're doing bingo and having a bit more of a laugh.

Sally: I find Friendship Group has helped, because if I'm down they always cheer you up.

Wilf: Friendship Groups, even sitting about talking, you can see by some people that they have been as low as you have, we've all been down, right to that bottom, hell really isn't it, and that I think helps you to talk to people, open up, because they've been through the same sort of pain.

May: riendship Groups make me feel part of a family.

1 = Responded negatively or with comments or suggestions

Stony: I found Friendship Group not that helpful because, while I was there people were talking about their illnesses and competing over their illnesses, and I didn't find that very helpful at all.

Transitional Recovery Group

11 = Responded

10 = Responded positively

Doris: I love Transitional Recovery, I absolutely love it. I think it's the group I get the absolute most out of, and I know that quite a lot of people here feel the same. It's a very empowering group, it's a group that gives you a chance to move on, it helps give you the tools to move on.

Stony: That's why I've started coming back, because there's methods for helping people who do want to move on.

Boris: It helps build confidence and helps you build new friendships and support one another, and it's really productive and really positive. Last week was really good hearing people's goals and looking at what stopped us achieving them.

Bling: It was a great opportunity for us to go on that outward pursuits, outward bounds for the day.

Fred: Transitional Recovery, I'm finding that really helpful, it's helping me find college courses and helping the route I actually wanted to go down, whereas I couldn't really pin the route I wanted to be on. Now I know how to get to that route, finding those bridges to cross. So I'm on the right path now which makes so much difference in my life. I know it's achievable now.

1 = Responded negatively or with comments or suggestions

Brunhilda: I personally haven't been much to it, and I think that's because I'd quite like there to be some connection to one to ones because I actually don't feel very comfortable to be in that group. I think it might be something to do with being older and perhaps, I've done courses, you know careers, that kind of thing doesn't seem quite appropriate for me, so I don't know. I'm just quite confused about it.

Creative Writing Group

11 = Responded Positively

Gemma: The Writers Group, writing things down, I use that as a coping strategy.

Jonny: Writing Group, there is a lot of honesty. It's been like that more or less from the beginning. But I've been surprised by what I've written.

Anne: I am finding Creative Writing extremely helpful, it's helping me to get a lot of my emotions out on to paper and being able to share them with other people as well has always been hard for me, but I've started to read out my work.

Doris: Writing Group gets things out of my head.

Natasha: Creative Writing, a good skill to have. I may write a book one day!

Donald: It has definitely given me a chance to say what I feel, and write down my feelings, which has been really, really helpful, and just listening to what other people have written, as well, it can be really insightful.

Arts and Crafts Group

9 = Responded positively

Harry: The Art Group, it gives you time away from your problems, it helps you to focus on something else rather than what's causing you distress.

Phoenix: Arts and Crafts is brilliant.

Daniel: I'm not good at art but I attend. You can wander in and out it you like.

Norris: We've done things like clay model making. I have gone home and got some clay. Me and my daughter have been doing that. That's like a distraction.

Life Skills Group

8 = Responded

7 = Responded positively

Alexis: I feel I've really benefited from the Life Skills Group, it's reduced my obsessional behaviour and encouraged me to mix with others and has really boosted my self esteem. It's been very beneficial dealing with anxiety, positive thinking, how to control panic attacks, confidence building and particularly in dealing with anger.

Cosmic: The Life Skills is brilliant because it's so varied, and I've learned a lot and it's good to be re-running the course as well, because if there's anything that I've missed, or wasn't paying attention.

Sally: Some of its hard this week but brilliant.

Brunhilda: I think Life Skills is pretty good to do it the second time around, it makes more sense, so I like that rolling programme.

1 = Responded negatively or with comments or suggestions

Ben: I find the Life Skills Group very threatening so much so, I haven't been able to sit through a whole one yet.

Gardening Group

8 = Responded positively

Sheila: Gardening Group is just good physical exercise which I appreciate, and you can have a laugh with other people while you are doing it, and obviously making things look nice.

Abigail: The work that has been done by everybody that goes, and personally I was shown photos of people that I have never seen smile before, which to me is what it's all about.

Crystal: I love gardening. I think it is beautiful to see things grow.

Daniel: Do people feel proud of the gardening group, well the ones that are doing it, yea!

<u>Pampering</u>

8 = Responded positively

Kim: *I love the face packs, or my hands being done, I feel like a queen.*

Rose: *Pampering, you feel so much better you do, you feel like a real person.*

Chloe: *The only time I'm really touched is when I come here, because I live by myself and don't have a partner. The pampering is a clear example of somebody actually touching you and that makes you feel that you are valuable as a person by being actually touched. Touch is really important.*

Harry: *I found pampering particularly good because I don't pamper myself and it's nice to feel you're worth something through having that done. I'm starting to learn that I'm not just what I do, I am a person as well and that I have needs.*

<u>Counselling</u>

7 = Responded

6 = Responded positively

Rose: *The counselling I'm receiving, I have been for quite a while, is just fantastic. I've had ten years of psychotherapy; I've still managed to avoid the issues. With the counselling I think it's the fact that it's here. It makes me feel safer which makes me take more risks than I ever have.*

Sally: *I find counselling very good and very helpful. It's helped me to talk freely and be able to trust other people.*

May: *I also have counselling once a week and I feel very safe talking to her, and she says it's my time, it's my space. I talk about what I want, and I'm not pushed to talk about anything I don't want to but I'm encouraged to talk about other things I find difficult.*

1 = Responded negatively or with comments or suggestions

Curtis: *I did have a few weeks of counselling, but it was at a time when things were very bad, and it was too much.*

<u>Other Activities</u>

7 = Responded positively

Elise: *I like helping with Open Days and the neighbours.*

Brunhilda: *I'm a member of The Haven Hat Society!*

Emily: I was quite apprehensive about joining. I wondered what kind of stories and how in-depth we had to go, but it turned out to be very light and very entertaining (Personality+ storytelling session).

Daniel: I've noticed it with the dog that even people that are in stressful situations, when the dog walks in it will spot that and it will come over to them. We want more of the Pat Dog.

Health and Fitness Group

6 = Responded positively

Fred: Health and Fitness I like as well, it's got me going swimming and generally eating better because I feel better about myself.

Ross: Health and Fitness, this helps my inner body, eases pain and helps me control my breathing, also gives me a chance to get out and about be it walking or swimming.

Brunhilda: I always feel better after doing it.

Other Complementary Therapies (head massage, hand reflexology)

6 = Responded positively

Tom: Head massage helps the pain in my head it does.

Crystal: I'm not a very touchy person because I haven't been brought up like that but I found what I had yesterday was really calming and I felt good afterwards.

Substance Misuse Support Group

3 = Responded positively

Emily: Substance misuse group is brilliant and everyone was so honest last week at what stage of their, where they were at, I found it very humbling and overwhelming the honesty in that group.

Nutrition Group

2 = Responded positively

Daniel: It's really beneficial, she's really clued up.

Chaplaincy Group

2 = Responded positively

Jonny: It's great when we've got the blokes there. It gives a more even balance.

Drumming Group

2 = Responded positively

Brunhilda: It's great because you can't think about anything else at all, when you're drumming, it's impossible.

COULD YOU SAY SOMETHING ABOUT THE HAVEN AS A COMMUNITY AND WHAT THIS MEANS TO YOU?

Of the sixty clients in the sample, fifteen were not asked this question as it was not included in the earlier Service Evaluation Groups. Of the forty-five respondents who were asked this question, five did not respond. Of the forty who did respond, thirty-eight responded positively, many stating in more than one way.

14 = The Haven Community helps me to feel accepted, valued and not judged.

Katy: I think it's very important it's a community. I think being non-judgemental against each other is very important, and I think it's very important that it's become a very close community.

Rose: I have a valid point of view. It's very important to me, the fact that it's a community made up of so many different people. There can by underlying things going on, but that's because it's a community. It's no different to the outside world.

Cosmic: The atmosphere and the feeling of the community is just getting better and better and it's reached a peak for me, there's no more cliquiness and it's really straightened itself out now.

Sally: We're very respectful of one another, the staff as well. We talk to each other as an equal.

Bling: The community aspect is really good, no-one picks on anyone, it's not a place where people pick on each other, there's no piss taking, there's no nasty bullying which you get elsewhere.

Elise: It's nice to have a cosy little environment where everybody gets on with everybody, but that isn't a true reflection of how it is in the real world and it's actually accepting differences and understanding that that's how things are.

Leska: You know you are not going to be judged, people are going to accept you for who you are, what mood you are in.

Tiffany: No-one is putting a label on each other like they do everywhere else.

Emily: I find when you walk into the room, the thing I like about all of them is, everybody has got the same illness, same problems, and this is where The Haven comes into its own, and walking into the room, people talk to you, they don't judge you, nothing like that, so I feel good.

11 = The Haven Community can provide mutual support.

Meg: Client interaction is vital. We are all prepared to assist each other.

Anne: It's what The Haven is all about; it's being there for each other through good times and bad.

Katy: The support we give each other is absolutely fantastic.

Pablo: There's great interaction between the clients at The Haven and the support is good.

Poppy: I get good support from the other clients.

9 = The Haven Community can provide friendship and togetherness.

Doris: It's all about human contact. I think a lot of people here realise what it's like to be lonely, we all know what it's like so we all make an extra effort to be friendly, to be nice, to make a cup of tea. Ah bless, I love the community at The Haven. I love all the friends I've made. I love all the people I wouldn't normally have spoken to.

Sally: I'd be lost without The Haven, everyone seems so friendly, all the clients seem so friendly, and make you feel welcome.

Gemma: There's always people around and you can hear them laughing, precious company.

Christine: Having somewhere like this to come takes away part of the loneliness and I've made a lot of good friends.

Donald: A Sunday roast because it was my birthday on Sunday made me feel really good and happy. It was one of the best birthdays I ever had.

7 = The Haven Community is about working together.

Boris: It's a whole big box of people together that are all striving for the same thing and the community is what you make it, and what you give to it, and how much people are willing to put into it.

Jonny: It's a learning curve for all of us, working as a team, staff and clients.

Jenny: I think The Haven works because it is a community, we all work together, and any problems that do arise we all get together and decide what's going to happen.

Fred: Everyone pulls together; I feel part of it now.

Brunhilda: It's such a great representation of what you would call a community, and I personally have looked for a community for several years and this is really what I think community ought to be because it's staff and clients all together have created this place.

5 = The Haven Community is a very different way of running things.

Rose: I haven't seen any NHS mental health people run things like this.

Jenny: I don't think I've ever been any place where there's been people around me that have got mental health problems and there's been such a good strength of community.

Ross: The community meetings are good. It's a chance for the clients to advise on what is required as a community. Having a say is a big step forward in our recovery.

Wilf: It's brilliant that we run it, and we decide what happens. I mean it's not, it's never nice to ban people and things like that, but at certain times we have to be stricter. I think it's important that we do run it and we decide everything really don't we.

5 = The Haven Community helps me to understand and feel understood.

Emily: I isolate and can't mix with people, but I can see people in The Haven, you are the same as me.

Meg: It's the community and having people here who understand you.

Phoenix: Being around other people, when you've been socially secluded for so long, in itself teaches you new skills, to re-learn and re-define.

4 = The Haven Community is a way I can help others.

Sheila: I enjoy cooking for people, cakes and things.

Lara: I just love helping people. I feel that when I'm helping someone it makes me feel better.

4 = The Haven Community is like a family.

Boris: It's like one big family together. You support one another through your needs.

Leska: The Haven community, it means a lot to me, it's like having a family all under one roof.

May: It's the family I never had.

Seven clients responded negatively. Of those seven, five had also responded positively, above, and two responded only negatively.

4 = The Haven Community makes me feel threatened or that I can't fit in.

Sheila: I would like to be able to join in the community more, but I'm not very good at interacting with other people I suppose.

Kim: Sometimes I do feel alone at the groups, I feel there's a lot of cliquiness and bullying going on. Maybe it's a clash of personality and I feel it should be looked at.

Phoenix: I struggle with this idea of community. Sometimes I feel very, very threatened, and sometimes I feel very safe, sometimes I feel comforted, but there are times I feel threatened and vulnerable.

3 = The Haven Community can be about illness rather than recovery.

Ian: Sometimes it's unhelpful if people were telling me things that they have done that are not good.

Stony: The Haven as a community isn't that good really, to be honest, because people are, like I said over again, focusing on the actual illness rather than trying to move forward with everything, and everybody's competing on how ill they are rather than trying to be better.

Cosmic: I think alcoholism isn't named for what it is. I think there's too many people that are not using self management skills and becoming independent. I don't see The Haven as a place to land, it's a place to touch down and spring from.

ARE YOU LEARNING ANY NEW SKILLS AT THE HAVEN? IF SO, WHAT DO YOU GAIN FROM THESE NEW SKILLS?

Of the sixty clients who were asked this question, twelve did not respond. The remaining forty-eight gave positive responses, many highlighting more than one skill.

11 = I am learning therapeutic skills at The Haven.

Harry: I was very fortunate to have DBT here, and we've done mindfulness and I've found that extremely useful, and I try to do it every day now, at least once a day.

Cosmic: Life Skills is brilliant, so varied, I've learned a lot.

Lara: I'm learning an awful lot in DBT, mindfulness, thinking before you speak, trying to change your actions and the way you think.

Karen: Life Skills Group is excellent. I've learned a lot from Life Skills.

Donald: I'm doing CBT and I find that very helpful. I feel I've come a long way since I came here three months ago and I'm pretty proud.

Poppy: I feel by going to Life Skills and Transitional Recovery Groups it's given me the confidence to go to college.

9 = I am learning academic skills at The Haven.

Doris: My maths is pretty much diabolical and, through the Transitional Recovery Group, I've found that it's not perhaps as diabolical.

Christine: From the Bridges to Education workshop I've learned the new skills of having to go back to college, hopefully in September.

Jenny: Transitional Group again, is getting me back into retraining my brain again, getting me like practising English papers and maths papers.

Fred: I'm learning some maths, because I'm useless at maths, and I need it to go on in college.

9 = I am learning to change my negative coping strategies at The Haven.

Masie: I've stopped cutting, I haven't done anything for eight months now.

