Social inclusion and personality disorder

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Abstract

Purpose – This study aims to investigate 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 and aims to examine efforts which attempt to reverse this social exclusion.

Design/methodology/approach – 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.

Findings – An examination of emerging themes, and the interplay between themes, gives insight into what participants considered 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.

Practical implications – 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.

Social implications – The Haven has emerged as a unique model where therapeutic community principles have been combined with a crisis unit which shows that it is possible to work effectively with a relatively large number of people with personality disorder, well in excess of 100 at one time, many of whom had not made progress in other service settings, resulting in significant financial savings to the health, social care and criminal justice system.

Originality/value – This study offers contributions to knowledge in terms of the service design and proposes a new model of recovery in personality disorder. This is defined as a journey of small steps highlighting recovery as a process rather than a goal, leading to the emergence of the new concept of transitional recovery.

Keywords Personality disorder, Transitional recovery, Social inclusion, Personality

Paper type Research paper

There is considerable evidence, as summarised in the Reaching Out Action Plan (Social Exclusion Task Force, 2006) that people with a personality disorder diagnosis comprise a client group which suffers significant social exclusion and which has a high impact on health and other public services. This paper offers a profile of the Haven Project in Colchester which has attempted to reverse this social exclusion as an aspect of the recovery process.

The Haven is a voluntary sector organisation which provides a range of day and residential respite services for people with personality disorders living in North East Essex. The service was developed in 2004 as one of 11 pilot projects across the country to implement service development targets set out in Personality Disorder No Longer a Diagnosis of Exclusion: The Policy Implementation Guidance (Department of Health, 2003). The organisation and services provided were originally planned around the views of local service users with personality disorder (Castillo, 2003) and they continue to play a major role in the development of the service and policy. The underpinning ethos of The Haven combines key elements of the therapeutic

Great thanks are due to The Haven Research Group and to the clients, staff and board of The Haven Project who have worked so hard at forging successful ways forward in the journey to social inclusion. Thank you to all those people who have donated to, and raised funds for, The Haven. Thank you to Research Supervisors at Anglia Ruskin University for their inspiring support. Finally, a special thank you goes to Nick Benefield, and the National Personality Disorder Team at the Department of Health, for their years of invaluable help.
community model with a crisis house and with recovery concepts. It is a service which emphasises supporting individuals to identify their own goals in their journey of recovery; to understand and manage difficulties; and to take control of their life and destiny. 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 five bedrooms, which constitute the Crisis House, where people may find respite from outside pressures for one night or up to three weeks. 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 18 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 and is the antithesis of what can sometimes be the stark clinical reality of an NHS environment (Figure 1).

The service soon began to demonstrate significant impact in terms of improving mental well-being and reducing use of health and other services, including an 85 per cent drop in psychiatric hospital admissions for its service users (Castillo, 2009). By 2006, The Haven was highlighted in the Care Services Improvement Partnership guide to the 10 High Impact Changes for mental health services as a personality disorder service demonstrating the impact of good practice that puts service users at the centre of decision making (CSIP, 2006).

In late 2006, as a response to the unique needs of people who have attracted a personality disorder diagnosis, The Haven began to consider issues around social inclusion. From its inception The Haven had espoused a recovery ethos, but its clients struggled initially with the challenging symptoms and crisis situations that this condition can cause. After two years of operation, however, a number of clients had achieved sufficient stability to begin to look outwards and assess opportunities in life:

The Haven should help us get voluntary work.

I now want to do my Access Course and I want to work in care.
Social exclusion can be exacerbated by the fact that the concept of personality disorder attracts stigma and discrimination. Short-term approaches for this diagnosis can also result in loss of progress due to the fragility of the recovery process for those who have usually had a very difficult start in life. The Haven’s solution to the above was to create a new category and concept at the project called Transitional Recovery. 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, suggesting a journey through transitional states. The philosophy of Transitional Recovery at The Haven means that progress is defined as a journey of small steps and making progress is not penalised by discharge but rather rewarded by being able to stay registered at the service and receive continued support. This results in less use of the service over time but a choice about whether to remain part of it.

Start-up funding was obtained from HM Cabinet Office, Social Exclusion Task Force and a Social Inclusion Unit was opened at The Haven in 2007, with a dedicated Co-ordinator, a part-time Assistant, a part-time Educational Tutor and a Parenting Classes Tutor. Plans were formulated to encompass all domains of social inclusion; income; benefits; housing; leisure; tackling stigma and discrimination; carers, families and children; education; voluntary work and paid employment. Transitional Recovery “took wing” and the Social Inclusion Unit’s many achievements are included in reports on The Haven web site, “Reports Page” (www.thehavenproject.org.uk).

Important developments in confidence building have also occurred, as part of the work of the Social Inclusion Unit at The Haven. This began with some visits to the Outdoor Centre on Mersea Island where Haven clients, of all ages, engaged in teambuilding activities and negotiating the assault course. The culmination of some of these wonderful days at the Outdoor Centre was to be brave enough to climb a tower and slide down a zip wire. Disabled clients, some even wheelchair-bound, negotiated this challenge with pride (Figure 2).

During the past six years Mersea Island has also offered other precious outdoor well-being pursuits in the form of Bushcraft activities and Care Farming (Figure 3):

A day here has helped me to ground myself and just be. The chickens don’t care how you’re feeling; they just want to be fed. I’m busy doing “real” stuff, being reminded of the food-chain and our place in it. Being productive and feeling valued.

Hopefully, it will also open up opportunities for future paid or voluntary work, to say nothing of the increased sense of well-being.

