Experiencing a Recovery-Oriented Acute Mental Health Service:
Home Based Treatment from the Perspectives of Service Users, their Families and Mental Health Professionals

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Introduction

The recovery approach in mental health has gained strength over the last decade. It had several origins, but in particular it arose out of the efforts of mental health consumers who worked together to publicise personal stories about what helped and hindered recovery, and who engaged in advocacy, networking, peer support and the establishment of innovative, consumer-operated services. A widespread emphasis on self-help and consumer involvement in health issues in Western countries provided a context for the growth of the mental health consumer movement (Deegan, 1988; O'Hagan, 2003). Also, research studies and developments in the field of psychiatric rehabilitation, emphasising renewed optimism and hope for people who experience mental illness, helped the recovery movement grow (Anthony, 2000; Harding & Zahniser, 1994).

New Zealand has been a leader in adopting recovery approaches for our mental health services, being one of the first countries to make the recovery vision integral to our national mental health policy. The Mental Health Commission's *Blueprint for Mental Health Services* (Mental Health Commission, 1998) directed services to "…use a recovery approach…" (p.2) Other countries, too, are increasingly emphasising recovery orientations at the heart of mental health service delivery (Australian Health Ministers, 2003; New Freedom Commission on Mental Health, 2003; NIMHE, 2004). But though recovery is fast becoming accepted in principle, it is not yet entirely clear what a recovery-oriented mental health service system would look like in practice, and how the services within it would best foster recovery.

To date, most published discussions of recovery in mental health have focused on individual journeys, emphasising them as unique and self-directed (Deegan, 1988; Lapsley, Nikora and Black, 2002). This suggests that recovery solutions will not be of the one size fits all type, but that a range of service models could potentially support the recovery process. Also, recovery is understood as being assisted by social and organisational processes that are far broader than mental health services alone. This means that stand-alone mental health services will only be part of the picture in promoting recovery for individuals.

Although there is a long way to go in developing and implementing recovery-oriented services, there is a consensus starting to emerge around the features that characterise such services (Farkas, Gagne, Anthoney & Chamberlin, 2005; Jacobson & Curtis, 2000; Lapsley, 2004; Mental Health Commission, 2004; Onken, Dumont, Ridgway. Dornan & Ralph, 2002). From our examination of literature on this topic, we can assert that a recovery-oriented mental health service, one that supports service users to lead their own recovery, will be characterised by the following features:

- a recovery philosophy
- accessibility
- services available in home and community settings
- diverse workforce, showing respect for culture and individuality
- service user advocacy and leadership
- choice of services and treatments
- delivery of treatments that are safe and effective and help with recovery as well as reducing symptoms
- availability of peer support and other forms of consumer-operated services
- respectful two-way communication
- provision of useful information
- collaboration with service users in decision-making
- conveying hope and optimism

- providing reassurance and safety

- 'whole of life' approach

- avoiding force against service users and upholding their rights

- countering stigma and discrimination

- encouraging appropriate involvement from family and friends

- priority on enhancing and maintaining wellness

- encourages access to good physical health care

- flexible services providing good linkages with services and supports relating to employment, housing, and community participation.

Recovery Research and Mental Health Services

How can research help to achieve the implementation of recovery approaches? So far, most research on recovery has focused on elucidating processes from the point of view of the individuals who experience them. For example, Lapsley et al. (2002) described key themes and processes in recovery following an analysis of narratives from 40 Māori and non-Māori New Zealanders who had recovered from disabling mental health problems. Other studies focusing on the recovery process in individuals include Garrett (1998); Tooth, Kalyanansundaram & Glover, (1997), Baker & Strong (2001), Jacobson (2001) and Mental Health Foundation (2001). A consensus is emerging via reviews of this burgeoning literature on key themes in recovery, which include individual agency, peer supports and social inclusion as well as helpful mental health services (Allott, Loganathan & Fulford, 2002; Ralph, 2000a, 2000b).

So far there have been relatively few investigations into services that are moving towards recovery-oriented practice, involving examinations of how such services impact on service users and their families.[2] This is particularly so in relation to service provision for people experiencing acute mental illness, perhaps because recovery ideals seem to have been more easily aligned to rehabilitation rather than to crisis services. Consensus is emerging on the key features that service users say they want and that recovery-oriented service providers say will work, but little research has been done on the translation of the recovery orientation into practice.

Researching recovery in an era of evidence-based practice raises issues around research paradigms and research values (Anthony, Rogers & Farkas, 2003). Recovery research, as an emerging field, is essentially consumer-focused, may have small numbers of participants in studies, and more often than not uses qualitative and interpretive approaches. Mainstream mental health research, in contrast, is dominated by quantitative methods. Randomised controlled trial designs, developed to test drug efficacy, are increasingly used to test other types of intervention, and are the most influential form of research in a climate of evidence-based practice.

There is a place in health research for all types of method, but in recovery research person-centeredness and service user involvement are central, and these values sit well alongside qualitative approaches. In the attempt to understand individual processes and experiences in new ways, and to evaluate services based on new ideas and values in politically sensitive climates, qualitative approaches are particularly needed. Such approaches elucidate subtleties of process and meaning and are sensitive to competing viewpoints and narratives. Although qualitative studies are unable to pronounce on outcomes with the degree of certainty achieved by quantitative studies, with their statistical designs, they tell us more of what we need to know about the quality of mental health service delivery.

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[2] The *Psychiatric Rehabilitation Journal* is a good source of literature on recovery-oriented services.

Home Based Treatment for People Experiencing Acute Mental Illness

Community-based services for acute mental illness would seem to be more compatible with a recovery-orientation than inpatient hospital provision, given that they occur in less restrictive settings and are more capable of focusing on strengthening support via the service user's existing social networks.

A range of creative treatment options have been designed over the last decades to offer realistic, community based treatment alternatives to inpatient care. As well as Home Based Treatment (HBT) – also known as Crisis Resolution, Acute Home Treatment, Intensive Home Treatment and Crisis Management – these alternatives include day care, crisis respite/ housing and community residential or transitional units.

What exactly is Home Based Treatment? By definition, it is treatment in the home setting, as opposed to in a hospital setting, and is distinguished from treatments offered through mainstream community mental health services in that it is specifically targeted at people who would otherwise require admission and treatment within an inpatient environment. It is essentially a 'hospital at home' service, targeted at people who are acutely mentally unwell, which

– offers an alternative to admission

– is open after hours

– provides a rapid response

– prevents admission, and

– facilitates earlier discharge from inpatient care. (Sainsbury Centre for Mental Health, 2001)

HBT services are designed to fit a context, rather than being all exactly the same. Services that work well have adapted the HBT model to local needs and have their own clearly articulated aims, objectives and philosophy.