Elise: I think my new skills have fundamentally been to be able to stop and question the reality of the situation and the most logical conclusions, and the most logical assumptions, and to think the whole situation through, rather than jump into the first panic stricken thought that comes into my head and act on it. It's the actual stopping and analysing the situation for what it really is, not what emotionally it's built itself up to be. That's the best skills I've learned.

Ben: I'm learning I don't have to be ill to be loved.

Rose: I used to cut but can have sharp knives in the kitchen now. My negative coping strategies, like opening a bottle of wine, are changing to picking up the telephone and leaving the wine in the fridge.

Katy: I have learned different strategies especially how to control my substance misuse.

Jasmine: I used to self-harm a lot and with help of staff in one to ones I've now started to recognise when I'm heading down that path and be able to phone before I actually do something.

Fred: I'm also clean and have stayed clean. That time they booked me the taxi I could have gone back to using without even knowing it was wrong, which I have done in the past, whilst I've been psychotic still. Kind of like instead of popping a pill, I come here.

9 = I have learned to communicate better and trust more at The Haven.

Rose: I've learned a lot of new skills from the Haven. I've learned to talk more openly to share how I'm actually feeling, rather than covering it up. I've learned to trust which enables me to talk which is a major breakthrough.

Boris: I've learned to share my feelings more instead of keeping them inside. Before, I was always frightened to express how I felt, if I got locked up, in case I was rejected again.

Anne: I've learned to trust more and it's helped me to be more open.

Luckie: I'm more truthful about myself and who I am. I'm not pretending to be something I'm not.

Ross: I think the new skills I'm learning at The Haven at the moment are interaction and communication.

7 = I have learned skills that are of practical use outside The Haven.

Sheila: I am learning to talk a bit more and that helps me outside. Just mundane things like going to the bank, I can actually speak to people behind the counter without just standing there and grunting at them.

Stony: A bit more independence, a student has taken me out on the bus to help me get used to buses.

Leska: One of the biggest new skills I'm learning is how to be a Mum, and I suppose another big skill I'm learning is to try and stand on my own two feet and try to deal with stuff, instead of asking The Haven for so much support, how to be patient, how to interact with someone who can't talk, and to love someone who's so dependent on you, learning to love you could say.

Tiffany: When I'm in a crowd I used to have to walk out, now I find I can stay in a crowd a little bit longer. It's a skill for me to actually get on a bus and a train. Without the tools that The Haven has given us, then I don't think I would have been able to have done it.

7 = I have learned to be able to socialise better at The Haven

Doris: I think one of the paramount skills I've learned since my time at The Haven was how to make a decent cup of tea! I've learned listening, I've learned how to make friends, and it's helped me to realise that I'm not such a pile of shit anymore.

Fred: I'm learning not to isolate so much and to, you know, be around people.

Carl: I'm learning to re-socialise; have fun with other people; joining in and laughs, and general well-being.

6 = I have learned to ask for help when I need it at The Haven

Rose: I am learning to actually ask for help before I act on things.

Sally: I just used to sit in my flat and suffer in silence, but now I'm picking up the phone.

Katy: I can call in from home and I've also been able to ask for help which is really new.

Jasmine: I find since I've been coming here I've been able to sort of open up what I bottle up inside, and that it is okay sometimes to ask for help when you need it.

6 = My self awareness has increased since coming to The Haven

Kim: I feel more aware of my insecurities.

Harry: I've been learning where a lot of my difficulties have stemmed from which is, hopefully, in the long term, helping me to overcome them.

Charles: I've learned a lot about myself, that I've got problems in certain areas, sort of anger and stuff like that, and you know, alcoholism.

5 = I am learning tolerance and acceptance at The Haven

Pablo: I have more tolerance, I'm less judgemental and more patient.

Abigail: I'm learning to be more tolerant of others because I always expected others to be as I expect myself to be and I am a very harsh person, so I am learning to be more tolerant.

Jonny: You're not chastised for slipping back if you do slip back. I think everybody who comes here learns to be more tolerant.

5 = I am learning how to be more confident at The Haven

Anne: I'm learning to be more confident in what I do, I'm getting a lot more confident also in learning to talk to other clients here, and I can be relaxed enough to be myself.

Fred: I gain confidence and self-esteem.

Cosmic: I've had the confidence to start voluntary work because you had the confidence in me to show me the advert, see, for the job, so there.

Boris: I suppose the dominant skill I'm learning at The Haven is being more confident that I can achieve more than I think I can.

3 = I am learning hope at The Haven

Wilf: Seeing the people who have moved on to college and stuff, you can set yourself a little goal then, can't you. They've done it, so you know, maybe there's a chance.

Milly: I think that Transitional Recovery Group gives you a lot of hope.

2 = I am improving/regaining old skills at The Haven

Ian: I'm learning to use skills, I know, better.

Cosmic: Brushing up on old ones, self-management skills.

One client also responded negatively.

Ben: No I'm not. All my one-to-ones are spent with me bubbling and them offering me tissues, but no way I've been taught techniques to help myself.

> *COULD YOU SAY SOMETHING ABOUT THE KINDS OF COPING STRATEGIES YOU HAVE USED BEFORE COMING TO THE HAVEN AND WHETHER THESE HAVE CHANGED?*

Of the sixty clients who were asked this question, nine did not respond. The remaining fifty-one gave answers ranging from a dramatic reduction in the use of negative coping strategies, a reduction, to no change or setbacks.

23 = Since coming to The Haven there has been a dramatic reduction in my use of negative coping strategies.

Pablo: My sobriety is unbelievable, my conscience is clear, I wake up clear. I mean the two things in my life that I do now that keep me together is that I eat well and I sleep well.

Anne: Before The Haven existed I was self-harming on a very regular basis, cutting and overdosing, but since coming here it's stopped, they both have.

Doris: They've changed dramatically. I used to be cutting, drinking too much and speeding off in my car and I think I've cut once in the past year.

Rose: I haven't cut for more than two years now, my overdosing has gone down significantly, and my drinking is getting to be more normal.

Sally: I haven't self-harmed for six months now. I normally phone The Haven up. Before I used to run away if I'd got problems, but now I don't I face up to the problems I've got.

Chloe: My coping strategies are completely different now. I have not self harmed this year. I channel my feelings and emotions more constructively. I do a lot of sport now.

Elise: Before I came to The Haven I used to overdose on a reasonably regular basis, I used to cut myself when anything went wrong. Basically, it was a whole host of maladaptive coping mechanisms and since coming to The Haven I have sort of redressed these. A lot of the reason has been because of the ruling about coming in when you have cut, or coming in when you have drunk alcohol. So you have to respect the values of the place. I now don't cut. To me to cut would be such a backward step I don't even want to go there.

Christine: I used two forms of negative strategies before I came here and it's now over seven months since I've done either.

Leska: Before I came to The Haven nearly every other day I was tying things around my neck, overdosing, cutting myself and since coming to The Haven I don't tie anything round my neck, I've had maybe one overdose and I've learned to talk and, when things get really bad, to phone and ask for support instead of acting on impulsive thoughts.

Alexis: I haven't touched alcohol for almost two years. I haven't self-harmed for almost nineteen/twenty months with the help of The Haven's crisis line.

Tiffany: My coping strategies was drinking, taking drugs, overdosing and harming myself, and now I don't do any of those things since coming to The Haven. The staff, they make you feel really guilty about trying to do something like that! The next day you might wake up and think, oh my god, I am so glad I didn't do anything.

Fred: Taking drugs, before in the past, that was all I knew from the age of thirteen, what I'd learned in order to survive, basically, on the streets. I've come beyond that and my coping strategies are to talk I guess, and phone for help.

Donald: I used to overdose probably once or twice a week and, in the last four or five months, that's stopped completely since I've come here. I never used to think about the consequences, I never used to think about who I was going to hurt, I never used to think there was other ways of dealing with things, and that you could actually talk to someone about things, instead of just doing it, so it's changed my life no end coming here.

13 = Since coming to The Haven there has been a reduction in my use of negative coping strategies.

Boris: They have decreased. Here I have broken the cycle of the pattern of behaviour into more constructive ways of dealing with it. Self harming, or picking up a bottle of wine, I tend more now to put pen to paper and let it out that way.

Abigail: I didn't used to eat properly, but I eat three times a day now. I used to drink as well and one of the reasons why I don't drink in the evenings If I'm feeling really

bad is just in case I need to come in here. It makes me think, "no you can't go in there if …"

Calvin: I can call in here now rather than pick up a drink.

Jenny: I used to self-harm a lot before I came here. Instead of doing that I've managed to pick up the phone. I used to like drink quite a lot as well, and knowing that if I do I can't come in here and speak to somebody, and I'd rather speak to somebody rather than pick up a drink.

10 = Since coming to The Haven there is beginning to be a reduction in my use of negative coping strategies.

Kim: Cutting has lightened up a bit because I have used the phone.

Ruth: I smoked a lot of cannabis but managed to give up two weeks ago.

Phoenix: I've used all sorts of negative, self-harming behaviour and it's probably too early for me. But I think the one thing I have noticed is that I'm more inclined to pick up the phone before I start drinking now.

5 = Since coming to The Haven I have not reduced my use of negative coping strategies.

Ben: I've hung on to my coping strategies which are distinctly negative because I feel that if I give them up them I'm lost. I've got nothing to replace them with, so I'm not willing to give them up yet.

Natasha: I've started using cannabis again in the evenings, but I haven't been coming here long, well that's a bit of a confession isn't it!

Harry: At the moment my self-harm has got a lot worse. But I'm going through a very difficult period at the moment and the thing I have to realise is that, although I'm getting less judgemental of other people, I'm getting more judgemental with myself. So I'm actually, at the moment, more likely to self-harm but I'm less likely to get myself into a fight with someone else.

SINCE COMING TO THE HAVEN DO YOU SPEND LESS TIME DISLIKING YOURSELF?

Of the sixty clients who were asked this question, twelve did not respond. The remaining forty-eight answered "yes", expressed tentative improvements, or answered "no". Answers have also been categorised in relation to how long respondents have been clients at The Haven.

17 = Who have been at The Haven for two to three years answered "yes".

Pablo: Yea I have started liking myself more, definitely, and I would squarely put some of that help in the Haven's ball court.

Boris: I think it's more about being comfortable with who I am. I'm content with who I am at this moment in time.

Anne: Yes I do. I used to really hate myself. I feel a lot better with the help from staff and clients. They have really helped me to start to see myself for who I am.

Leska: I know something has changed because I don't feel like a thing anymore. I have more time to try and like myself.

Elise: I now find things to like about myself, and I go out and treat myself to nice clothes because they will make me look nice, and get my nails done.

Bling: Absolutely, definitely, yes!

Fred: I think how far I have come. When I think of that, I think no, I have done really well, and I know now, it's not an excuse, things that happened to me while I was in care and on the street, it wasn't my fault.

Harry: I think I used to dislike myself a lot. I don't actually dislike myself now, although I dislike my behaviour at times, which is a massive difference and I'm actually able to go out and buy new clothes. So being able to spend money on myself has come from being at The Haven and being made to feel worthwhile.

Carl: I feel human again and not an outcast.

Brunhilda: At The Haven you get so much positive feedback and just logically, if quite a lot of people think that you are a decent human being, logically you must be. Eventually, yes, you get re-programmed, it definitely does filter through.

5 = Who have been at The Haven for one to two years answered "yes".

Tiffany: The staff make you feel special in your own way. I am beginning to believe in myself a little bit more than I have ever done in my life.

Natasha: I think I do like myself a bit more than I did.

3 = Who have been at the Haven for less than one year answered "yes".

Chloe: There are things about myself that I do like. There are qualities and parts of my character that I think are as valuable and specific to me. So I value myself, so yes I do spend less time disliking myself.

Milly: Yes I'm feeling more able to look at communicating with people differently, and getting better results, so I suppose it's improved my self-esteem.

4 = Who have been at The Haven for two to three years expressed tentative improvements.

Jonny: There's less time to think about it, but it's very deep rooted, the very core.

Katy: I still have a problem, I feel very worthless, but when I'm on the premises I like myself, coming helps me to like myself.

Rose: I spend less time disliking myself, I get out more, don't feel quite so useless.

2 = Who have been at The Haven for one to two years expressed tentative improvements.

Lara: I like myself here but I don't like myself at home. I still can't look in the mirror.

5 = Who have been at the Haven for less than one year expressed tentative improvements.

Ian: I dislike less, I think so.

Christine: I don't dislike myself less just spend less time thinking about it.

Karen: Not all of the time, but hopefully as time goes by I will start liking myself.

4 = Who have been at The Haven for two to three years answered "no".

Sally: I still dislike myself. I don't know if it will ever change, it's always as far as I can remember for such a long time ago, that's just how I feel about myself.

Jasmine: No I still hate myself but my feelings here have changed, I'm not 136'd so often now, the police station used to be my second home.

2 = Who have been at The Haven for one to two years answered "no".

Charles: I'd like to think I like myself more, loud and brash, but behind closed doors I'm pretty depressed.

6 = Who have been at The Haven for less than one year answered "no".

Kim: I hate myself, my self-esteem is so low.

Masie: I feel I spend more time disliking myself because I see hordes of people out there, in here, that are able to cope with life and I don't feel worthy.

Ruth: I still hate myself.

Crystal: No I haven't learned to like myself, there's a long way to go.

> **IN WHAT WAYS, IF ANY, DO YOU FEEL YOU HAVE CHANGED AS A PERSON SINCE ATTENDING THE HAVEN?**

Of the sixty clients who were asked this question, eleven did not respond. Of the remaining forty-nine, forty six answered positively and many responded in a variety of ways, some highlighting more than one change.

22 = Since The Haven I have changed as a person by becoming more confident.

Ian: More confident and more able to talk to people, slightly more outgoing I suppose, and I laugh a lot more than I did.

Rose: I now speak up for myself. I have a lot more confidence in the community.

Boris: I am stronger in my beliefs and I fight for what I think is correct.

Harry: My confidence has risen enormously. A year and a half ago I was never leaving the house. I like the fact that when I do the Personality Disorder Awareness Training all the professionals there, they're actually looking up to me, and that's a big thing because I've always had very low self-esteem.