Figure 2 Finding my courage
Researching the process of recovery

As a new service, from its inception research structures were built into The Haven. Over a period of five years, in an effort to map the process of recovery for people diagnosed with personality disorder, research data was gathered from 60 Haven clients and additional family members and carers (Castillo, 2013; Castillo et al., 2013). Themes emerging from this research are presented diagrammatically below as a pyramid representing a hierarchy of progress. This map provides evidence that the creation of strong foundations, or healthy attachment, is crucial for people with personality disorder in achieving progress towards social inclusion. Each level of the pyramid is then discussed in sequence, from the base upwards (Figure 4).

Figure 3  Learning to love and be loved

Figure 4  The Haven Hierarchy of progress in personality disorder
Haven hierarchy of progress

The journey of recovery for personality disorder

A sense of safety and building trust. Clients had come to us with widely swinging emotions, chronic hyper-arousal, terror, rage, despair, hopelessness, guilt and shame. 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 or others:

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.

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:

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.

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:

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.

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 and creating a culture of warmth. The study also revealed the importance of feeling cared for as a finding and participants described care in terms of first contact and acceptance. 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 always look pleased to see you coming through the door.

It’s been excellent, a kind ear, a cuddle, cup of tea, respite when I need it.

I don’t do hugs, but I do now.

A sense of belonging and community. Our families are supposed to provide a place in which we feel safe and learn to trust. 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:

I isolate and can’t mix with people, but I can see people in The Haven, you are the same as 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:

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.

Voicing their newly developed sense of healthy attachment, participants began to regain, or gain for the first time, a sense of home and family:

It’s like having a family all under one roof.

It’s the family I never had.

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. Family member participants set the scene with some of their observations about behaviours:

She was stoned on Wednesday before we turned up. I’m also aware she’s sold drugs, I caught her out at Christmas time drug dealing to children.

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

Living too long with untenable emotions and in a state of chronic hyper-arousal, people with a personality disorder diagnosis 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, these become deeply ingrained coping strategies and this damaging expression of pain needs containing measures.

All this represents boundary setting and the social and moral limits that need to be present, clear and known to create a safe community. The Haven’s Acceptable Behaviour Policy was created in collaboration with its clients and is administered by the clients:

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

The process of democratically setting and applying boundaries is a learning process which addresses respect, not just for the reality of self, but also for the reality of others, enabling an individual to take control and responsibility:

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, 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:

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.

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.

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.

Containing experiences and developing skills. Recreating healthy attachment opens the door to therapeutic work. Healing is about integrating experience by making sense of what has happened. Prior to this stage, reality has 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:

I’m 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.

I think my new skills have fundamentally been to be able to stop and question the reality of the situation, 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.

**Hopes, dreams and goals and their relationship to recovery.** 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:

> 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.

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:

> 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.

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:

> Before The Haven I wanted to die. Now I want to live.
> I look to the future more than I ever did. It exists now.
> My goal is to get through college and do my degree.

**Achievements, identity and roles.** What participants 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 per cent 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:

> 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.
> 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 while I was on the street, it wasn’t my fault.

Participants spoke of external achievements in terms of the different domains of life and social
inclusion such as homemaking, parenting, leisure activities, education, voluntary work and
employment, and how these achievements had given them a role and contributed to growing
confidence:

> Before I came to The Haven I was locked up in a secure unit. I used to wake up every day wanting to die,
trying to find a way to actually harm myself, to actually end it all, and now I’m actually going to college.
> I’m actually working now and earning a reasonable amount of money. 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 so
difficult, my self-esteem and confidence have risen massively.

**Transitional recovery.** Over time participants began to express fears about losing their secure
attachment and sense of home if they recovered. Many 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:

> 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.
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.

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, 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, defining progress as a journey of small progressive steps which would not mean discharge but ensure an individual’s self determined retention of support at The Haven:

I don’t think we should clip our wings; we just need a nest to come back to.

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

The vehicle of implementing Transitional Recovery became the Social Inclusion Unit at The Haven, the additional part of our service which developed as a product of organisational learning, and where clients continued to work specifically on personal development skills related to their aspirations and achievements outside of The Haven. This led to the development of a Transitional Recovery Group at The Haven devoted to personal development skills and building connecting threads to other enabling and confidence building activities such as the Activities Camp, Bushcraft and Care Farming.

Conclusion

The Haven has emerged as a unique model in personality disorder services where therapeutic community principles have been combined with those of a crisis house and where recovery principles and social inclusion activities have developed as an integral part of the service. The Haven offers crisis support, therapeutic work and a social inclusion service as a continuum of support under one roof. The type of service model and the lessons on the journey of recovery show 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, at different stages in their journey of recovery, many of whom had not made progress in other service settings. This has resulted in significant financial savings to the health, social care services and the criminal justice system.

Transitional Recovery re-enforces The Haven ethos of reward for progress rather than a response to illness and dysfunction which characterises mainstream services. It 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.

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About the author

Heather Castillo worked for many years in Mind Organisations in Essex, developing advocacy for people with mental health problems. She has worked with service users, training and supporting them to become legitimate researchers in the mental health arena, and her work with them regarding the personality disorder diagnosis was published as a book entitled Personality Disorder, Temperament or Trauma? Nine years ago, she helped to set up, and became the Chief Executive of, The Haven Project which is a National Innovation Site for the support and treatment of personality disorder. She has published a chapter in The Art and Science of Mental Health Nursing, Second Edition entitled “The person with a personality disorder” (Open University Press). In 2011 she completed a doctorate about the process of recovery in personality disorder and has co-authored a recent article in International Journal of Social Psychiatry based on this research. Heather Castillo can be contacted at: Heather.castillo@thehavenproject.org.uk

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