HBT is not usually intended to replace inpatient services in a mental health service. Rather, it is an additional treatment option that should be integrated into a whole system of care. It was originally based upon the rationale that by providing intensive acute treatment in the community the need for hospital admission could be significantly reduced. The development of HBT owes much to the pioneering work of John Hoult in Australia and others in North America and Europe (Hoult, 1986; Marks, Conolly, Muijen, Audini, McNamee, Lawrence, 1994; Muijen, Marks, Connelly & Audini, 1992; Smyth, 2003; Smyth & Hoult, 2000). Historically, HBT was aligned with the deinstitutionalisation movement, rather than the more recently identified recovery approach. However, on the face of it, HBT seems very congruent with recovery values, given that its delivery means working collaboratively with service users, family/ carers and existing community providers (Reet, Gingell & Littlejohns, 2003).

Recovery possibilities are evident in the crisis work that is at the heart of HBT, as the following quotation demonstrates:

> People, alone and together, have a need for self determination and self sufficiency. A crisis in someone's life can be a critical turning point, presenting both opportunity and danger. Successful resolution of a crisis requires a collaborative approach between tangata whaiora/ service users, whanau/family and clinicians. It is a working partnership using all available resources. Overcoming a crisis successfully maximises opportunities for personal growth, self determination and self sufficiency while minimising any risks associated with the crisis.
> (Capital and Coast HBT team statement of philosophy, adapted from Roberts, 2000).

Home based treatment of acute mental illness is now considered a best practice form of service internationally. Within the United Kingdom the development of Crisis Resolution/Home Based Treatment teams are recommended within their National Service Framework for Mental Health (Department of Health, 1999) as an essential part of comprehensive mental health service provision.

RESEARCH ON HOME BASED TREATMENT

Most research on HBT occurred before the recovery paradigm had emerged. Its focus has been on evaluating HBT as an appropriate and effective (and possibly cheaper) alternative to hospitalisation for people experiencing acute mental ill health.

Hoult and colleagues carried out a randomised controlled trial in Sydney, Australia that demonstrated that service users could be successfully treated in the community as an alternative to hospital admission (Hoult, 1986). The research team reported that the alternative, home based community treatment, reduced admission rates, improved clinical outcomes, cost less to operate and resulted in overall higher levels of service user and carer satisfaction with treatment. A number of other studies have validated these earlier findings, establishing HBT as safe, effective and feasible for up to 80% of service users who would ordinarily be treated in acute in patient hospital settings (Dean & Gadd, 1990; Muijen et al., 1992; Smyth & Hoult, 2000)).

Models for delivering HBT have developed over time, with a stronger focus on brief interventions and crisis resolution. This means that more recent research may be describing somewhat different kinds of service delivery than the earlier studies did. Joy, Adams & Rice (1998) undertook a review of reports of research on crisis intervention (HBT had its roots in crisis intervention), finding that crisis intervention services were both viable and acceptable models of treatment. The review summarised the advantages of the crisis intervention approach, 'a form of home care' as including improvements in cost effectiveness, reduction in the number of patients lost to follow up, less family burden and greater acceptability to families and patients alike.

A number of recently published evaluations also cite reductions in admission rates and duration of inpatient stay, alongside improvements not only in service user satisfaction but also in job satisfaction for staff working within such teams (Brimblecombe, Sullivan & Parkinson, 2003).

Owen, Sashidharan & Edwards (2000) carried out a postal survey of 229 mental health trusts and 123 purchasing authorities in Britain. An overwhelming majority – 97% of providers and 100% of purchasers – indicated their support for the home based treatment and their acceptance of research findings that such an approach resulted in greater patient satisfaction.

Despite the range of positive findings reported in the literature, enthusiasm for the approach needs to be tempered with caution and Minghella, Ford, Freeman, Hoult, McGlynn & O'Halloran, 1998 warn against home based treatment approaches becoming seen as a panacea. Some service users will need and some will prefer an episode of inpatient or non-residential treatment. Brimblecombe, Sullivan & Parkinson (2003) investigated reasons for, and predictors of admission, among service users accessing an intensive home treatment service in Hertfordshire, England. 21.1% of people treated by the home treatment service required admission at some point in their care episode, most frequently because of risk to self.

The issues of economy and effectiveness are important, but Orme and Cohen (2001) argues that demonstrations of cost savings and effectiveness do not count for anything if service users do not feel they benefit from the service. More recent evaluations have explored a range of factors, both clinical and non-clinical, in attempting to understand why it is that HBT is often times more successful and preferred among service users. More recently, too, there have been a wider range of methods used in HBT research, including more use of qualitative methods, which have added to our understanding of how HBT works (Minghella et al., 1998); (Bracken & Cohen, 1999; Brimblecombe & O' Sullivan, 1999; Harrison, Marshall, Marshall, Marshall, & Creed, 2003).

The need to explore the views of service users in greater depth has been suggested by Burns & Santos (1995), who rightly assert that although most investigations of HBT yield high levels of expressed satisfaction, this needs to be further explored. As Williams (1995) suggests, basic measures of client satisfaction based on questionnaires sometimes overestimate levels of satisfaction, whereas interviews studies can more accurately capture the subtleties of feedback on

services. Cohen (1999) used a narrative approach when researching the experiences of Bradford home based treatment service users.

The views of family/carers are also ripe for exploration. Some studies have looked at 'family burden' as an aspect of HBT service delivery, with a proportion of these reporting reduction in stress and burden in family members over time, when measured via a variety of rating instruments (Dean, Phillips, Gadd & Joseph, 1993; Howey, 2000; Marks et al., 1994). One study from Victoria, Australia, though, found that service users and family members were not satisfied with short-term treatment and a crisis intervention approach. Frequent changes of staff, lack of continuity in relationships and limited involvement were what they were unhappy with (Kulkarni, 1996).

A Canadian study reported that although expressed family care burden was high at the commencement of treatment, this decreased markedly by the time of their relative's discharge (Howey, 2000). This study echoed early findings from research that families and 'patients' preferred home treatment rather than hospital treatment and were highly satisfied with care (Dean et al., 1993; Marks et al., 1994; Muijen et al., 1992; Smyth & Hoult, 2000).

Factors that may be important for families include greater collaboration and involvement in care decisions, feeling better informed about mental illness and ways of dealing with difficulties that may arise, and hence developing greater competence and confidence in assisting with recovery (Bracken & Cohen, 1999; Hoult, 1986; Sainsbury Centre for Mental Health, 2001).

Finally, the views of staff working within HBT services are worthy of more detailed exploration. Concerns have been raised in the past about the difficulties of providing community care, including the impact on staff morale (Wykes, 1995). Despite these concerns, negative impact on staff does not appear evident in the few studies that look at staff working within or alongside HBT. Howey (2000) found that positive attitudes to HBT became even more positive following the experience of working with the approach. Smyth & Hoult (2000) are quite clear in their assertion that HBT is not associated with low morale or burn-out among staff. Stress levels among HBT staff have been compared with other mental health teams, with no significant increases in burn-out or dissatisfaction noted (Minghella et al., 1998).