Cosmic: I think I've gone down from PD platinum to PD bronze! The idea is to work your way down isn't it? I've found that, since being in a group situation, it means it jars your confidence to leave this room and go and join other groups.

Elise: Fundamentally, it's given me the confidence to go and be my own person and to leave the relationship that was holding me back as a person, and that's been because I know I've got the support here that I can now go and stand on my own two feet. I've got a lot more self respect, my self-esteem's definitely improved, but it's basically self-respect.

Jasmine: I never used to like going on public transport or getting in a car because of panic attacks, but since I've been here I've been able to get on trains and on the bus, and getting on the taxi run.

Jenny: My confidence as well has gone up a lot. It's not that I'm a diagnosis. I understand a lot more about it and I've got support from here, so I know my rights, and I know what to say really.

Tiffany: Staff and clients build you up and make you feel very confident about yourself.

Daniel: Since I've been coming here I've actually gone to several conferences and had enough courage to speak as one of the guests.

16 = Since attending The Haven I have changed as a person by learning things about myself.

Doris: I've learned a lot about myself. I rediscovered the fact that I am good, I am not as bad as I think I am.

Chloe: I actually feel that my behaviour has changed. It's become, in nursing jargon, more appropriate, it's less extreme the majority of the time.

Harry: I am a lot more insightful into my condition. I pick up on things earlier so I can sort of try to change, avert a crisis before it happens.

Max: I'd like to think I'm not quite as impulsive as I was.

Connar: Trying to help other people to distract from your own personal issues and problems and facing up to your own demons, by distracting from my personal issues what I was doing was making them worse, so that's what I've learnt from that.

Katy: I've changed in lots of different ways and I've learned that the voices I hear are actually in my head.

Poppy: I don't get stroppy anymore and walk out in a huff. Although the depression has been really awful and painful at times, I think I've learned more about it and I realise, by talking to a lot of other people, not just at The Haven, that there's a lot of depression around, and I think it's made me more caring and sincere towards other people's problems.

Daniel: I don't boss people about, I'm not as aggressive. I used to be a big bully.

12 = Since attending The Haven I have changed as a person by becoming more sociable and better at communicating.

Ross: I'm far less arrogant and pretentious and self-centred and I try to think of others.

Cosmic: I feel more secure. I used to feel like a freak. Why am I so different from the neighbours? But this is a whole club full of them and I keep in mind that I'm not alone.

Carl: I can now have a conversation and make a conversation.

Diana: I'm re-engaging with clients and staff, talking a lot more. I used to sit there and say nothing, but now I'm talking.

Daniel: I've come out of my shell.

10 = Since attending The Haven I have changed as a person by becoming more open and trusting.

Boris: I'm more honest, I'm more open, I'm more trusting since coming to The Haven, and I've managed to drop my barriers more, a lot more than I ever used to since coming here. I've been able to let more people in.

Norris: When I first came here I couldn't let anyone near me, or in my space, without being completely drunk, this was outside here, and now I can. Most of the time people can hug me and be close to me without, you know, that would have never happened before I started coming here, without me being under the influence.

Poppy: I've opened up quite a lot. I used to hide my feelings because I was told that it was a bad thing to show feelings, it was a sign of weakness.

Brunhilda: I'm more able to demonstrate affection without feeling too vulnerable.

9 = Since attending The Haven I have changed as a person because I am beginning to find myself.

Doris: There was a period when I lost myself, I lost the person that I am when I became ill, and I feel I've regained some of that but, in regaining some of it, I've picked out the bits that I liked.

Rose: The change is due to actually learning who I am, I've been something else before now.

Abigail: I've spent decades hiding behind drugs and a career and I've had to face up to the actual reality of what is me and learn who is me. So, changing as a person, I am changing.

Leska: I've started to find my identity and I've started to live life again.

Tiffany: I'm finding I'm getting back some of my old personality, the bubbly, loud me.

Donald: People have helped me to reach inside myself and get back to the cheeky little monkey.

7 = Since attending The Haven I have changed as a person because I feel I am getting better.

Lucy: I'm feeling better in myself.

Jenny: I think I changed, I can't even really remember when I first came here, I was that unwell. When I first came I was really unwell, lost in my own thoughts really, and I think I obviously have changed a lot, I don't know how.

Tiffany: I'm not as attention seeking and my moods are not as low.

Carl: I'm content with life.

Brunhilda: I'm more down to earth. I used to be off in another galaxy.

4 = Since attending The Haven I have changed as a person because I have more hope for the future.

Rose: I look to the future more than I ever did. It exists now.

Jonny: I think, well I know, I've survived it. The other thing is, I think The Haven gives hope to everybody, that there's something better in the future. So you're not written off.

3 = Since attending The Haven I have changed as a person because I am able to feel safe.

Igor: Coming here makes you feel safe enough to change.

Crystal: I feel safe and relaxed here.

3 = Since attending The Haven I have changed because I have regained my sense of fun.

Doris: I am less serious. I have rediscovered my sense of humour and I have rediscovered my ability to make other people laugh.

Brunhilda: I feel I have become light hearted again.

3 = Since attending The Haven I have changed as a person because I am learning to live my life.

Leska: I am learning to live again, not just exist

Chloe: I would like to say that I am certified sane! I don't have a mental health diagnosis at all. I have actually discovered life. It's not even a rediscovery. It's a discovery. Looking at how I am living now, I haven't lived up to now, I have just been surviving. Now I am discovering what it is like to be too busy to ring someone back whereas before I had too much time to think what to do with. I now live a full, active and healthy life and I am thoroughly enjoying it.

2 = Since attending The Haven I have changed as a person because I now want to live.

Stony: When I first attended The Haven I didn't like myself, I was wanting to commit suicide. I never though anybody would like me or love me in any way. Now I don't even, I don't want to die.

May: Before The Haven I wanted to die. Now I want to live.

Three clients answered only negatively.

Ben: I feel more vulnerable now. I feel like I've got exposed wounds. But everyone here is universally kind so I'm hoping eventually they'll heal.

Phoenix: It's loud and aggressive, that's when for myself I can find it intimidating and more than offensive.

Charles: I don't think I've changed as a person but I feel that I have to take responsibility to be a civilised individual here, for the sake of others obviously, and the sake of myself, and obviously my membership for the future.

> *HOW WOULD YOU DEFINE RECOVERY? DO YOU THINK RECOVERY IS FRIGHTENING?*

Of the sixty clients who were asked this question, ten did not respond. The remaining Fifty clients who answered this question responded to the concept of recovery in a variety of ways, some defining it in more than one way.

15 = Recovery is an individual journey taken step by step.

Doris: I think the journey to recovery is like a road up, a country road that's full of speed bumps and windy corners, and you travel along it any you think, yea you're getting somewhere, then you go over a bump and you get set back a bit, but you have to keep going and eventually you'll get to the end of the road and you'll find another road that goes somewhere that might be less bumpy.

Boris: Recovery for me is just taking it step by step and just seeing where I get to in the end. There's no finishing line for me.

Jonny: I think recovery is part of the journey and it's like change in anybody's life, it's scary unless you continue with the journey. That's probably the most positive thing that The Haven has given us, the chance to continue our journey and to progress, and that's the most important thing, the journey.

Cosmic: I see recovery as not really a game of snakes and ladders, it's just where you are at each day, and it's still a step forward.

Elise: It's an ongoing process, you never actually get there. You are always recovering. For me recovery has been able to actually function on my own, with minimal support, because of the things I've learnt. So, for me, recovery represents now. I'm well into recovery because I've actually developed enough internalised strategy in my brain to cope with things when they go wrong without resorting to emotional crisis. So therefore I would say I am in recovery. But, to be honest, I think everybody's in recovery from the minute they enter the door way of The Haven, unless they desperately don't want to help themselves, because recovery is a journey and it starts with admitting that you've got the problem to be there in the first place.

Jenny: It's probably the hardest thing I think I have done in my life, and I'm not even there yet. I don't even know if I'm half way there. I don't even know what 'there' is like. I believe it's a journey, but I don't know if the journey ever ends.

Brunhilda: I think recovery means something different for each person and also I don't think recovery is finite.

15 = Recovery is frightening because of fear of failure.

Sally: I'm thinking do I want another job or don't I want another job, am I capable of wanting another job, would I be able to do it, would I have the confidence, or how long would it be before it goes wrong?

Boris: I think recovery is frightening because for so long in my life I had so many people telling me I was never going to come to anything, spend my whole life in hospital. I am petrified that I am going to fail and I am going to prove everyone right. I sit there and I work on my journey to change things with the whole doubt in my head going, what happens if I don't achieve this, what happens if it goes wrong, what happens if I still go backwards?

Masie: Something will happen that sets me about ten steps back and I'm right back at the bottom of the pile again. So therefore I'm frightened to continue on my road to recovery because each time I get a certain way something just knocks me back down again.

Chloe: Success can be frightening. What if I fail?

Harry: It's not the process of recovery that's frightening for me, I'm quite revelling in it actually, it's the thought that I can't guarantee I won't slip back at a future date, that's the thing that's frightening.

Tiffany: I'm frightened of getting well then not being able to work. Like coming off benefits, that's what frightens me most.

Fred: The world I was in before was so black. I was petrified of becoming well and failing every time. Before I wanted to be dead rather than fail again because I just couldn't handle anymore failure.

14 = Recovery is frightening because it's about change and the unknown.

Meg: I think basically it's going into the unknown. I do get frightened, but when I see the staff we talk about it, it's shared, and it's reduced in some way.

Elise: I think there's an awful lot of people at The Haven that have lived in a world of inner torment for so long, and have lived a psychiatric based life for so long that to move away from that, even though they don't particularly like the life they have at the moment, but to move away from that and take on something new, with a whole new perspective and everything, it's always going to be scary. It's like moving to another country or a new flat. The change is what's so scary because it's so unpredictable.

Crystal: With recovery you've got to change, and change through life there's always changes, but if you are the type of person who doesn't know how to change, or has never been taught to change, then it's very hard and you are stuck in that time warp and you have got to find a way of trying to move on.

Alexis: Extremely frightening! We're used to living with what is most familiar to us, it's our routine and it's what goes on day to day, month in, month out.

Ross: It's only natural to fear change, it's the not knowing what's going to happen. That's what we are in fear of.

Eustace: Maybe the process towards it is frightening. Where does it lead you to?

13 = Recovery is frightening because I've always been this way.

Ben: Very frightening! Personality disorder is all I've got. If you take that away I've got nothing left.

Sheila: Yes, because it's all I've ever known, is this personality disorder, all this mental illness, ever since I was very young.

Kim: Fucking scary, cos I've never known recovery. I've been in and out the system since 16.

Gemma: I think when you've spent half your life, it's a real struggle. I've found that, since the age of fourteen when I started self-harming, over the years I have picked myself up, and now I have gone down again without realising it. In the end you can be so sick and tired of the struggle. You know the will to do it is so hard, it's just so hard. I don't have the energy the strength or the will. Literally last week I tried to end it. I woke up three days later. If I'd had the support, like there is nowadays, with phone lines you can ring, with better understanding of mental health, if that was the case when I was fourteen. I was in hospital when I was sixteen. If I was sixteen now I

would not have gone backwards and forwards into hospital all my life. It would have made my life completely different if I'd had the understanding and not just be called attention seeking because it wasn't, it wasn't.

Igor: Of course it is, psychosis is a nice safe little place.

Leska: It's frightening for me, for the fact that I've spent the last eleven years in hospital, and the thought of people trying to rush me into recovery when I've had it done so many times before, where people have tried to make me recover, where it hasn't been done at my speed.

9 = Recovery can be frightening but desirable.

Ian: At the beginning I think it is because it means you have to take a lot more responsibility and sometimes it's scary that people aren't around so much, and you have to deal with things a lot more on your own, but afterwards it makes you proud.

Stony: Yes, but it's good. It is a bit frightening, a bit daunting, but you know, you see so many normal people around and you just want that. I feel like that, people who can go to work and do things for themselves and manage alone.

Curtis: I used to think it was frightening, because it's such a big step, but now I find I'm looking for it, I'm wanting it.

Rose: Yes I think it's frightening, but I also think it's exciting now.

Bling: I think it should be welcomed with open arms.

9 = Recovery is about achieving things in the outside world.

Stony: Getting on with life, having a career or a job that you like, and liking yourself.

Doris: I think it's more of a renaissance because I think I've been given a chance now to take stock, and go back to college and do all the things I meant to do before I got ill. I feel I've been given time to reinvent what I really want to do.

Katy: My recovery would be having my family back with me, going back into education, having positive steps forward and regaining my employment status.

Natasha: A more normal life, perhaps even working.

8 = Recovery makes me wonder who I am.

Sally: Sometimes you don't know, it takes time to find out who you are and to start to try to change who your are, that takes quite a while.

Abigail: I find recovery is knowing yourself and it's very frightening because you're suddenly finding something that you have never known before and accepting them for who and what they are. I think the frightening thing is that you haven't got that person that's at the end of the line.

Boris: That still petrifies me to this day because what happens if I do recover to the extent where I'm happy and I do like myself and are people that know me going to like me? Am I going to be the same person, am I going to be the person people know now and probably like, because I don't want to be any different. I know I am only the person I am due to where I've come from. I'd like to think that once I had recovered that I was always the same person but there's always that fear inside me that I might not be that person.

Milly: It's frightening for me because I don't know whether, by recovering, I'm going to lose my relationship, because I don't know whether my partner can accept me if I change.

8 = Recovery is about having more realistic goals.

Pablo: I asked somebody about recovery some three years ago and she said I'm 99% well and I asked, don't you ever expect to be 100% and she said no. I always thought 100% was going to be my goal and subsequently since then I've realised it's a long process and I don't think 100% is achievable on my old stats. On my new stats I think 100% is more than achievable.

Doris: I think it's bloody hard work. It doesn't just happen, you don't just wake up one morning and think hey, I'm going to be better today. I'm not going to fall down, I'm not, and you have to take it upon yourself and keep doing what you were doing the day before.

Chloe: Everyone has the potential in them to succeed, but it's about taking it each step at a time. It's about setting achievable goals.

Katy: I've got more realistic goals. I've got more realistic about my own boundaries and in my own confidence and if feels, as the weeks go by, I feel safer and safer.