What does appear evident, however, is the need for appropriate skills training and support to HBT staff. It seems that staff working in HBT services need to be highly experienced in order to cope with the demands of dealing with high levels of disturbance on a daily basis outside of the hospital setting (Brimblecombe et al., 2003).

HOME BASED TREATMENT IN NEW ZEALAND

To date, there appear to have been no published reports or descriptions of HBT services within New Zealand, despite growing interest in the potential application of the approach. It does seem some services within New Zealand may be offering HBT in an informal way, or at least offering some of the components of service delivery which make up an intensive home treatment service. This is particularly the case in remote areas where the availability and access to in patient facilities may be limited by geography.

A recent reconfiguration of adult mental health services undertaken by Wellington's Capital and Coast DHB during 2001-2002 provided the opportunity for the development of a Home Based Treatment team, as an integral component of reformed services. It is this team that is the subject of this research project, and we describe it here.

The Capital and Coast HBT team is integrated into existing service provision with links to Acute Day Care, Crisis Respite and Community Assessment and Treatment team (CATT) services, enabling cover over the 24 hour spectrum. The model adopted by Capital and Coast DHB Mental Health Services is one where the focus of treatment is on short term intervention with ongoing or continuing care being provided via well-established community mental health teams. The recovery emphasis is inherent in the philosophy statement relating to crisis and opportunity, referred to earlier in the literature review.

During the first year of the HBT service a number of positive outcomes became apparent. Anecdotal reports from service users and families appeared to support the function of the service in averting admission from the inpatient unit and helping to

sustain service users in their usual environment. In addition, staff within the new service reported feeling energised and remotivated by working with very unwell service users in the community. HBT seemed to be providing the opportunity for personal and professional growth.

Referral and output statistics from the ongoing audit of the team's work demonstrated a picture of a busy, albeit small service that appeared to be effectively treating people outside of the usual hospital setting.[3] During the first year, the time period during which this research was undertaken:

> 241 referrals were received, Community and Crisis Team referrals making up the majority. Referrals from these sources involved accessing the service as an admission alternative. The Inpatient service also made up a significant body of referrals in order to initiate early discharge and transition to community care.

> The acceptance rate of referrals increased from 57% to 75% to over 90% at the end of the first year, as the role and potential uses of HBT as an adjunct to or alternative from hospital admission were increasingly understood and made use of. Review and communication of operational criteria to referrers was a relevant factor in improving the number of appropriate and timely referrals.

Only 21 (11%) of tangata whaiora/service users treated by HBT team in the first year required inpatient admission.

61% of people referred to and treated by the HBT team required ongoing community care, suggesting the team is providing a service to tangata whaiora/service users with severe and enduring mental illness.

An internal survey conducted in May 2003 found the service was valued by other Capital and Coast mental health service providers, with high levels of satisfaction from staff being reported.[4]

In total the team has treated 339 service users since the commencement of the service almost two years ago.[5]

The opportunity to undertake an exploration of the work of the team, beyond a traditional summative evaluation prepared for the provider, was seen as an opportunity to look at this particular HBT service in more depth using recovery perspectives.

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[3] Information provided via access to internal records and reports of Capital and Coast DHB General Adult Mental Health Services.

[4] Unpublished Capital and Coast District Health Board report.

[5] Summary figures as at April 2004.

Research Aims

This research investigated an innovative home based treatment service that was trying to use a recovery philosophy in its practice. Its aim was to utilise narratives of service experience, obtained from service users and their families as well as service providers, in order to develop understandings of how particular practices might promote recovery in times of acute need. This qualitative study, with its narrative approach, was designed to contribute to the research literature on home based treatment as well as to the emerging literature on evaluating services against identified recovery dimensions. Finally, we wished to give some guidance in local debates around recovery-oriented provision of acute services.

Research Methods

METHODOLOGY

The research was qualitative in nature, utilising interviews to explore the experiences of those receiving or providing home based treatment services. Interviews were analysed using narrative and thematic techniques, to arrive at a description of home based treatment from four different viewpoints: those of service users/tangata whaiora[6], family/whanau[7], Home Based Treatment team members and allied professionals.

The research team was developed as a collaboration between New Zealand's Mental Health Commission and Capital and Coast District Health Board, which provided the service. The research team was interdisciplinary, including people with active involvements in nursing, psychology, Māori mental health, and consumer issues and advocacy. Four of those who worked on the project had no close links with the HBT service, whereas one researcher had been involved in setting up the service and another was currently a nurse on the HBT team.

STUDY DESIGN

This is a small, qualitative interview-based study focused on the Home Based Treatment Service of Capital and Coast District Health Board in Wellington, New Zealand. It was decided to focus most strongly on service user experience, and that led to a decision to conduct more interviews with service users than with family members. Since the HBT team was small, all those current members who had substantial experience with the team were interviewed, as were a selection of allied professionals who worked alongside the team.

6 A Māori term for service user.
7 Commonly understood Māori term for family grouping/extended family.

ETHICAL ISSUES AND CONSULTATION

Prior to commencement of the research, consultation was undertaken with Capital and Coast mental health services, particularly with those involved in the service configuration that included the HBT team, as well as Māori Mental Health Services and Health Pasifica. Capital and Coast Health's Consumer Advisor was also approached for advice and guidance.

Ethical issues pertinent to the research design included informed consent, confidentiality and safety issues. All participants were given a letter explaining the research process and informed consent was obtained at each interview. They were reassured that their participation or not would have no effect on future services (particularly important given that some of the research team worked in services). Confidentiality was assured, other than in relation to those working on the project.

In relation to support and safety, potential participants were also offered the use of a free phone telephone number to call for advice and information. All participants were advised that they could have support people during the interview. They were phoned within one week of the interview to ensure there were no ongoing issues resulting from the interview. All participants were given a koha in recognition of their time and effort in taking part in the research.

Ethical approval for the project was sought and obtained from the Wellington Ethics Committee.

PARTICIPANT SELECTION

Thirty interviews were conducted in total: 12 with service users/tangata whaiora; six with family/whanau; five with HBT team members; and four with allied professionals. The selection process was different for each group.

For the service users, all clients who had made use of the HBT service were identified, listed and assigned a number. This database was reduced once those who were known to have moved, were no longer contactable or were currently unwell were taken from the list. In order to ensure that Māori tangata whaiora were adequately represented in the study, purposive sampling was used, and of nine potential interviewees identified in this way, three were interviewed (four were not contactable, one lived too far away and one declined). In order to yield the other 20 possible participants, each sixth person was randomly selected as a potential subject. Of these, two declined to take part and nine were unable to be contacted or had moved, leaving the remaining nine participants who had volunteered to take part in the study.

The selection of family/whanau members was initiated by asking the 12 service user participants whether they would be happy for their family member to be interviewed. Where approaches were made as a result of this process, all but one family/whanau member agreed to be interviewed, and as a result, six interviews were conducted with family members. In three instances, more than one family member (in all cases, these were both the parents of the service user) contributed to the interview, so in total, the views of nine family members were taken into account.

The research team was keen to include Pacific Island people in the study, and again, purposive sampling was used. However, very few Pacific Island people had used the service, and neither of the two contacts with potential participants led to interviews.

In relation to service providers, criteria for selecting HBT team members for interview were that they should have worked for the team for a minimum of four months and be currently working for the team. These criteria led to the inclusion for interview of all of those involved in delivering the HBT service at the time of the research.

Allied mental health professionals were selected from services that worked alongside or referred clients to HBT. Potential interviewees were selected by analysing referral data and determining clinicians who had made more than one referral to HBT. From this list six staff were randomly picked, two of whom declined to participate. The remaining four agreed to be interviewed.

INTERVIEWING

Interviews were conducted by four members of the research team. An interviewer with a consumer background interviewed service users, their families and most of the HBT team members; a Māori interviewer interviewed all tangata whaiora and their whanau; and a research team member who was part of the HBT service interviewed the allied professionals.

Interviews were conducted mostly in their own homes (service users and families) or in places of work (HBT team members and allied professionals).

Interview schedules allowed for open-ended interviewing, and contained prompts that encouraged an indepth exploration of experiences of home based treatment. Interview schedules were separately designed for each type of interviewee (family, service user, etc) and covered life before HBT, experiences of mental illness, experiences of HBT and recovery.

Some demographic questions were asked in the interviews, and further information was obtained from client records.

ANALYSIS OF DATA

Interviews were recorded by means of a digital voice recorder, downloaded and then transcribed. Interview files were imported into N*VIVO, a qualitative data analysis programme. Interviews were coded according to initial categories developed from the interview schedule. For service users and families, the initial categories were based around a narrative structure allowing 'the story' of HBT experience to emerge, whereas the HBT and allied professional interviews were categorised more thematically. The research team examined print-outs from the initial categories and in a group meeting identified key themes and sub-categories. The process of writing up an initial report on the results involved further coding in order to clarify data relating to sub-themes, and occasional recoding of data to more accurately represent it. N*VIVO allows for this particularly interactive style of translating data into a written report.

FOLLOW-UP WITH HBT STAFF

Members of the HBT team, as well as mental health service managers, were given the opportunity to discuss and provide interpretations for the emerging findings of the study, in two separate sessions. Some of their reactions and concerns are reported in the discussion section of this report.

PARTICIPANT ATTRIBUTES

Of the service users/tangata whaiora, three-quarters were women. Their ages ranged from 21 to 48 and the average age was 34. As mentioned, three were Māori and the other nine were non-Māori New Zealanders.

Two individuals lived alone, four lived with parents, four lived with their children and one lived with a partner and child. The remaining person moved in with relatives during their time with the HBT service. Eight of the 12 were employed at the time HBT was involved in their care, and some were involved in studying or parenting.

Only two were experiencing their first ever episode of mental illness at the time of HBT use and for one other, it was their first experience of mental health services. The other nine had used mental health services and all had previously been hospitalised, some many times. The length of involvement with HBT varied greatly, ranging from three days to 44 days. The average length was 21 days. No data on legal status was collected; however, the theme of choice and compulsion was explored during interviews.

Five interviewees had been referred to HBT from the inpatient service, four from the Crisis Assessment (CATT) Team, one from a community mental health service, one from a GP and one from a Māori mental health service. Following their exit from HBT, eight were referred to community mental health teams, three to an early intervention service and one to Māori mental health.

Of the nine family members/whanau, three were Māori. Four of the family members were mothers of the participant, three were fathers, one was a husband and one was an aunt.

Of the five HBT members, two were non-Māori New Zealanders, two were English and one was Samoan; there were three women and two men. Length of service in the team ranged from six months to two years, with the average length being 12.8 months.

Of the allied health professionals, two were non-Māori New Zealanders, one was Māori and one was Asian; and three were women. One was a social worker, one a staff nurse at an inpatient unit, one a psychiatric registrar, and the other a community mental health nurse. All had referred clients to, or worked alongside, the HBT service.

Research Findings

The findings of this study are presented in five sections. In the first three sections we draw on the narratives of service users/tangata whaiora and family/whanau members to describe home based treatment; and in the last two sections we explore the perspectives of HBT team members and allied professionals.

1. PATHWAYS TO HOME BASED TREATMENT: VOICES OF SERVICE USERS/TANGATA WHAIORA AND FAMILY/WHANAU

Criteria for access to HBT involved experiencing an episode of mental illness severe enough to warrant inpatient treatment. We asked interviewees to tell us in their own words about their experience of mental illness and the events leading up to using the HBT service.

Some of the service users reported increases in symptoms leading up to a crisis situation, and a few mentioned stresses that led up to their episode of illness. These stresses included being separated and losing custody of a child, and exam pressure.

Various mental illness conditions were mentioned, including bipolar, depression, schizophrenia, psychosis, anxiety and anorexia. The accompanying feelings and states of mind included "anxious", "agitated", "out of control", "scary", "unsafe", "down", "high", "self-harm" and "stressed".

Some interviewees said only a little about their illness – "things were distorted in my mind", "trying to hurt myself real bad", "I was just so high" – whereas others gave much fuller descriptions of how it was for them, emphasising catastrophic thoughts and emotions, sometimes accompanied by uncharacteristic behaviour, such as out-of-control shopping and/or increased use of alcohol and drugs. One young adult described his experience as follows:

> "I developed this belief that I had some sort of super powers revolving around reading other people's minds…. But then it developed into other people could read my mind as well, I was worried about that and then I had this whole idea that this guy was against me and he had a vendetta against me and I believed he was trying to kill me and he was going to poison me in my food. I had to have mum taste my food before I ate it because I was convinced he was going to poison me…and I thought that I was Jesus; super powers to heal people and this had all sort of developed overnight."

As mental health problems worsened, service users or their family or friends contacted mental health services. HBT was not the first port of call (referral sources for HBT were described earlier); some had spent time in hospital and had been discharged early into the care of HBT, whereas others were referred via services located in the community.

Those who had been inpatients were usually visited on the ward by someone from HBT; for others, the first meeting with HBT occurred at home or at a mental health service. Most described the initial meeting with HBT in favourable terms, with the team members making a good impression on service users and families. In that context, though there were several comments about how many mental health workers had been met recently, and one family member said that this was detrimental to beginning a good relationship with the HBT service:

"Everywhere he went there were different faces and that was really stressful, really unhelpful, because he felt that he had made a significant connection to the very first people he saw when he was really unwell…He told them he was manic, he told them all this stuff about himself that he had never told anybody before…then every time he went to see different people he would start his story again… So by the time he got to them [HBT] there was a barrier."

HBT is seen as being a choice, but with the alternative being hospital, it was not always seen that way by service users:

"I got out [of hospital] on the precondition that I would have that care from HBT….I don't know if I really had a choice, it was sort of something that was implemented for my safety and well being."