7 = Recovery is about having hope and a concept of a future.

Donald: I'm twenty-six and I've had twenty-four years of rubbish and it's hard to see a path of recovery but, since I've been coming here, I can see a light somewhere, not sure entirely where it is but I do feel that I could make the next twenty-six years of my life a bit different.

Emily: I define my recovery, I've got hope now.

Rose: I'm looking to the future, which I would never have done, and I'm hopeful.

6 = Recovery is about having a good quality of life.

Ian: Learning to deal with things in a positive way so you can have a good quality of life.

Chloe: I'm talking about success as in how happy and content you are as a person; success in life rather than qualifications and a good job. It's very individual for each of us. It's about breaking out of your own mould that you've made or other people have made for you. It's about breaking out of that mould.

Brunhilda: Is personality disorder an illness or a disability? Because, if it's an illness, there's a possibility of a cure but, if it's a disability then the way to approach it, just as it is of a physical disability, is that it's possible to learn to live a fruitful life.

6 = Recovery is about regaining control and independence.

Sheila: Being able to stand on my own two feet, without calling for help every five minutes.

Ross: To regain control. We spend too much time looking for a cure when there is none. We can only learn to live alongside our illnesses by re-thinking the way we think, to retrain the way we go about our daily lives and to learn to use our past experiences to guide us to where we want to be in life rather than carrying on the way we do.

Natasha: Freedom to do what you want without being stopped by disability, getting on with your life in a productive way.

6 = Recovery is having less negative symptoms and more feeling of emotions.

Fred: Stopping drugs, feeling the emotion and learning from it.

Rose: Recovery for me is being able to feel the real emotions I have run away from for so long.

Meg: No more nightmares.

5 = Recovery is about social interaction and being socially included.

Brunhilda: That I am actually part of society at large.

Poppy: Socialising, not just with people from The Haven. Being able to get on buses, go to the supermarket.

Anne: To find the real me inside and to fit in.

2 = Recovery is something you have to want.

Doris: All the help in the world is great but you have got to want to get to where you want to be. It's nothing you can be shown. You have just got to get your own fight back.

Charles: Wanting to do it is the main issue. There's nothing wrong with slipping back, it's trying to learn from it.

2 = Recovery is about balance and stability.

Cosmic: I'd say that in life everything is striving for equilibrium, to find balance, not being too left or too right, ups or downs. That's how I'd define recovery, to find balance that you once had or to regain what you've never had.

Anne: Stability!

2 = Recovery is about growing up.

Lara: Recovery can also be a way of growing up, or finding a new way to grow up again and be at one with yourself and accept yourself as you are.

Bling: I was having an adult conversation, as a normal thirty-three year old would. All of a sudden something in my brain said, no that's not alright you effing cow, who do you think you are to judge me, well I'll see you in the effing hospital then when I've taken another overdose, bitch. When I got angry it was how the thirteen year old child, how the teenager would deal with things, instead of what I'd call a normal adult, and it would be something like, well I hope you die in a car crash on your way home, until about three or four years ago, until I got the help that I wanted.

2 = Recovery is about regaining control but still having a safety net.

Leska: I personally think recovery is still being able to ask for support and say you are struggling but also know that you are getting better and that you don't need the services as much as you did when you were ill.

Cosmic: Well, if I saw a tortoise on its back I think recovery would be putting him the right way up, because that's something he can't do for himself. There's no way a tortoise wanted to get on its back and it was there for circumstances beyond its own control. So, if you help him by putting him back on his feet, and he goes plodding along at his own pace, then who is to say those circumstances won't arise again. So I don't think we can actually confidently say, now I've recovered, you see, but as long as the Tortoise Rescue Centre is still there we'll be alright.

2 = Recovery is not possible for me.

Abigail: Yes it's frightening, I can't change and I don't want to change.

Phoenix: I hope that I recover enough to define recovery because I really do not know what it is and where it is or if it's possible anymore. If I was able to do something like cure world poverty I don't think that would ever be enough. I know a good line from a song which goes, 'dying is easy it's living that scares me to death', and I think that maybe says it for me.

> *CAN YOU SAY SOMETHING ABOUT HOPES, DREAMS AND GOALS FOR THE FUTURE, AND WHETHER YOUR VISION OF THIS HAS CHANGED SINCE COMING TO THE HAVEN?*

Of the sixty clients who were asked this question, forty-six responded, many answering in a variety of ways.

12 = My hopes, dreams and goals are about education.

Rose: My goal is to go to university to get my MA and then take it further.

Boris: I want to go to college and do English and Maths with confidence.

Ben: Since coming to The Haven I've had an idea implanted in my head to go back to university and I'm at the stage now where I'm getting the curriculum and believing I might be able to do it.

Alexis: I hope to do Mathematics.

Poppy: My goal is to get through college and do my degree.

Katy: My goal is to go back and do my MA. That's my long term goal.

12 = My hopes, dreams and goals are getting through the day.

Stony: I want to get on a bus and breathe at night without panic.

Kim: I want the thoughts of 30 years ago to go away. I should have been in care, I blame my family and my school.

Sally: To be happy, lead a normal life, and come off all meds. I can only cope with one day at a time.

Cosmic: My goal for many years was just getting through the day. I wouldn't know where to start.

Christine: The dream for me is taking one day at a time. Dreams are about finding our destiny and our purpose in life.

Lucy: Trying to feel next week like I've felt this week.

11 = My hopes, dreams and goals have changed and I see the future now.

Ian = It has changed. Well, I'm not sure that it's changed, I've always wanted to do something, but now I feel I can actually do it. I have more belief in myself.

Rose: My vision has changed. I didn't even think about the future before I came here. It was as much as I could do to survive today. I hated the thought of tomorrow. I never wanted it to come. I feel I am learning a lot and I would like to put that to some use.

Emily: Do you know what, I never dreamed I could have hopes and dreams and goals for the future until sitting with this lot.

Leska: I actually thought that I have got a future now, it was really bleak before, but it actually looks like there is something now. Now, when I am just unconsciously sitting there, I do find myself wondering and thinking about the future. I don't feel on my own.

Tiffany: I can only say that since I've come to The Haven that I've actually got hopes, goals and dreams, because I've never had them before.

Donald: I never had any before I came here.

8 = My hopes, dreams and goals are about work and having a career.

Boris: I would love to train to be a social worker. I want to work with children. I'd rather help children younger, try and steer some kids at a younger age to go out there and chose the life they can.

Elise: For a long time my little aim was to come back and work at The Haven. I do think it would be a very noble thing if we did have people who were former clients coming back to work but, as I've gradually got better, I've discovered there's a whole world of possibilities and employment prospects out there and it doesn't have to all centre around this sort of several walls The Haven is, and I think for me the significant breakthrough is realising there's other things in life that would be just as enjoyable as coming back to work for The Haven. I'd actually like to go and get a decent job and earn a reasonable amount of money so I can have a nice life style to go with it.

Natasha: I've got high expectations for my future. They are big aims, probably not that easy, but I've got the commitment and I'm quite stubborn, so I hope The Haven can help me get where I want to be.

Jenny: I now want to do my Access Course and I want to work in care.

7 = My hopes, dreams and goals are now more realistic.

Charles: I wasn't being realistic. Rome wasn't built in a day.

Abigail: My hopes and dreams have been totally shattered because of me. I'm learning to accept how things are and I've taken my expectations down, and since I've taken my expectations down everything's gone up.

Calvin: To feel fulfilled, filled up. Not 2.5 children and a garage and a beautiful home. I want to find a way to make a personal goal. Now I don't feel alone. I feel we are in a boat and it's a safe boat.

Katy: Since The Haven my hopes and dreams are becoming a lot more realistic.

5 = My hopes, dreams and goals are about family.

Stony: I want to find someone to love me, someone to share my life with, and have a family and things like that, and be in a family.

Pablo: Hope my son nourishes well, and grows up as a balanced kid and I don't, you know, cause him any problems.

Poppy: My dream is to find a nice bloke, get married, have kids and a dog.

4 = My hopes dreams and goals are about changing the system.

Jonny: What I want is for all the projects, not just The Haven, to be successful, because the more working together you get the better service you are going to get as a result. I want to educate mental health services.

Harry: I've always been a campaigner for mental health and I want to try and make a difference nationally. My hopes and dreams, they're not dreams anymore because I'm doing it with the Personality Disorder Awareness Programme.

4 = My hopes, dreams and goals are about voluntary work.

Abigail: To continue with two voluntary jobs.

Alexis: I've recently started helping with the special needs groups at the church.

4 = My hopes, dreams and goals include travel.

Masie: My goal is, I'm going to Spain for ten days.

Anne: I haven't been on holiday for probably twelve years, so that was one of my hopes and dreams, to go back abroad. The way I am going on holiday is with somebody I met here.

4 = I have no hopes, dreams and goals.

Igor: I've got no dreams apart from nightmares.

Crystal: I've got no hopes dreams and goals. I feel empty inside.

3 = My hopes, dreams and goals were just to stay alive.

Chloe: When I first started coming, when it first opened, my hopes and goals were just to stay alive at that point. Now I want to continue to be happy.

Jenny: Before I came to The Haven I was locked up in a secure unit and my only hopes and goals were to end it all. I've changed everything really, my hopes, dreams and goals, and the whole vision. Before I came to The Haven I used to wake up every day wanting to die, finding a way, thinking of a way that I could harm myself while I was in hospital, trying to trick people into thinking I was okay, trying to sneak things in. That was my life, trying to find a way to actually harm myself, to actually end it all, and now I'm actually going to college!

3 = Hopes, dreams and goals are a risk.

Cosmic: At fifty-one to say that I've recovered is putting a hell of a lot at risk. I'll have to be forced out of this safety net, not that I'm lazy. It's the Government want to get people back to work, and that's what this is, isn't it. I'm getting DLA, rent paid, but I've got a dread of going back to what it was like before. I would overwork, do all the hours under the sun, then come down with depression and alcoholism. I might self-harm then two weeks later get back on my feet and be able to do agency work, work myself to death again. To become a more ethical person, yea, to be able to live in the here and now, to be able to forgive, to be a better Dad, but a career, because of my age, I think I'm over the hill on that one.

Milly: I have a goal but I'm scared I'm not going to fulfil it and will feel a failure.

3 = My hopes, dreams and goals are to work at The Haven.

Harry: My goal is to actually work here on bank staff.

Rose: I'd like to study and work within the service.

2 = My hopes, dreams and goals are to show them.

*Chloe:*I guess my goal was just to prove to mental health services that everything is treatable but it's not always in hospital. I think of all those nursing staff, when I was in high secure hospital, I'm now in employment. I'm in my own flat. They would never even envision that happening. And I think I've shown it to them, you know.

Boris: I have one goal I know I'll achieve and that's to turn around and say to all the fucking twats that have fucked up my life and say, fuck you, I've won, you've lost. If I can't achieve anything else in my life that's what I want to achieve and will achieve.

2 = My hopes, dreams and goals are to live in the now.

Brunhilda: I think for most of my life I've had no direction and I've ended up doing all sorts of weird and wonderful stuff. There's a kind of certain way of looking at life which says hopes are illusions, it takes you out of the present and the whole point is to live in the present. My vision of the future has changed since coming to The Haven because, when I first came, I thought I had absolutely no future except endurance. So I feel more positive about the future but I don't really have many goals or dreams. I'm much more able to live in the present and to enjoy the present as well sometimes. I quite often enjoy the present.

1 = My hopes, dreams and goals are that The Haven continues to be here.

Pablo: I hope The Haven remains there to handhold me on my bad days, not many. I know it's a lot to ask, but that's the truth of it.

1 = My hopes, dreams and goals are to find me.

Anne: My dream has always been to find the real me inside and I think The Haven is starting to help me to find the real true me. One of my hopes and dreams was to fit in, into this world, and being at The Haven I think I've finally started to fit in.

1 = I think it is important to have hopes, dreams and goals.

Bling: It's good to have goals, it's important to have goals.

WHAT ELSE DO YOU FEEL THE HAVEN COULD DO TO SUPPORT YOU IN RECOVERY?

Forty-eight clients were asked this question and thirty-eight responded, some giving more than one answer.

10 = Providing outreach support would help my recovery.

Elise: One of the ways that recovery can be supported is if people are actually helping you live lives in the actual community, outside the four walls that are The Haven, maybe helping people have new flat starts and that kind of thing. If people actually get to the point where they have recovered to the extent that they want to go back to work then maybe there can be some support package drawn up.

Leska: I have had a baby and I am feeling quite isolated and it's so hard to kind of still stay positive when you haven't got the support that helps you along with that and keeps you afloat.

Natasha: Self-esteem and confidence, it's quite a major issue, I am getting some one-to-one support in going to college, someone's going to college with me. Going to college is quite a big deal.

Fred: I need a little bit of help with moving.

Poppy: I do feel I need outreach work for when I'm at home.

8 = The Haven is already doing all it can to support me in recovery.

Sheila: I think they are doing all they can.

Curtis: I don't think they can do any more than they are now.

Meg: I genuinely feel that sufficient is being done by the staff, community and the people here.

Sally: They are doing as much as they can at the moment, you can't ask for no more.

6 = The Haven staying as it is would support my recovery.

Pablo: It's in place really, it's well thought out. I hope it doesn't get institutionalised.

Phoenix: I think quality, not necessarily quantity, is important in that you do so much here and so much that is amazing, and it would be awful if that were to be diluted and sort of try and stretch too far.

Bling: What they are doing is absolutely brilliant and they don't need to change.

5 = Tackling stigma and educating the outside world would support my recovery.

Christine: We need to educate.

Calvin: I think to let some of the naïve world, the outside world, sort of like people from the A & E Department, they need to be addressed, they need to come along and make an effort to see what goes on, and the police who do 136's.

Jenny: I just want to do something. I just want to stop this whole stigma around it and I think getting it out into the media, because they are the ones who are portraying it so badly, that we are all going out and killing people. I just think this thing, like Personality+, is going to be really good. I think if we can actually get out there and keep on doing these conferences and everything so people are aware that we are not all mad.

5 = The Haven can support my recovery just by being there.

Ian: It's just knowing it's there.