Another person mentioned being grateful that they had averted hospitalisation because of HBT:

"I was bordering on maybe under the MH Act, maybe bordering on going into hospital. I was quite unwell and not able to look after myself."

2. EXPERIENCING HOME BASED TREATMENT: VOICES OF SERVICE USERS/TANGATA WHAIORA AND FAMILY/WHANAU

In this section we look at accounts of assistance provided by HBT ("what they did"), and then at thoughts about the ways in which this assistance was helpful or otherwise ("how they were").

What they did: components of HBT service delivery

The helpful components of HBT, as described by service users and their families, were:

- practical help
- being around
- being available to talk
- providing advice
- providing information about mental illness
- hooking up with other useful services.

Practical help involved a variety of tasks, including picking up medication, helping someone get their household organised after returning from hospital, getting a video for someone's son, and organising a person to go walking with a service user who was agoraphobic. Help was given with daily routines that some people were too distracted to accomplish, like taking a shower, going to bed, taking medication and getting a meal. On occasion, the team backed up family members by encouraging boundaries or by intervening in an awkward situation, such as this one described by a family member:

"When I had taken J's Eftpos card off him and J. wanted some money and I didn't want to take him, just him and me, down to the money machine, because I knew that once we got there he'd be stimulated and he'd be quite hard to manage and get him back in the car and he'd just be unpredictable. So I said to them, "Would you take us down so J. can get some money and bring us back?" and they did that."

Just *being around* was helpful and comforting in itself:

"Just … their presence was what I found so reassuring, they were just solid people." *(family member)*

Being available to talk was also strongly emphasised as useful. As one service user said:

"I did have a minor crisis when I was at the respite house and I wanted to talk to somebody and one of the guys came and I managed to talk through some things that were bothering me and yeah, it was really good, actually."

Another said that the team would ask questions, like:

"How are you feeling? how was today? what have you got on for tomorrow? have you had tea? what's your mood like? what's your suicidal thoughts like? that kind of thing."

Family members also spoke with gratitude about talking through problems and issues with the team. Both service users and family members reported being given *helpful advice* about how to cope with symptoms, medication, services and the outside

world. One service user said:

"I had a really good conversation with [team member] and she managed to get me thinking rationally again, not irrationally."

Another said that team members talked to her about how to manage being back at work:

"Some of their advice was really good, for example protecting myself so I wasn't going to say something to someone and find that I've embarrassed myself or whatever."

Providing information about mental illness was a regular part of the team's service and what was given out was usually appreciated by family members and service users, although it was common for people to feel that they still needed to know more about what was actually going on. For example, one family member said that information helped them make "informed decisions", but another said that getting "heaps of A4 pages" containing jargon was confusing. As one put it, when you are in the home situation "the feeling of not having sufficient information or direction is still a pervading sort of feeling".

Some service users mentioned that it was hard for them to take information on board: "There was a lot for me to deal with." When information about mental illness was woven into general conversation, one service user said that he was reassured:

"…that people were much the same wherever they went…so I felt that I wasn't the only one…things like that, just what came up in the conversation. They told me little bits and pieces, so yeah…it was ok."

Another service user was less happy about that aspect of the service:

"I think that is one of the things that they could have done better. I can't remember anyone saying to me what was going on at the time. Nobody sat down and said this is a chemical imbalance in your brain and these things that you have been thinking and saying aren't real; I don't remember anyone doing that. It was more like they wanted to know what I was thinking and what my mood was."

People were keen to know about diagnosis and about what the future would hold, but such specific information was not necessarily available:

"I remember asking, 'How long is she going to be like this?' And the answer was always very vague, because I thought she was always going to be as sick as she was in the first three weeks, but they didn't like to put a number on it and say she'll be better in umpteen weeks."

"G. would be, like, 'How long will I have to be on this medication?' and they'd be, 'Think it will be a bit longer than that', so they had kind of opened him up to the idea that this would be something that would be ongoing for him but they didn't say this will be forever….He wasn't really accepting it that he was unwell, so you had to be quite careful."

One family found the resources given were depressing when it came to describing the future:

(Father) "It was supposed to be enlightening but it was…."

(Mother) "I think it was this whole tone of words…."

(Father) "Yeah, you're doomed but you'll learn to live with it."

HBT was able to *hook up with other services* to provide wraparound care. Family members were very appreciative about being given a break from the work of caring:

"They were incredibly accommodating, they arranged for an OT to pick him up in the morning and take him out to the day programme and then they would bring him back and do a handover, tell us how he had been during the day, and do a check on him, his medication, how he was, check in with us and then they'd go."

Service users had mixed feelings about the day services which several used. "Good, but not that good" was one comment, and another was that "the nurses were caring". One person felt safe there – "I didn't feel like I wanted to hurt myself anymore" – whereas another felt unsafe because people were allowed to leave the premises:

"I'm not well and these other people are unwell, and we're free, roaming, we could get onto a bus and go into the city, we could be lost forever."

A couple of service users had complaints about the environment of one particular day service. As one said:

> "It was good for me to get out and be able to talk to other people…[but] there were things I didn't like about the centre, because it was an ex prison, high prison windows and stuff, and you were allowed out but it was still rough, I found it very intimidating."

Night staff were sometimes provided so that families could sleep, or in one case, go away for a few days. When one family felt uncomfortable with apparently unprofessional attitudes from the night staffer, HBT had a registered nurse come in instead. Respite care could also be arranged; and for one family the one night that the service user spent away allowed them to sleep and "gave our batteries a bit more of a charge."

The CATT team psychiatrist was involved in care. On the whole, not very much was said during the interviews about psychiatric consultations (though people sometimes spoke of issues around getting medications right). What was said was mostly positive, such as this from a family member:

> "She also was really great to work with, also a terrific sense of humour, warm and professional, she was just really great, we could ask her lots of things, she told us lots of things."

How they were: interacting with HBT

Service users and families provided thoughtful comments during the interviews about why they had found HBT helpful (and in some cases, comment about how HBT could have been more helpful). To summarise, the reasons that they found HBT helpful were:

- their availability
- their flexibility
- people were treated as individuals
- HBT worked well together as a team
- HBT was supportive to the family as well as the service user
- strong relationships were established
- hope and encouragement was given about the recovery process

- HBT went the extra mile for people
- family and service users were included in decisions
- HBT dealt sensitively with issues around choice and control.

Overall, the evaluative comments about HBT were strongly positive, with service users and family members making remarks such as "wonderful", "a caring, compassionate bunch of nurses", "fantastic" "outstanding" and "just amazing":

> "They were there when I needed help….If they were not there, I probably wouldn't be giving this interview."

> "I found them to be non-threatening, non-medical people. They don't talk necessarily in a medical sort of way. They are like a bridge."

> "It's heaps more user friendly than anything else I've had. And I've had quite a bit!"

There were a few less positive comments, but these were more lukewarm than critical in nature.

The *availability* of the HBT team was often a marked contrast to other mental health services, in terms of service user and family experience. Only one person reported an instance of not being able to contact HBT on an occasion when there was a problem, and one would have liked longer contact, but otherwise it was all praise:

> "[They] said that I can ring them any time I like. Don't be scared to use us, and ring us up when you're feeling really low." *(service user)*

> "You just needed to ring them and if they weren't on the end of the phone, the longest I ever had to wait was 15 minutes." *(family member)*

> "They had mobile phones which we could ring to speak with them, rather than an answer service leaving a message. It's very important." *(family member)*

One service user had felt at the time that HBT was rather too attentive:

> "I found it kind of annoying having them coming around all the time, it's very repetitive. But when you are well you understand the reasoning behind why you are doing it, but when you aren't well you just don't."

The HBT team's *flexibility*, in taking individual's needs into account and coming up with practical solutions, was strongly emphasised in the interviews.

> "They were really flexible, like coming up with different ideas, flexible about when they visited and, like, if we asked something of them." *(family member)*

> "They'd pretty much bend over backwards to do what they could do for you." *(family member)*

Interviewees appreciated being *treated as individuals* and their responsibilities, such as work and parenting, acknowledged. Someone said how important it was that the team respected her own understanding of the problem:

> "They didn't criticise the way you were or think you're all just loopy up in the head, and that you were being a hypochondriac."

A number of interviewees commented on how HBT *worked well together as a team*. There were no complaints about lack of continuity when visited by different team members:

> "It was really quite sturdy, it was like the four people in the team had worked together for a long time before, even though I don't know if they had or not." *(service user)*

> "They worked really well together and separately. I couldn't have been blessed with a better team if I had asked." *(service user)*

HBT came across, in the interviews, as *supportive to the family as well as the service user* and, for the most part, this did not seem to involve any conflict. Family members were grateful that HBT made home care possible in a highly stressful situation:

> "Without them I don't think [we] could have looked after [him] at home, because having them come into the home, it was something we could structure the day around."

> "They strengthened her and us."

> Interviewer: "If HBT hadn't been available what would have happened?"

> Family member: "God knows, not me. I don't know. I could have run around with a machine gun and shot everybody!"

Service users also expressed gratitude for the help that the team gave to the family:

> "My parents more than anyone else needed them, my parents really needed the support."

> "She [my partner] needed as much help as I did, so they were really good with her…so she could understand a bit more."

> "I could see the benefit for Mum and Dad, because Mum took everything (responsibility for caring for me) upon herself. They gave her a break, gave her somewhere to shake things off."

Even though the HBT contact lasted only a few weeks, *strong relationships were established* rapidly. Team members were liked and accepted into the family, and sometimes a degree of emotional intensity developed that was surprising, unless understood in the context of the highly stressful situation.

Service users said:

> "I just felt as though they were a friend."

> "I mean sure they were nurses and what have you, but it was more the person that counted, and I think they really add a lot of value as caregivers because of the people they are not just because of their training."

> "Everyone has been kind, no one has been cruel, everyone has been very lovely and kind and caring. Everyone. There's nobody that I've seen that has been cold or inattentive. They've all been good. Blows me away actually."

Another service user recounted:

> I remember one night in respite, I was having a real bad night, and I was in tears and I was talking to the house person and HBT came round to see about somebody else in respite, and was [female HBT member] who came over, and she looked at me, and put her arm around me, and she sorted out my problem as well, there and then…"

Not everyone enjoyed the attentions of HBT:

> "I didn't think they needed to come and see me… I got real pissed off when they came and saw me sometimes, they'd sit there and I'd be like [expression] and I didn't know what they were doing but then I … realised that maybe I actually needed, I needed to talk to them, and my parents more than anyone else needed them."

Family members said:

> "They did feel like members of the family, because we spent such a lot of time with them, and baring your soul to people, and they were so nice about it all."

> "They also used humour, so that was a really big part of relationship building."

> "That really built a bridge with [her], that was really good that they could do that."

> "We really felt like they had [his] best interests at heart, and they came to personally know him as an individual and all his foibles and ways!… They were part of the family."

HBT was praised by several for *delivering hope and encouragement about the recovery process*, and helping them understand the process, along with its setbacks. They were grateful for help in "seeing the bright side of things" and for faith in recovery.

> "I couldn't see a time where I'd be better, I just couldn't envisage a time when I would be well and my old self ever again…. Looking back now, yeah. I was just able to do more and more. I'd have days where I'd slip back…but I suppose I learnt to take the good days for what they were and go with the flow of it all….I just wonder how well my progress would have been if I hadn't had that assistance from them."

Another said that having "positive reinforcement" from HBT and being told that down times were "only a setback" was very helpful.

HBT members were seen as *going the extra mile*, putting in more effort than could reasonably have been expected in terms of their professional duties. In the words of family members, "They went above and beyond"; "Some just went that extra bit to make you feel even more special."

The HBT team's *willingness to include family and service users in decisions* was highly valued.

Service users said:

> "Yes, they would consult me and say what they were going to do because they thought that this would be best for me right now, if it didn't work out then we could go back to the original plan, or whatever it was. So they did consult me in everything."

Family members said:

> "I feel they just embraced us as part of the team, I think they really respected our judgement."

> "I can't recall any sense of them withholding information or doing their thing, and sort of bollocks to you sort of stuff."

One family member talked about their relative finding it hard to stay on track during the team visits, but nevertheless:

> "He was definitely part of it, he was always there at the table and he would always join us. And we'd always say 'what we're talking about is this and that'. Yeah, it was inclusive."

Related to inclusiveness are *issues involving choice and control, which the team dealt with sensitively*. Mental illness can lead to difficulties in making decisions or choices, or to making choices that others do not approve of. Mental health services often make choices for service users, are notoriously risk-averse and sometimes use compulsion to control service users. In their interviews some service users commented on not being well enough to make their own decisions during their period of crisis, or engaging in behaviour that was difficult for others:

> "When you're sick … you know you're quite hard to manage…. I don't know if it's because you're sick but also because you're not sleeping and that and you're just so tired and you're just charging along."

Family members recounted difficulties they experienced with the behaviour of their relatives, particularly with getting them to do things they judged necessary, like drinking too much or not taking medication. They were relieved when HBT

reinforced them:

> "They gave us backup on placing boundaries on him."

> "They were with us for about a quarter of an hour. They had to talk him in to taking his medication. You couldn't communicate with him."

They were generally reluctant to deprive their relatives of choice, though. As one put it, in commenting favourably on the outcome:

> "So the HBT team left [him] with his … self esteem and sense of control over his life."

One family member who was less happy with the HBT service overall was disappointed that they did not manage to get her son into respite care:

> "No, he would agree and then he wouldn't do it. He would just walk out, it was a waste of time. The real safety side of it was my concern. Because of his age he is an adult and we were left in the lurch."

Service users, on the whole, felt that HBT had helped with decisions, cajoled them and sometimes made choices for them, but had not acted in a destructive manner towards them.