Eustace: Just be here.

Charles: Keeping me in a safe place within myself and continuing to do so, and just keep coming and using the place.

4 = The Haven would support my recovery by having more outings.

Anne: More days out in the summer.

Ross: Send us all on a holiday.

3 = The Haven would support my recovery by having a mini bus.

Igor: Get a mini bus.

Wilf: We'll have to get a mini bus.

2 = The Haven can support my recovery by sticking to policies and boundaries.

Doris: Basic things like sticking to policies would be useful, so everyone knows where they are at, not just useful for my personal recovery. We all do things that are socially unacceptable but it is really better to make them a little less acceptable, like they are in the big wide world.

Boris: I suppose the biggest issue for me would have to be the boundaries of The Haven, and the policies need to be kept because to aid someone's recovery you need boundaries and that's what so many people lack.

2 = The Haven would support my recovery by giving me more knowledge.

Crystal: I'd like to learn a lot more knowledge about The Haven and what goes on here, information and knowledge.

Brunhilda: I like the idea of, I think it's called transitional recovery, or something like that, and I'd like to know more about it.

2 = The Haven would support my recovery by giving me prompts when needed.

Doris: A kick up the arse when needed.

Poppy: A kick up the backside.

1 = The Haven would support my recovery by concentrating on those making progress.

Cosmic: The staff could be more accessible and stop spending all their time on attention seekers and people that just go home, get wrecked and come back, and are on that cycle.

1 = The Haven can support me by providing more help to get people to recovery.

Stony: I think they are doing enough for people who want to be in recovery, maybe they should do more in supporting people to get to that stage.

1 = The Haven would support my recovery by providing support for Carers.

Harry: The other thing is I'd like to see something for carers. Carers get forgotten. Our carers need support as well.

1 = The Haven would support my recovery by helping me get voluntary work.

Tiffany: The Haven should help us get voluntary work.

1 = The Haven would support my recovery by having the Pat Dog every day.

Wilf: Meg every day.

1 = The Haven would support my recovery by having faith in me.

Ross: Have faith in me. Instil faith.

1 = The Haven would support my recovery by linking clinical work with recovery and goals.

Brunhilda: I think at some point in the focussed one-to-ones I could be helped to look at questions 10 and 11.

HAVE YOU GOT ANYTHING MORE TO ADD?

Twenty-four clients had something more to add and three has more than one thing to add.

7 = I would like to say thank you to The Haven.

Jenny: Thank The Haven for helping me get this far, which I never thought I'd be able to do. To tell the truth I didn't even want to come here at first. I'm so glad I decided to try and actually get some help.

Anne: I'd just like to thank The Haven for teaching me not to run away from everything all the time, but actually stay and face what the problems are.

Fred: Can I give an apology here. When I was ill I was shouting my head off and swearing at the staff because I thought they were demons. I didn't do that meaning to hurt or be nasty to anyone. I really didn't know what I was doing or saying. So, whoever was on that day, thanks, you know, for not sending me away.

Leska: Since I've come to The Haven I have never met such a wonderful bunch of people, and staff especially, and the kindness and everything that you can imagine really, that a lot of people haven't had, it's just out of this world and, if it's okay, I would just like to add a great big thank you, and I hope this is the way it will always stay.

4 = I would like to say that The Haven is a wonderful service.

Curtis: I love The Haven, I think it's a wonderful place, a wonderful project, and long may it continue.

Daniel: I'd like to say to all staff members at The Haven that they are doing a brilliant job.

3 = The Haven is unlike any other service I have known.

Cosmic: This is the most effective system of care I've ever seen.

Sheila: After a lifetime of using mental institutions The Haven's the only place that accepts you as you are and doesn't try to dictate to you. They are not critical and are just accepting.

2 = The Haven needs to keep track of community members that aren't around.

Daniel: Sometimes a client gets sectioned and you don't know about it, no one knows do they.

Harry: I think if someone's not been in it would be rather nice if a staff member could keep a note of the fact, just making a quick call to make sure that person is okay.

2 = The Haven involves us in research and policies.

Harry: Can I just say that it's really important, the fact that The Haven has included us in the research, and I feel very privileged to have been able to be in that group.

Brunhilda: I think it's great the way clients take such a part in research and setting parameters and policies.

1 = There are some things I would change about how The Haven is run.

Pablo: I'm disappointed with the way staff are selected. I wouldn't choose some of the staff we have here at initial interview. I'd choose them after I'd seen what they are. It does bother me that other people would like to give up smoking and can't. They're not being given the opportunity to stop because they are being pressured into coming for a fag. I'd like results from some groups sometimes, like the gardening group, it would be nice for their plans to be published on the wall for a week or two before, so everyone can go, cor that's a good idea, or, what about that. To end on a positive note, I am proud of it, I feel good about it, I like the people here and I like the staff, and I like what goes on. I've got no regrets about what I've just said.

1 = The Haven has improved.

Stony: I think The Haven's doing better now, with the behavioural policy in place, and the fact that they have a move-on group, the Transitional Recovery Group.

1 = The Haven Pat Dog is great.

Doris: The other group I love, or part of the group that I enjoy most is when Meg the Pat Dog comes in because I bring my puppy in and we all go for a big hairy walk around hilly fields and they all love it.

1 = The Haven should be more honest.

Tom: I think the staff and the clients should be more honest, I do. When things go wrong it shouldn't take so long to sort out because the honesty does affect each one of us.

1 = The Substance Misuse Support Group is very helpful.

Rose: The Substance Misuse Group is extremely helpful.

1 = Last Christmas at The Haven was the best I ever had.

Cosmic: Last Christmas was the best Christmas I ever had, at The Haven. There was more of a family atmosphere here than I've ever had with my family.

1 = The Haven has become my family.

Tiffany: I just feel The Haven have become my family, the family that I lost.

1 = If The Haven is used in the right way it works.

Charles: It's a good place you know, use it, don't abuse it, and it will work for you.

1 = Dependency on the Haven should be discouraged in a gentle way.

Elise: I think, fundamentally, people with PD need a certain amount of love and care and TLC and pampering and I think The Haven's taken that well on board and has supplied that, where other statutory units have failed dismally. I do think it's very easy to pour out the love and concern and that's so important because so many people haven't had that, but then I think there's a danger that that then becomes an emotional crutch and people don't particularly want to move on. That dependency shouldn't be fostered; it should be actively discouraged in a very gentle way. The programme of activities that runs needs to be constantly developed towards developing life skills for people so that, at the end of the day, they can actually go out and live that life.

FINDINGS FROM

FAMILY AND CARER

QUESTIONS

FINDINGS FROM FAMILY AND CARER QUESTIONS

> *DO YOU THINK THE TERM 'CARER' IS APPROPRIATE? IF NOT, DO YOU FEEL ANOTHER TERM WOULD BE BETTER?*

Six family members or carers were asked this question and five responded, two responding in more than one way.

4 = The term 'carer' has practical uses in relation to professional bodies.

Sammy: There are new laws coming in, in respect of carers, where, if you suddenly do away with the term, human resources, all of these departments won't actually accept. There are a lot of new things carers are getting, so we've got to be careful about changing terms.

Dinah: I've had to use the word carer recently but it was to my employers to explain why I might need time off and it needs to be a word that they understand the meaning of and that's why I used the word carer.

Tony: It does help to throw that word in if you are trying to chase up prescriptions, speak to a chemist, whereas in those areas the word carer does come in handy.

Rob: We did decide that we needed to use the term when talking to professionals.

2 = The term carer is acceptable.

Alex: I can't think of another term that would be more appropriate, personally.

Sammy: I have no objection to it.

2 = A prefix of 'informal' or 'family carer' could make the term clearer.

Sammy: Quite often you have to preface it with the word informal carer, because we are not carers supplied by the County Council. A lot of professionals actually think carer means someone who is a paid professional. So you don't get confused with people who work for care agencies, just to differentiate between us who are very professional and the so-called professionals!

Tony: What about suggesting something on say, family carer, to make it more specific. We are supporting a relative or a loved one, rather than carer, sounds sort of very formal doesn't it, but if you throw the family in front of it.

1 = A family member does not mean a carer.

Rob: I don't like the term carer. I don't do anything different because of who she is, I'm just a husband, you're adding something that's already there.

> *DO YOU FEEL THE HAVEN HAS HELPED THE PERSON YOU SUPPORT?*
> *IF YES, HOW? IF NO, WHAT WOULD YOU LIKE THE HAVEN TO DO FOR*
> *THEM?*

Six family members or carers were asked this question and all responded.

4 = The Haven has provided support that has been very helpful.

Alex: I feel, definitely, it's helped my daughter. It's somewhere safe for her to come, somewhere without any bad memories. She's got friends here, I think she feels even the staff are her friends as well, and I just feel that she feels that it's more her home now. This place has taken the place of her home, although that's a very hard thing to accept as her Mum, but I do thank you. Her communication skills, she can talk to us as a family now, having somewhere to go when she feels things are getting on top of her and you guys seem to have time and patience, and the understanding and reassurance and you've gained the trust I think, which is one of the things when people come out of hospital, or before they come here, that they haven't got trust in anything. I mean the people that love and care for them, not in the mental health system, they don't trust anyone. But when they come here it's a gradual trust in people. They don't feel they are going to be let down and that's a big positive and then they gradually can begin even to trust themselves to do things and take responsibility. But that only comes when they begin to trust other people, and then other people begin to trust them.

Sarah: I have to say that I just think The Haven is just a calm, happy, just a caring place. To be honest I found the hospital a hustle and bustle, and just total chaos. I personally feel that, total chaos, and nobody really, I don't know how to explain it really, nobody really, I'm sure they are trying to help, but I have reservations on that, because they just did not help my son at all, and if I asked for help I don't really think I got any help at all. I can honestly say I got nowhere, absolutely nowhere. I have to say, I might have a tear in a minute, I have to say that The Haven is just, it's a wonderful place really. I really mean that.

Rob: She has been dealing with things for a long time and, since the diagnosis, and getting the help, she has got much, much better, and coming, she doesn't just come if she's in crisis, she comes and has a bed which she arranges in advance and uses that, and she really does work hard while she's here, talking and making use of everything that's here. She's doing things at home she wouldn't do before. Gradually it kind of sinks in, and that helps in your relationship, because once you start understanding what the problem is then you can start to work towards a better way of carrying on, mustn't say cure must we! It does work; well it works for my wife. It's keeping her alive, I don't think she would be alive without The Haven. She tried to kill herself desperately under the care of the hospital and previous regimes. It's the right treatment, the right care, and it's obviously working. I'm fortunate enough to see how similar projects have helped their clients and it just didn't compare. I can see it's not right for a lot of other people there, it's depressing, it's horrible. Promise to be around forever.

Sammy: I think it's been absolutely useful her being here, my wife. It's actually given her motivation that for many years prior to coming here, that we tried to get her to get up and do things. Coming here has given that to her and the ongoing support, no matter how many times a week you come, there is a plan and people phone her which has given her support outside of when she's here. But to actually see her wanting to do different things and actually doing different things in-doors now, is far better. It's the motivation we've been trying to give her for years. But to pick up on what Rob was saying, and relate it directly back to The Haven, The Haven serves a specialist community in a very specialist way. The hospitals and the community mental health teams, their only speciality is mental health, where The Haven is catering for a group of people and a limited number so, actually, you can work far better with those individuals and be more focussed, so we certainly don't want it to go away.

1 = My partner doesn't always use The Haven

Dinah: It's coping skills that we need and those are the strategies I hope The Haven will give to my partner. My partner's a bit naughty in that I will actually wave her good-bye because she's going to The Haven, but it's only sort of a few weeks later that I discover she's not going. So I've got a continuing problem, she's not coping very well at the moment, and now I know she's not coming in. My partner has a ferocious temper and aggressive behaviours, and it's frightening, I find it very frightening, and for years I've put up with it, frightened in my own house, when she goes into one. I can now say,' you are frightening me you will leave now', and she has to go. We get these suicide attempts and we've been to hospital numerous times. I've run out of sympathy quite frankly because the first time it's ,'oh my god', you know, the second times it's, 'oh', the third time it's, 'not again'. I'm not going to play the game anymore. I'm being pushed to a point that I'm having my strings pulled and I can't, I can't cope with all that manipulation that's being put on me.

1 = My family member has worsened since receiving the diagnosis.

Tony: In times of crisis it's very helpful but I've found with my Mum, since she's had the diagnosis, the title, she has completely given in to it. Whereas prior to that she used to fight, she used to try and do things to rationalise things, to work through them, whereas I've found, since she's had the personality disorder diagnosis she, I know it sounds hard, but she almost uses it as an excuse,' I'm in crisis, I'm not going to deal with this, I've got a personality disorder', and gives up, and never actually challenges what it is that's causing the problem. The biggest problem with my Mum is drug-induced. She's quite a bad drug addict, cannabis, which does encourage psychosis anyway, and drug-induced psychosis if it's used an awful lot. I have been telling my Mum for a couple of years now; the drugs have got to go for her to improve. As far as I'm aware Mum's making no effort to stop. She was stoned on Wednesday before her three children and her grandson turned up. I'm afraid that I'm at the end of my tether because of drugs and, as far as I'm concerned, are keeping my Mum ill and she doesn't seem prepared to let it go. So, if you can help her in that aspect that might help. I'm also aware my Mum's sold drugs, I'm really concerned, I caught my Mum out Christmas time drug dealing to children. There's a 16 year old child in my house at the moment, so any advice you're giving to handle it, or anything

I can find out. Drugs are a huge issue. What I've tried to do for my Mum is also issue an ultimatum, 'it's your drugs or your children or your grandchild'. My auntie hung herself a couple of years ago, which is a very huge issue, because I was very close to my auntie, and with my Mum's self-harm and suicide attempts I am terrified to lose another one. So if I withdraw, although it's tough love, is that going to happen again?

DO YOU FEEL THE HAVEN INVOLVES YOU IN THE CARE OFFERED TO THE PERSON YOU SUPPORT? IF YES, HOW? IF NO, WHAT WOULD YOU LIKE THE HAVEN TO DO TO IMPROVE THIS?

Six family members or carers were asked this question and five responded, some answering in more than one way.

3 = The Haven has provided an acceptable level of involvement.

Sammy: I think it is fair to say that The Haven is here primarily to support the client. I would say it doesn't support me directly; it does indirectly by the fact that it supports the client.

Rob: It's about the right level I think, for me. I haven't been refused an answer.

Alex: Every time I've contacted they've always been very supportive.

2 = I don't want too much involvement.

Rob: I don't get dragged into anything, I don't want to get dragged into it. If I want to phone anyone and talk to anyone there's never been a problem but, as I say, I don't really think you contact me a lot. I suppose, in theory, I just hand her over to you, you know, just drop you off, there you go, carry on and come home when you've had your session.

Dinah: I'm not sure I want to be involved in the care of my partner's recovery, and to qualify that is that it is my partner who doesn't have the ability to cope with life, and if you give her a crutch, which is me, she uses it. I'm completely capable and I end up making all her phone calls, or could I do this, could I do that. She's got to cope on her own, and learn strategies and own her problems and deal with them.

1 = I am very careful not to shatter trust by speaking directly to The Haven

Alex: If I am a bit worried about my daughter, and I'm going away for a week and she's not coming, then I think I would tend to talk to her CPN who would then relay the information to you. The reason I do that is there have been times when my daughter alienates the family, cuts us off and not wanted us to know anything. Then it puts you in a precarious position because I feel it is important that she knows she can always come to you no matter what and that you are never going to tell us anything

that she doesn't want us to know. I don't feel that I would pick up the phone and ask you anything that might jeopardise how my daughter feels about you. This is her haven, this is her one place that nobody ever lets her down and I can actually turn around and say to my daughter, no I haven't spoken to The Haven, I haven't told them anything, and I won't be lying.

1 = I would like the Haven to get my side of the story.

Tony: My Mum's a compulsive liar, it's part of her. If Mum's got a problem with me talk to me because she invents things, and the first I know about it is when I get phone calls from friends of my Mum. Perhaps contact with the family, ask our side of things that are actually happening perhaps, to try to get to the root of it, because obviously my Mum is in crisis for a reason, and rather than dealing with the reason she's making one up. Perhaps to be involved on a quiet level, an up-date of what is going on perhaps on the family side of things, and as much or what you can say of what's going on my Mum's side. My Mum would, if I'm there all the time, lean on me and it's exhausting, and my back aches through carrying the weight. But to be involved like I say would help her, but not too much in the foreground, to find her own two feet. A member of staff I spoke to, I appreciated it so much at that particular time. When I have had contact it has been very helpful.

1 = Set up an informal Carers Group at The Haven.

Sammy: I would like to see some kind of informal Carers Group run through The Haven.

> **RESEARCH SHOWS THAT CARERS OFTEN EXPERIENCE DIFFICULTIES IN CARING. DO YOU THINK THIS STATEMENT IS CORRECT AND IN WHICH WAY DO YOU THINK THE ROLE AFFECTS CARERS?**

Six family members or carers were asked this question and five responded directly to the question, however, participants felt that there were relevant responses to this concept implicit in statements made in response to other questions.

5 = The caring role can impact negatively, cause stress and have an effect on one's own mental health.

Dinah: Because they know how to push our buttons, don't they, to get themselves back to the centre of attention.

Alex: The answer is yes, there are difficulties in being a carer, and one of the ways it affects carers is their own mental health, because I think when the person you are caring for is extremely low, then you can't help it but, you know, it's very difficult to keep on top of it and keep bouncy yourself. It's very easy to start going down that slippery lane yourself and ending up ill, and then it's harder for the person to bounce

back again, because you're low, and it's just a vicious circle, becomes a vicious circle and you don't know who's bloody most depressed in the end, the carer or the person.

Rob: *I used to explode. You say depressed, I used to call it having the hump! And my hump was for a reason, you know, the person I love is hurting the person I love, and that gives me the hump, and wasting a lot of time in A&E, I hate hospitals, you know, hanging around wasting time, and I would explain exactly why I've got the hump, being you know, down, depressed, whatever.*

Sarah: *At one stage, with my son, it was just like a rollercoaster, and I had family members saying to me, 'just let him get on with It', you know, because my son would always ring me, and I would be going up to the hospital picking him up, or whatever, ambulances and all sorts, and I suppose as a Mum I couldn't not go. I was bombarded with, you know, daughters, brothers, husbands, 'you shouldn't be doing this', and trying to explain to them the little I knew then. It's off-loaded so much from my shoulders; I have to say, because I think I was the one that went through most of it with my son.*

Sammy: *Being a carer's a very easy job when things are running very smoothly, but when they dip, for the person you care for, they become very stressful. So, in getting the hump, feeling depressed, feeling low, but the person you care for it plateaus off and starts coming up the other side, and levels off again, but the stress as far as I'm concerned, for the person who's caring, carries on for a longer period of time than it does for the person who's plateaued off because, what you are then starting to look for is, has it actually done the plateauing off? Or is it just about to do this again? So, the person who's been down, feeling suicidal, doing things, hearing things, whatever, goes away, they plateau off, maybe a week, ten days, two weeks, two months, whatever, but for the carer that experience you've got to add another percent of time on to that when you are still in a stressed state.*

> ### *ARE THERE WAYS IN WHICH YOU FEEL YOU COULD BE SUPPORTED BY THE HAVEN IN YOUR ROLE?*

Six family members or carers were asked this question and one responded directly to the question, in two ways, however, participants felt that there were relevant responses to this concept implicit in statements made in response to other questions.

1 = Information and knowledge about personality disorder would help me.

Sarah: *I don't understand, you know. I'm a bit green really, in this.*

1 = A stay, for my family member, in a respite bed at The Haven helps me.

Sarah: *That was just amazing really. I knew that I could probably go to sleep and that he was going to be okay and safe.*

DO YOU FEEL THAT THE PERSON YOU SUPPORT HAS CHANGED SINCE ATTENDING THE HAVEN?

Six family members or carers were asked this question and four responded directly to the question, three in more than one way, however, participants felt that there were relevant responses to this concept implicit in statements made in response to other questions.

3 = The person I support has changed for the better.

Sammy: Yes, for the better.

Alex: Oh definitely positive - yea.

Rob: Yes, without a doubt. She's coping with this move.

3 = The behaviour of the person I support has changed since attending The Haven.

Rob: The person hasn't changed, the behaviour has changed.

Alex: Yes, I agree with that, the person hasn't changed, the behaviour has changed.

Tony: I think the only positive thing is perhaps the self-harm and suicide attempts aren't as frequent.

1 = The person I support is more motivated since attending The Haven.

Sammy: A lot more motivation, getting up and doing things.

1 = The communication of the person I support has improved since attending The Haven.

Alex: Her communication skills are definitely a lot better since she's been coming here.

DO YOU HAVE HOPE ABOUT THE FUTURE IN RELATION TO THE PERSON YOU SUPPORT?

Six family members or carers were asked this question and five responded.

4 = Yes I have hope about the future in relation to the person I support, but with some reservations or fears.

Rob: Yes, I've got hope but I always worry about The Haven being there. That it'll grow. Your community has a size at the moment that obviously works. I hope she can get better and better, but life at the moment's not bad, you know, touch wood. It's a certain level of living, not just comfortable, happy, you know, some of the time, laughter.

Sammy: Yes, I do have hope for the future. I have a bit of a concern the person I care for expressed to me. What happens if The Haven sort of consider that she has got to a point where they can't help her anymore? The problem is what she's worried about is if she's been under mental health services for thirty years. I think this is the fear of, 'well everyone perceives that I'm, you know, I don't need this anymore?'

Sarah: I would like to say that we do seem to be, at this present time anyway, he is very much better.

Alex: Yes, I have never given up hope, ever, and recently, for the last six months I've had more hopes than ever. My daughter's turning the corner and able to live a fairly normal life, as normal as she can. I would say she seems better in herself, more able to perform the normal things that people do. I think it is scary hoping. I think we are all frightened to hope too much.

1 = No, I can't invest anymore hope.

Tony: No, I'm so sorry, until my Mum puts drugs out of her life, no, none whatsoever. I'd love to be positive and, to be honest with you, it's hurt so much over the years I can't invest any more hope in my Mum. I'm sorry, that sounds awful, very callous and mean. Social Services have been involved with my younger brothers and drugs have been an issue for both my brothers from the age of sixteen. Mum's still blatantly open and obvious about her drug taking and, unfortunately, I nearly lost one of my brothers before Christmas and, after seeing your son almost die from an accident that was because of drugs, if that's not an incentive to start doing things right I don't think there will ever be an incentive that's enough, so, my hope's gone.

HOW WOULD YOU DEFINE RECOVERY?

Six family members or carers were asked this question and four responded, one in more than one way.

3 = Recovery is a journey individual to the person.

Sammy: Not the way most professionals do. Recovery is an individual thing. It is not necessarily, as a lot of professionals will lead you to believe, about getting a job. At the end of the day, for some people, it might just be getting out of the house for the first time in five years. It's an individual thing; it isn't a model, although some people try to tell you it is. It's a concept and it's an individual concept. It's not about government targets of getting a million people off of incapacity benefit. It's about a journey that somebody takes, and The Haven is assisting people in making that

journey, some will fall back, some will go forward, but it's nothing that is actually, for me, specific. It's a totally individual thing for each person. I cringe when people say the Recovery Model, there is no Recovery Model, there is no such thing, it's individual for everybody. Recovery is a goal for the individual and little steps along the way. But whether they will ever be recovered is a totally different thing altogether. You will never, ever know until you get there. I get annoyed by general services that have an end goal that recovery is work. Stand the ministers up in front of me and I will shoot and gun them down because they haven't got a clue what they are talking about. I get totally cheesed off by some of these people with power, this idea of getting everyone back to work. A particular minister actually said one thing at a meeting I was at. A hundred thousand people the Prime Minister keeps on talking about, it's rubbish. What we need to be doing is trying to stop future generations falling into the big back hole that we are in today because ninety thousand of those hundred thousand will still be claiming benefits in ten years time. I suppose that the first bit of sense I've heard is actually admitting that the targets are a load of rubbish, I know they are rubbish. You are not going to achieve getting all those people back to work.

Dinah: *I don't think recovery will ever be a position where you are declared well and put all this behind us, it won't be like that. I think this is going to be one of those things that will go through my partner's life forever and that certain trigger points, crisis points, certain issues will set her off again and we'll take a step back and there'll be times when we take a few steps forward and life's comparatively easy. How I define recovery for my partner is that she has her own life, and she feels capable of doing things outside, meeting friends, having a bit of a social life, where I'm not standing behind her propping her up or anything, and she has a little bit of a life of her own, and doing the shopping without having a major panic, that's recovery, it's not a set definition. She's never going to hold a job down in a million years. I think my partner's always going to be happy to do a bit of farming, or looking after animals, a much easier life, where the demands are there but in a different way. I think that will be recovery.*

Rob: *I just think it's the individual thing. One thing I did think is there's no definition, but while they are moving forward they're in a state of recovery. If they keep moving that's good.*

1 = Recovery is about having a more normal life but, for a young person, there may be more pressures.

Alex: *Just having the ability to live a fairly normal life and be happy in themselves. Perhaps it's different for different ages. I think if you are a young person then you obviously want to do more. So it's harder, I don't really know. I think, unlike you guys with your wives, you can shelter them from a certain amount of things, I think. If you keep them well they plateau. I'm looking at my daughter, she wants to go to college, she wants to do this, she wants to do that, when she's feeling well, and I think to myself, all those things are extra pressures on her that nobody can take away. When it's exam time, or when she's going to college every day, there's not anyone who will say, oh I will do that for you, is there. It's something she's got to do for herself, she's got to go down that road.*

1 = Recovery is seeing again the person I used to know.

Dinah: Another part of recovery which I suppose is that I get glimpses of my old partner. There are times when you recognise the woman you loved, you fell in love with, that sparkly, exciting, dynamic, creative individual who attracted you in the first place, and I wasn't attracted to the depressed, crying, cutting, tablet nibbling individual that I live with. To see what I saw originally, through all that, that's part of recovery, and I like to be with her, I like to spend time with her, she's fun.

> ### HOW WOULD YOU KNOW THAT THE PERSON YOU ARE SUPPORTING IS MAKING PROGRESS IN THEIR RECOVERY?

Six family members or carers were asked this question and all six responded.

3 = The person I support has hope.

Rob: I think hope. They have hope, because I know with my wife, she didn't want to be around, so there was no tomorrow and now she has hope. She can see the future.

Sarah: They can see light at the end of the tunnel, they can see a bit of future really.

Sammy: The periods of wellness are greater than the periods of illness. Probably eighteen, twenty years ago there was absolutely no hope; they had no hope at all. We've had the conversation more than once, 'yes I am glad I am now alive, where twenty, twenty-five years ago I wasn't happy that I was alive. I want to be alive now, I want to be well, I want to carry on living'.

2 = The person I support is, or would be, happy.

Alex: They are happier in themselves, and they view the world differently, they have the ability to consider other people, not just themselves.

Dinah: If they're happy, I'm happy.

1 = The person I support would be working again.

Tony: You see my Mum used to, she used to be in a good job, and I don't understand what happened. We had a series of difficult things happen, but then we've always had a series of difficult things in my twenty-six years of life, if you go back through our family history we've had physical abuse, sexual abuse, through my family, children given away, so we've had so much stuff going on. What I don't understand is how she functioned for so long. It wasn't until she came back to Colchester, and it all went wrong. So why have we got this shell of the person we had before, 'why have you bothered coming back because you are no good to anybody?' We've always had

hiccups, something, dramas, whatever, from word go. So why now, over the last two or three years has she given in to it, because like I say she always managed to brush herself off.

WHAT ELSE DO YOU FEEL THE HAVEN COULD DO TO HELP YOU AND THE PERSON YOU SUPPORT IN THEIR RECOVERY?

Six family members or carers were asked this question and three responded.

3 = Ensure that The Haven gets its funding and stays here.

Dinah: I do fear for the funding. I've never had any dealings with mental health until I met my partner and I'm appalled that how I see it as the Cinderella subject in the health service and disgusted at the way any cuts come down on the mental health side first. You continue to get your funding and I know it's difficult in this economic climate. I've seen the economics cut £10,000 where it would save you £50,000 later.