> "The HBT team were great, they'd sort of sit me down and say, 'the reason we've done this is because of this' and I could still reason with logic and be ok, that's fine."

> "I think they obviously acted in my own interests."

> "In hindsight I wish they'd done that earlier, if they'd known to take my phone, because I'd rung people and it was really embarrassing."

> "They weren't like prison guards, they were like, they were really lovely."

Finishing with HBT

There were often strong apprehensions when the time came for HBT to stop visiting and hand them over to another service, usually a community treatment team. The strong attachments that had developed in the very short time with HBT contributed to an emotional response:

> "And then I started thinking that I really like these people and I thought they were going to be here for me for the next few months….[At handover time] I just felt like shit, eh, and they didn't feel happy either." *(service user)*

> "We felt bereft actually, we were absolutely terrified." *(family member)*

> "How are we going to cope without these guys?" *(family member)*

> "At the time [I felt] terribly panicky because I knew that they told me it was going to end and I just felt as though I'd been hit with a bomb. It was, sort of, the whole world had fallen apart. It sounds very dramatic, that's just how I felt at the time." *(service user)*

When it came to the actual exit, some interviewees found the timing appropriate, others were ambivalent or resigned, some clearly felt that they had still needed support and only one or two actually initiated the exit themselves. Those who thought it was the right time to finish were recovering well and had confidence in other services:

> "The hours dropped off in the end, and then I had a nurse with me who came into my home and stayed for a few days. Then I started doing normal things after that." *(service user)*

> "…they ended about the right time, because it was about the time that [he] decided to go back to work and go back to his flat and get on with his life." *(family member)*

Some felt they still needed support, or a slower transition:

> "At the time I thought it was a bit harsh because at the time I felt I still needed to have them coming, but I was probably getting too dependent on them, and rather than have that happen, they probably wanted to get me back as quickly as possible to me being independent." *(service user)*

"I was brought to the…clinic and there was…a changeover of files and I was suddenly handed to another team and that was when I got really, really upset." *(service user)*

For many, however, the actual handover went well:

"We gradually just got it down so that I was having fewer and fewer days going up to the day clinic, until I was eventually on my own with just my case managers coming and visiting me every now and then…We just all staged this off well." *(service user)*

Some interviewees expressed disappointment at lack of follow up from HBT, partly because of the established relationship, or because they were unhappy with the other support provided:

"But I only had them come round once, I think [afterwards], and do a home visit which I thought they could have done a little bit more, but they are busy and they have other people who have got more problems than me." *(service user)*

"I thought they might follow up just to see how I'm doing months down the track." *(service user)*

"A couple of times they did call on the phone after going out of HBT [but] we could have done with some back up."

One family – the only one in the study that was not particularly happy with the HBT service – felt that the discontinuance of HBT, against their wishes had left them under severe stress. Their son disappeared and apparently made a suicide attempt in the period after HBT support had been withdrawn.

Comparing home based treatment to hospital inpatient stays

Service users and family members were asked about whether they preferred home based treatment to an inpatient stay. Most, but not all, of the service users had experienced hospital at varying times in the past. On the whole, the hospital experience was described in very negative terms. At best, hospital was seen as a place to go when unwell, but one that is not especially conducive to recovery. Being around other very unwell people was seen as difficult. Also, there seemed to be nothing to do and no one to talk to about issues, and treatments seemed to be entirely medical. Lack of choice, lack of input, compulsory confinement and treatment were also seen as undesirable features of the hospital stay. At worst, inpatient stays were seen as "scary" or, to quote one, "just the worst experience ever."

A couple of service users would have preferred to go to hospital. One, receiving HBT in a respite setting, felt he would had had more opportunity to "solve" his issue and would have felt safer. Another, who had not experienced hospital, felt lonely at home during the day and felt she depended too much on her mother and put too much stress on the family.

Family members were sympathetic to service users' reluctance to go to hospital, and that was part of their motivation to participate in home based treatment. Several people mentioned that a benefit of home based treatment lay in avoiding the stigma of having been in hospital:

"I think being on a ward he would have lost control and he would have felt like he was mad, whereas I think he's left feeling that he went through some sort of episode or experience, he needed some help and he got it and he's ok. You know I don't think he's taken on board this message, 'I'm a nutcase, I'm a fruitloop, or I'm mad'" *(family member)*

In terms of family stress, how did HBT compare with hospital in people's estimation? On the whole they were pleased to have averted hospitalisation because they felt that being at home was better for the service user, and they also learned a lot more about how to best support the service user in times of crisis. But some did emphasise that it was a delicate balance:

"There's no doubt that having her at home has affected our family, and in some ways it probably would have been easier to have her in hospital had that been a suitable alternative."

"I'm pleased he didn't go in. If he got unwell again because he stopped taking his medication I don't know that we'd go through it again… it was probably one of the hardest things I've done in my life, I think."

3. LIFE AFTER HOME BASED TREATMENT: VOICES OF SERVICE USERS AND FAMILIES

Services after HBT

Mostly, handovers were to community mental health teams. Service users' satisfaction with this form of care was mixed, with some very appreciative of the support and care, and others less so.

One said that she was "covered very, very well" by two case managers, another was pleased to be referred to a psychologist, and another was about to be referred to a GP and will cease using mental health services. One vote of confidence was:

> "I have never felt not supported in the entire time and it's been six months. I've always known that there was someone in the system that was contactable and the HBT team were an integral stage in that."

Not everyone had such good experiences, though. A family member felt that what the community team delivered did not meet their relative's needs for:

> "…a different kind of support, not the intensive wrapping around, like the HBT team gave him … but more strategising, how to cope with going back to work …, how to cope with things like flatmates, how to just manage his life. And the CMHT just wasn't there to come in and do that different type of support."

One service user said she did not like her case manager and was unable to change. During a crisis, when she spoke with someone on the Mental Health Line, she was told that the case worker would be informed of the call, but there was no follow up:

> "She thinks I'm doing ok but I'm not, but she doesn't know that because I haven't been able to talk to her about it. And I need to ring her and I'm scared to ring her because I know she'll put me down again…. If I could ring the HBT team, if I was still involved with them, and say 'I'm feeling this low, I've put a knife to myself, what do I do?' they'll probably send someone around. But, see, I can't ring my case manager after hours and it gets really frustrating at times."

Other services discussed – mostly in a positive manner – by several service users, in addition to community teams, included the Early Intervention Service, Māori mental health services and the eating disorder service.

Recovery: strategies for getting well and staying well

People were interviewed more than six weeks after HBT had been terminated. This research did not involve any thorough investigation into outcomes; however, what service users said about their progress is interesting, in terms of service provision issues, as well as for understanding recovery pathways.

Some people felt that they had completely recovered since their time with HBT, using terms like "back on my own feet", "feel like my old self" and "I feel normal now, just like I did before my episode."

Others were getting there, sometimes with a "two steps forward, one step back" process.