Rob: I still worry but I have seen some wonderful figures about how much money it saves. Just keep going.

Sarah: I would just say lets hope it carries on being here.

HAVE YOU GOT ANYTHING MORE TO ADD?

Six family members or carers were asked this question and four responded.

3 = It really helps family members and carers to talk to each other.

Alex: The chats that we have as carers, I think we can learn a lot from each other because we are discussing something with somebody else who knows where you are coming from and that just makes a difference. It's good for us all to see a different side isn't it.

Sarah: Yes, totally, you are right, my first time here, I didn't have any support before, and listening to everybody.

Rob: I've got something from you too, because you have an entirely different perspective, and we had a daughter last time; different ways of looking at the same thing.

1 = Don't let The Haven get too big and keep treating everyone as the individual they are.

Sammy: There are different labels, but within the label everyone is still an individual and that's what gets lost in the majority of services that isn't lost here. It would be if

you tried to double your capacity. What's wrong with general services is they are trying to support everyone as best they can, and for some they do it very well, for some they do it very, very badly, but for the majority of people they just do it averagely. Here, for ninety percent of your clients it's an individual and absolute positive. It aint going to be for a 100% of people because nothing fits everybody.

The Haven
Annual Report

2009

Contents

1

The Chairman's Report

Reg McKenna,
Chairman,
The Haven Project
1 Glen Avenue
Colchester C03 3RP
Tel/fax: 01206 287316
Email:
reg.mckenna@thehavenproject.org.uk

It is with great pleasure that I present the annual report for The Haven Project Community Interest Company for the 2008/2009 financial year. My fellow directors and I are extremely proud of our association with this project and the continued strides it makes in finding and developing effective and sustainable treatments for our clients.

We are also very proud that our service continues to be a beacon for individuals and other projects around the country who wish to develop Personality Disorder services – our open days and outreach presentation activities are in ever increasing demand.

The financial year to the end of March 2009 proved to be very busy.

The Social Inclusion Unit has continued to involve a very high proportion of our clients in recovery oriented and socially inclusive activities, many getting into employment, education and/or volunteering.

Our crisis and day services staff teams have been involved with some first class activities and providing excellent programmes. On behalf of our board I would like to thank them for their reliability and commitment in providing a consistently high quality service to our clients.

In the difficult financial climate that this country is in we are confident that The Haven will rise to the challenge, in terms of partnership working and innovation, during this and the coming financial year.

Once again on behalf of the Board of Directors I would like to thank everyone associated with the project for your continuing support, to staff members for your dedication and very hard work and to our clients for making this a model project that is leading the way in Personality Disorder services of which we are very proud.

Reg McKenna
Chairman

Transitional Recovery clients constructing a bridge at Mersea Youth Camp

Happy 5th Birthday Dear Haven

It was a great cake. We had a display of photos through the years too, and press clippings, a lot of good publicity, very impressive. As an early bird to register here, I've seen the place grow and change as we've grown and changed together. It's about believing in yourself and having other people believe in you. It's about how we've all changed and grown. If all the clients here were still stuck where they were five years ago, how awful would that be. We could turn it all into a film. George Clooney could play Alan and Meryl Streep could play Heather C.

The Chief Executive's Report

Heather Castillo,
Chief Executive,
The Haven Project
1 Glen Avenue
Colchester C03 3RP
Tel/fax: 01206 287316
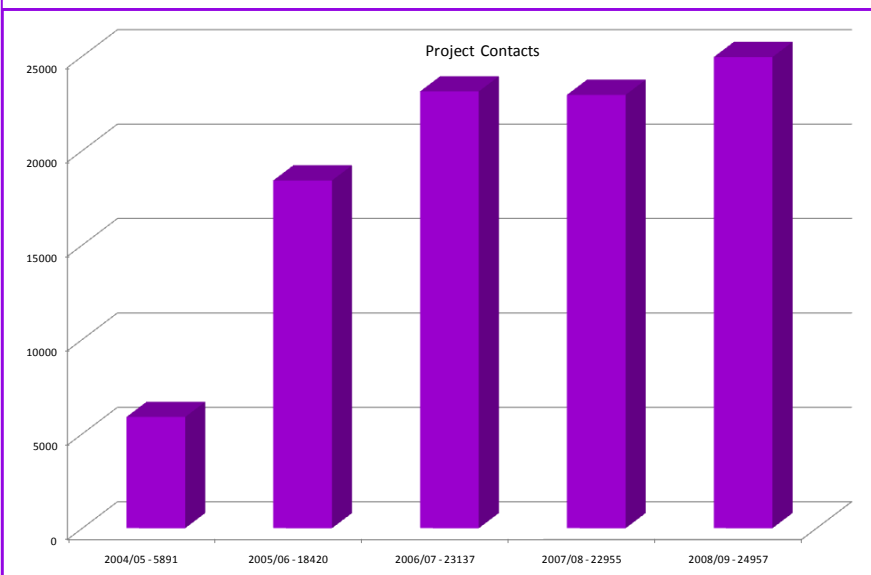Email:
heather.castillo@thehavenproject.org.uk

During the period of this Annual Report we entered our fifth year and, in July this year, The Haven celebrated its 5th Birthday, see opposite page. This past year has been the most settled and productive to date. Project contacts, below, have maintained around 2,000 a month and clients registered are our highest ever at 135. Haven research results have also born fruit and the lessons learned, about the journey of recovery in personality disorder, have become embedded in our service.

Once again, there are so many people to thank. I would like to thank my staff team who have worked so hard, and with such commitment, over the past year. I have seen their skills grow and blossom and they are a team to be proud of. Our Finance Officer, Helen Garland, moved on to full-time employment this year and is thanked for all her hard work. Yvonne Hall is warmly welcomed as our new Finance Officer. Thank you to our Steering Group and Board who have offered such ongoing support. Thanks to our Bank Workers, Volunteers, and Sessional Therapists, who are all essential to our service. We owe our gratitude to David Olive, who set up and ran the DBT Skills Group at The Haven for four years and has now left to be replaced by David Dickinson, who is warmly welcomed. Thankfully, David Olive's Pat Dog, Meg, has not gone to part-time working and is still with us, see page 7. Thank you to the National Personality Disorder Team for their unfailing support, to our local Commissioners especially Yvonne Srinivasan who has moved on after several years of very valuable guidance, to the local Mental Health Partnership Foundation Trust and other statutory and non-statutory bodies locally for their commitment to our clients, to our Website Consultant, our Accountants, our Clinical Supervisors, to all those who have provided training sessions for our staff, and to Academic Supervisors at Anglia Ruskin University who have helped to guide Haven research which has had such an influence on the development of our service.

Finally, my thanks go to our clients. The Chair of the client group is not an easy role and a mutuality of trust between Chair and Chief Executive is very important to The Haven. I would like to thank Helen Price, and her predecessor Freya, for the superb contributions they have given as Chairs over the past few years. Within the spectrum of clients who have been with us for differing timescales, we see new clients come to us with damaging attachment experiences and who struggle through sadness, fear, pain and anger. But the Haven Community is strong and committed to helping its members through the process of learning to trust, respecting boundaries and beginning to contain experiences. This process has yielded many and varied achievements and a new feature at The Haven is awaiting GCSE results for some of our members. The Transitional Recovery Group continues to develop skills and engage in outward bound activities, see page opposite. Achievements in the various domains of Social Inclusion are detailed in our 134-page LIFEPATHS Manual, see page 6 for details. We hope to celebrate these achievements at this year's Annual General Meeting.

Heather Castillo
Chief Executive

Project Contacts

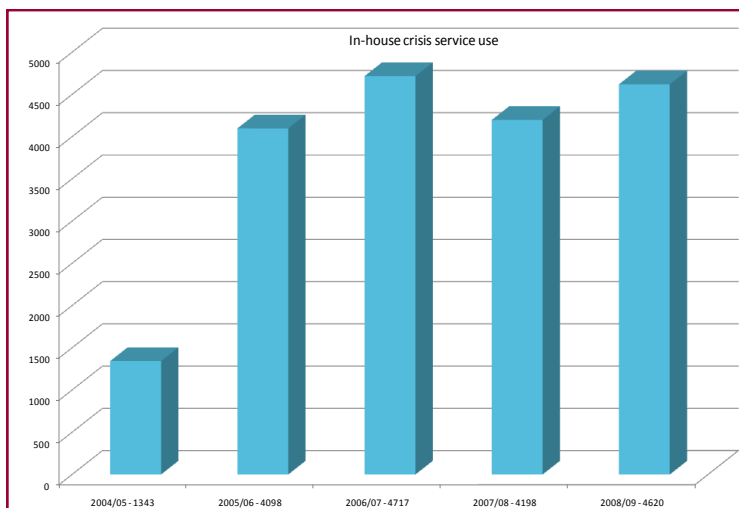| Year	Contacts
2004/05	5891
2005/06	18420
2006/07	23137
2007/08	22955
2008/09	24957

The Crisis Services

Heather Shackleton,
Service Manager
The Haven Project
1 Glen Avenue
Colchester C03 3RP
Tel/fax: 01206 287316
Email:
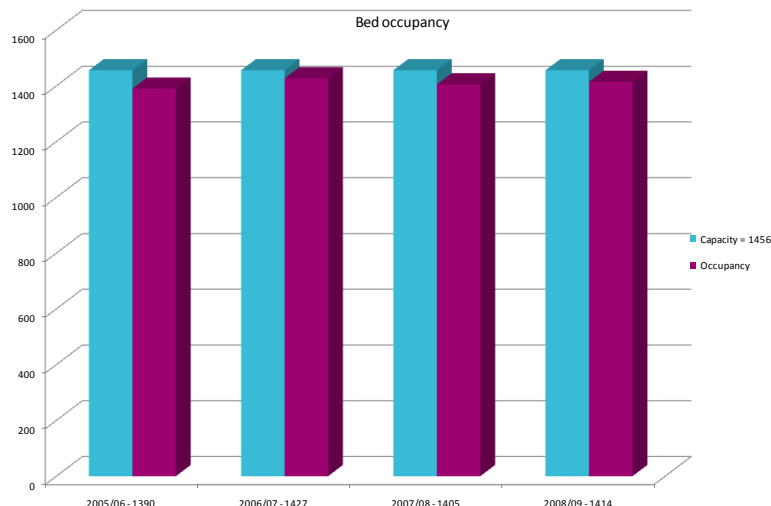heather.shackleton@thehavenproject.org.uk

The past year has been a busy and productive one for The Haven Crisis Service. Statistics for bed occupancy and use of crisis services such as telephone contact and one-to-ones have shown similar patterns to the previous period, and we have welcomed many new clients to the Project who have been keen to engage with the support we have to offer. The team's ability to successfully embrace new clients has been made possible by the fact that many of our longer term clients are making good use of the excellent input of Therapy Services and our Social Inclusion Unit, which has supported a number of individuals through successful college courses, training and work of many kinds.

The range of crisis services has continued to grow and expand over this period, with staff involving themselves in a variety of creative ways of working with our client group. An increasing number of clients are engaging with individual staff members for weekly 'focussed one-to-ones'. These provide opportunities for more in-depth work to take place in a safe and containing therapeutic space. In addition, certain staff are involved in outreach work with clients who have particular needs outside of The Haven and in their own homes. Also, a number of staff with specific skills are supporting the group programme with gardening, drumming, life skills and substance misuse support, together with complementary therapies such as hand reflexology and head massage. Some staff continue to engage with personal and professional development including counselling and other therapeutic training, in their own time and at their own expense, which serves to enrich and enhance their existing skills for the benefit of our clients. All this, I believe, is evidence of our continuing and abiding commitment to the Project and all it stands for in terms of client support, progress and recovery.

In-house crisis service use

2004/05 - 1343 | 2005/06 - 4098 | 2006/07 - 4717 | 2007/08 - 4198 | 2008/09 - 4620

I would like to thank each and every member of the team, together with our committed band of bank workers and volunteers, for the hard work and dedication they've consistently shown over the past year. May we continue to move from strength to strength in terms of the scope and breadth of what we have to offer our clients as we move into the next, challenging but exciting period.

Bed occupancy

Capacity = 1456
Occupancy

2005/06 - 1390 | 2006/07 - 1427 | 2007/08 - 1405 | 2008/09 - 1414

Heather Shackleton
Service Manager

Therapy and Group Services

Ines Hunns,
Assistant Service Manager,
The Haven Project
1 Glen Avenue
Colchester C03 3RP
Tel/fax: 01206 287316
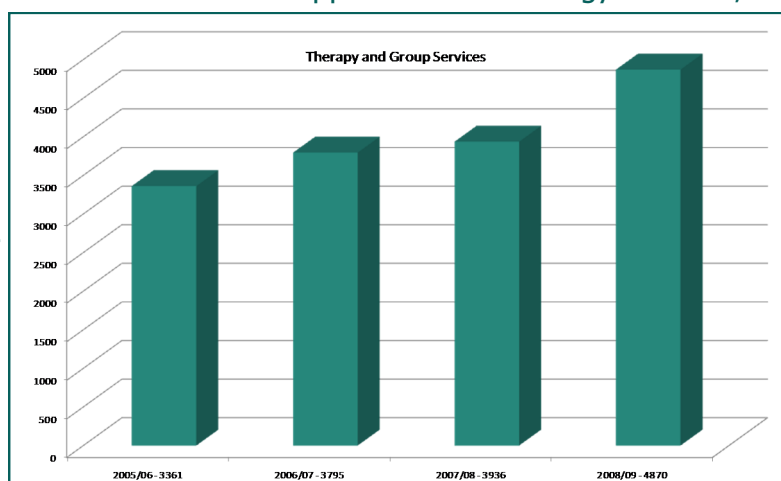Email:
ines.hunns@thehavenproject.org.uk

The therapy services continue to be a busy, growing and varied part of the project. We have regular groups running throughout the year, and day-to-day support for our 130+ clients, which includes attending appointments with them and helping to fill in benefit and housing forms. Claire, our day Project Worker is invaluable with her knowledge of local and government services and an excellent understanding of our clients and their issues. We owe her eternal thanks for her patience, kindness and hard work. With much help from Helen, our administrator and our house-keeper, Sharon, we have a cheerful and dedicated team who are an absolute pleasure to work with.

The therapy services also have much support from volunteers and social work students, and currently I would like to acknowledge the wonderful contributions made by Angela to Cookery group and Lyndise to Art group. We were sorry to lose John on Fridays but glad that he is continuing his brilliant client work at weekends now, and Mariana who now visits on Monday and Thursday evenings, congratulations to both of them on their full-time posts. Last year's students, Jenny and Caroline did some important outreach work. Our two social work student, Karen and Kerry, have now started.

Thanks to Judy for her Life Skills sessions with Heather and to Janet and Richard for Nutrition and Chaplaincy groups respectively. We have welcomed David Dickinson as our new DBT skills facilitator after David Olive stepped down, Debbie continues with her much appreciated reflexology sessions, our counsellors, Merrill, Jackie, Jeannette and Maria continue their valuable input, and Meg still comes three times a week to greet people with her wagging. Monthly Drumming and Substance Misuse groups are held by Tony and Mich and the garden is looking lovely thanks to Sue and her crew. Our gratitude goes to all of them and to the crisis staff and social inclusion who complete the team during a day shift.

Ines Hunns
Assistant Service Manager for Day

Therapy and Group Services

Monday	Tuesday	Wednesday	Thursday	Friday
Reflexology by Appointment	**COOKING** Open to all **Healthy Living** 11 am – 12 noon	**Arts & Crafts** 10 am – 1 pm	**Friendship Group** 10 am – 1 pm **Monthly** **Haven Community Advisory Group** 11 am – 12 noon **Life Skills Group** 10.30 am – 12 noon	**Gardening Group** 10 am – 1 pm **Monthly** **Monthly Substance Misuse Support Group** 11.30 am to 1.30 pm

One to ones and counselling by appointment

Monday	Tuesday	Wednesday	Thursday	Friday
DBT SKILLS Closed Therapy Group 2pm-4pm	**Friendship Group** 1 pm – 4 pm **Indian Head Massage** By appointment	**Monthly** 1st **Nutrition Group** 2 pm – 4 pm 2nd **Drumming Group** 1.30 pm to 3.30 pm 3rd **Chaplaincy Group** 2 pm – 4 pm 4th **Families and Carers Group** 2 pm – 3.30 pm	**Transitional Recovery Group** 2 pm – 4 pm	**Creative Writing Group** 1.30 pm – 3 pm (Last Friday Book Club) **Head and Hand massage and Trauma Reduction Therapy** (by appointment) **Monthly** **Open Day Session** Last Friday 1pm to 3.30 pm (clients welcome to help)

**Weekly Therapy and Group Programme**

The Social Inclusion Unit

Inez Davies,
The Haven Project,
1 Glen Avenue,
Colchester, Essex C03 3RP
Tel: 01206 287323
Fax: 01206 287316
Email:
inez.davies@thehavenproject.org.uk

With two years under our belts, Social Inclusion at the Haven continues to make a difference to members' lives. People are moving through their own personal transitions at their own pace working on their particular life domain, whether it be leisure, education, housing, or work, to name a few. For some the steps are small and consistent, for others its two steps forward one back, three forward one back and over time their resolve becomes stronger. It's brilliant to be a part of it. Many are taking massive leaps, taking a chance, but everyone is facing their own personal challenge. The Unit compliments the clinical and therapeutic work at The Haven by offering one-to-one transitional support, group work and outreach, all of which has an outward facing approach to breaking down the barriers encouraging a feeling of participating in something bigger. Our pie chart, below, gives the reader a flavour of the variety of achievements, how much people are participating and overcoming what appeared impossible barriers.

Our weekly Transitional Recovery group continues to be well attended always working on personal development, confidence building and forever generating a positive take on difficult feelings and situations. The group inspires, coaxes and convinces members that many things are possible, many things are achievable and even more so because there is a group of people backing each other up. Our programme has included a range of outward bound sessions, annual Mersea Camp, building bridges – very technical with lashings of team work, daring assault courses and enjoying new surroundings, laughing and having fun. Secretly, some develop new skills and fantastically, reclaim old skills! It is fabulous to see members of The Haven simply 'letting go'. We have incorporated Bushcraft into our sessions and are hoping to develop a partnership programme that will include field events like archery, fishing, orienteering and clay pigeon shooting but, at the moment, the group often escapes the humdrum to build fires, dress in camouflage, explore fauna and flora in local woods and talk. We have a desire that we are all hoping to fulfil in camping under the stars and cooking a meal...something that we are all getting rather excited about! Can you tell that the staff here love their jobs?
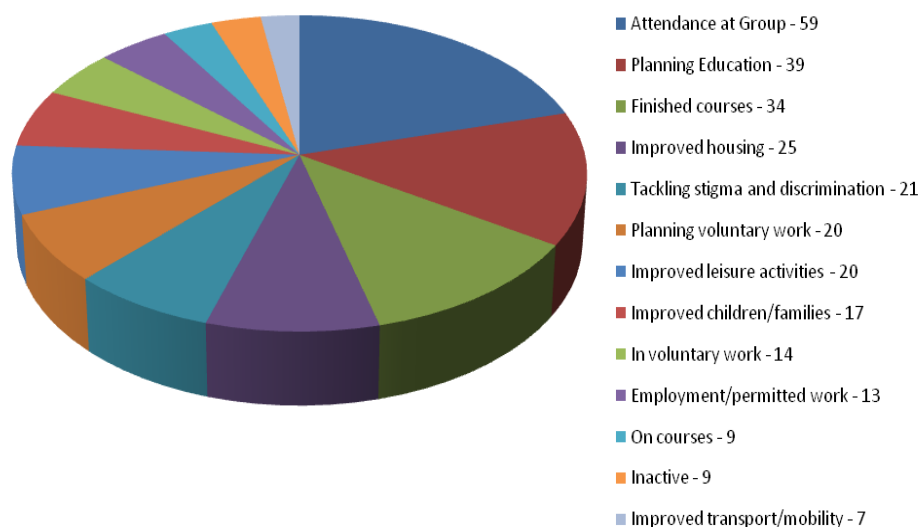

Outreach Hours
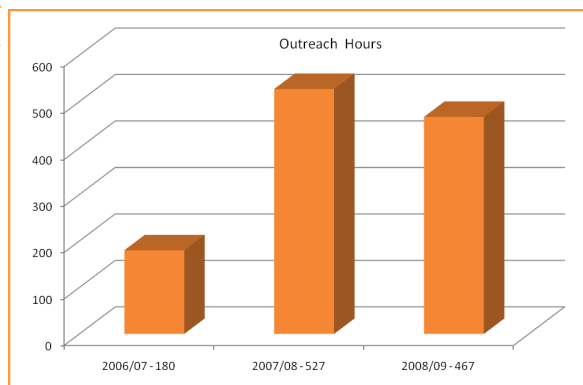
Outreach support is extremely sensitive to individual needs. The Haven team provides regular outreach throughout the year and we are fortunate to have added resources to have great spurts of outreach when students join us on their work placement at The Haven (see chart above). The support is varied, from assistance with practising the use of public transport, to setting up a new home. We have recently seen quite a rise in the number of members moving house and many have been supported with paperwork, practical shopping, installing new equipment, applying for Community Care Grants and purchasing furniture.

A major development for Social Inclusion has been the creation of our new 134 page LIFEPATHS manual. A collaboration of specialist knowledge from the team, stacked full of useful information....each section represents a different domain of social inclusion including having a home, income, family networks and social support, tackling stigma, leisure and recreation, vocational and educational pursuits, meaningful occupation and employment. The final section incorporates a series of personal development skills sessions that offer a framework for people to make a journey... A great resource for group work or individually for those ready to take a chance, change something small, dare you! Order forms are available online.

Inez Davies
Social Inclusion Co-ordinator

Social Inclusion and Transitional Recovery
sixty-seven Haven clients

- Attendance at Group - 59
- Planning Education - 39
- Finished courses - 34
- Improved housing - 25
- Tackling stigma and discrimination - 21
- Planning voluntary work - 20
- Improved leisure activities - 20
- Improved children/families - 17
- In voluntary work - 14
- Employment/permitted work - 13
- On courses - 9
- Inactive - 9
- Improved transport/mobility - 7

The Haven Community Advisory Group

Helen Price,
Haven community,
Advisory Group Chair,
The Haven Project,
1 Glen Avenue,
Colchester, Essex C03 3RP
Tel/fax: 01206 287316

I'm just finishing my second tour of duty as Captain of the Good Ship Haven, during 08/09 (the first one was in 05/06) and the ship hasn't sunk! It's a learning curve, being Chairman of The Haven Community Advisory Group, learning to think on your feet and attempting to remain diplomatic. I think The Haven Community is great, morale is high, and the sense of responsibility keeps growing. I will be handing over the reins to my successor in December, and I wish them all the best.

Much as I love this community I think, for me, my attention is now turning outwards to life. I finally conquered my big demon this summer, by passing my Maths GCSE, which now opens so many doors for me. I am continuing at college and in voluntary work. I do intend to continue to work with The Haven in tackling stigma out there and in educating about Personality Disorder. I hope to continue to give talks at conferences and to be involved in things like NIACE (National Institute of Adult Continuing Education) who are taking ten people around the country to tackle stigma in the work place.   Guess what, one of the ten is me!

Helen Price
Chair of the Haven Community Advisory Group

The Haven Community

We are a community, it's like a family to me. We all get support from each other. When it's your birthday you get a card from everyone and it makes you feel wanted and loved.

Meg the pat dog

Meg's brilliant!
Meg's fantastic!
She's great,
we love her.
She's never been up
for a Community
Discussion either!
She's a good girl.

Outward Bound at Mersea Youth Camp

My muscles ached both from laughing and stretching. It was great teambuilding.

Climbing over the wall made me feel that, with a little help from my friends, what else can I achieve?

Who's who at The Haven

Haven Community Advisory Group

*Helen Price	- Chairperson
*Dave Duncan	- Deputy Chairperson
*Membership open to all registered Haven clients	

Staff Team

Heather Castillo	- Chief Executive
Helen Boyden	- Administrator
Yvonne Hall	- Finance Officer
Sharon Bailey	- Housekeeper
Heather Shackleton	- Service Manager
Martin Pender	- Assistant Service Manager Shifts
Ines Hunns	- Assistant Service Manager Day
Claire Beacham	- Project Worker for day
Inez Davies	- Social Inclusion Co-ordinator
Tracey Davidson	- Social Inclusion Assistant
Susie Rosenwald	- Project Worker for shifts
Tony King	- Project Worker for shifts
Tony Woodley	- Project Worker for shifts
Michelle Cunnane	- Project Worker for shifts
Sue Duncan	- Project Worker for shifts
Nigel Warren	- Project Worker for shifts
Russell Smith	- Project Worker for shifts
Karen Bosnor	- Student Social Worker
Kerry Goodwin	- Student Social Worker
Elle Hailey	- Bank Worker
Marylyn Pullum	- Bank Worker
Sue Sandeman	- Bank Worker
Stephanie Santerre-Ware	- Bank Worker
Sophia Dunbar	- Bank Worker
John Campbell	- Bank Worker

Volunteers

Judy Acland	- Therapy Service
Angela Carter	- Therapy Service
Lyndise Tarbuck	- Therapy Service
John Campbell	- Crisis Service
Mariana Florea	- Crisis Service
Jackie Lloyd	- Counsellor
Jeanette Johnson	- Counsellor
Maria Brooks-Dowsett	- Counsellor
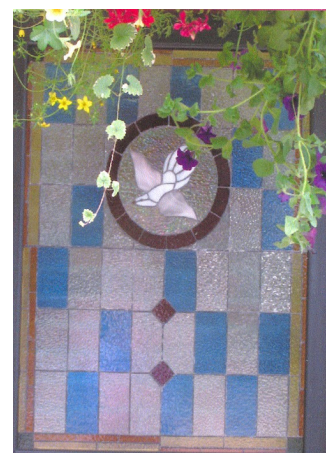
Sessional Therapists

Debbie Juby	- Reflexologist
Merril Mathews	- Counsellor
David Dickinson	- DBT Group facilitator
Meg	- Pat Dog
Rev. Richard Smith	- Chaplaincy Group facilitator
Janet MacDonald	- Nutrition Group facilitator
David Proven	- Educational Tutor
Becky Dowling	- Parenting Classes

Steering Group

Heather Castillo	- Chief Executive, Chairman Steering Group
*Reg McKenna	- Involving Essex, Chairman Haven Board Directors
Judy Acland	- Deputy Chairman Haven Board Directors
*Val Sach	- Haven Director and Treasurer
Pernille Petersen	- Co-ordinator Colchester Nightshelter, Haven Director
Jackie Tizzard	- General and Development Manager Phoenix Group Homes, Haven Director
*Catherine Hayes	- Haven Director
*Toni Aldous	- Carer, Haven Director
*Helen Strivens	- Service User, Haven Director
Dan Kessler	- Director Colchester Mind, Haven Director
Tina Hurley	- Area OT Lead, NEPFT
Emma Ling	- The Lakes, NEPFT
Julie West	- Mid Essex PCT
David Maby	- North East Essex PCT
Lt. Col Hughes	- Consultant for A & E
Thomas Fitzsimmons	- Housing Strategy Officer, Colchester Borough Council
Jackie Liveras	- Associate Director Colchester, NEPFT (minutes only)
Patrick McGlynn	- Region Personality Disorder Lead (minutes only)
Insp. Tony Dale	- Col Police Mental Health Liaison Officer (minutes only)
Dr. Neil Coxhead	- Consultant Psychiatrist, NEPFT (by invitation)

Haven Board of Directors

*Reg Mckenna	- Chairman
Judy Acland	- Deputy Chairman
Heather Castillo	- Company Secretary
*Val Sach	- Treasurer
*Helen Strivens	- Director
*Toni Aldous	- Director and Carer
Pernille Peterson	- Director and Co-ordinator Colchester Nightshelter
Jackie Tizzard	- Director and General and Development Manager Phoenix Group Homes
Dan Kessler	- Director and Director Colchester Mind
*Catherine Hayes	- Director

* Denotes use of Mental Health Services

www.thehavenproject.org.uk