> "I hit rock bottom, I have then been slowly going back up the ladder and then I revert and I go back down a peg or two and then you know you sort of come back up again."

Some felt that though they had improved, there was some way to go. They made comments like:

> "I have a bit more stability now."

> "I think I'm a lot better than I've been but I'm not nearly 100%."

Several were still quite vulnerable. One person, who said that she had been "too proud to admit that I was sick", found it hard to respond to a question on how she was doing now. She told us that she had felt a few weeks previously that she should perhaps have gone to day hospital again, but had not done so. And another referred to concerns that she might self harm again, even though she said, "I'm not too bad at the moment…"

Recovery, for many people, was measured by the extent to which they had got back into their normal daily life, rather than only by how they were feeling and what symptoms they were experiencing.

Work was a big component. Some had returned to their previous employment, or to their studies, and were coping well, and others had new work. In certain instances, credit was given to HBT:

> "I wouldn't be [doing her two part-time jobs] because I wouldn't have those skills, … you know, I'm back within society. I'm not isolated. I'm back amongst people who can think rationally and that makes me think rationally if you know what I mean…."

People spoke of having learnt more about themselves from the illness experience, and making personal decisions about recovery. Some referred to being conscious of the need to avoid situations that are stressful. Another point mentioned by several was the need to notice early warning signs and seek help early.

> "It's made me more aware of just how to look after me."

> "You work out for yourself why it happens and you get the point where you can learn what to do to avoid it."

In terms of what they felt about their illness, people sometimes felt quite shocked about their experience having been given a label. H. said:

> "It was really really, big scale, big September 11th…. a big blow."

And L. said:

> "I didn't like to be given any sort of a label, and I felt very embarrassed about having this whole mental health thing… I didn't know how accurate it was either. I thought they were desperate to put a label on me and say that they had."

However, HBT had been reassuring to her:

> "Their spin on things was quite different to the psychiatrist's, they were a bit more mellow about it, saying 'These are the boxes, but people are people and they fall where they fall kind of thing."

The idea of having had a mental illness was difficult for some to absorb. G. said, "If you had told me six months ago that I would go through a psychotic episode, I would have said 'No way!'" It was felt that HBT had helped people deal with the stigma surrounding mental illness. W. said that they had reinforced his "intuition that I wasn't really mental". A family member said that her son, because he did not go to hospital, was able to avoid thinking of himself as "I'm a nutcase, I'm a fruitloop, or I'm mad".

Others seemed happy to apply a diagnosis to their experience. As mentioned in the section on "the crisis", service users described themselves as experiencing a range of mental illness conditions, including bipolar, depression, schizophrenia, psychosis, anxiety and anorexia.

Talking about the future, there were distinct anxieties for some:

> "I'm quite scared, like basically I take my meds in the hope that I won't ever have it again, but the stats say that you're going to have it like three times or something."

> "Well, I hope, just all good things, you don't tend to think that you'll get ill again, but I guess I sort of know the signs and to get along to my doctor and say this is how I'm feeling."

> "The only thing that scares me is that once you have had a psychotic episode that there is quite a high chance of a repeat. But that the chance is significantly reduced if you keep on your meds and stay well."

People said they knew how to contact services again, though only one person referred to having a formal risk management plan (although others may have had one), negotiated with HBT and their case manager:

> "They have helped me get this far and I just hope they continue helping me when I need it, because it's a really scary thing."

4. ALLIED PROFESSIONALS: REFLECTIONS ON HOME BASED TREATMENT

The allied mental health professionals that we interviewed reflected on a number of themes, including:

– **access:** on the whole they believed that there was good access to the service for their clients;

– **communication and relationships between teams:** this, too, was seen as good, although from the inpatient unit there was a sense of caution, given that the processes involved in discharge were delicate (pressure on beds could be a factor at times) and that a strong relationships with HBT was needed to work through issues;

– **HBT philosophy:** it was noted that HBT had attracted enthusiasts who are committed to the philosophy of the team;

– **the benefits they had noticed for service users:** mostly, HBT was seen as very positive and some success stories were mentioned. In particular, the avoidance of the trauma and stigma associated with hospitalisation was seen as a great benefit.

5. THE HOME BASED TREATMENT TEAM: REFLECTIONS ON PRACTICE

The five members of the Home Based Treatment team are all registered nurses who joined the team through their association with other mental health services in Capital and Coast, particularly the CATT team. Between them they had a wealth of experience of inpatient and acute care (in New Zealand and the United Kingdom). Most joined the team because they enjoyed acute work, and wanted to extend their experience and be part of a new initiative that had an interesting philosophy and was client-focused.

Practical arrangements were mentioned by a couple of people – HBT were working 12 hour shifts with four days on and two off – for one this meant a delay in taking up the initial offer.

The interviews with HBT staff covered a range of issues, which we have organised under the headings that follow.

Referrals

HBT has relied on other teams to make referrals to it, rather than being involved in the initial assessment, which may have been preferable. Receiving inappropriate referrals, and sometimes not having an appropriate client referred, were sources of frustration, and in some instances hospitalisation could have been averted by an appropriate referral. Team members thought that there was room for more education of colleagues, so that they were "quite clear on the criteria".

What the work involved

HBT members gave much the same picture of their work as service users and family members did. It involved providing a broad range of assistance. As someone put it, you are doing "everything":

> "You are doing counselling and then you are doing nursing type stuff, education, and medication. It's very practically based, we look beyond the illness at what they are going through and what their stresses are, and it might be simple things, like I had a client who had overdosed and vomited into the garden and lost her front teeth so I had to go back to the house with her and searched the garden for these teeth. Or going back to the house with them and checking their emails, etc."

HBT members also talked about providing information, preparing management plans, organising family meetings, going to WINZ (Work and Income) with clients, liasing with psychiatrists attached to the team, particularly over medication, and arranging hookups with other services, such as the night stays.

One or two references were made to crossing the usual nursing boundaries because of their emphasis on responding to people's needs. However, they emphasised that this was not "unsafe" but rather, a result of the close engagement with clients and families. This "is what nursing is about…everything else is so medically…orientated…but it never quite gets there. Whereas this is really real,…it feels like you are working with someone, not that there's two sides."

Caseload and flexibility

HBT team members valued the fact that their small caseload and less time pressure meant that they were available to respond to urgent requests and to sort out issues properly, and meet their needs:

> "I am working with a client at the moment where there are a lot of aspects of her care and I'm making a management plan for her to go home, family meetings, organising WINZ, so today that will take up a lot of time and things get done quite quickly because I can sit down and see it through."

Relationships with service users and families

HBT nurses emphasised the importance of the relationship that develops with service users and families. They referred to "partnership", "therapeutic alliance" and "working alongside":

> "It's about partnership as opposed to the nurse, I'm a professional, and you're the client, and you're going through something and I know what's best for you... It is about working together, and it's about mutual respect about the care and what we need to do … we are more engaging. We do see people at their worst, and we see them at their best, but we are there for them and we are really real with people, and normal, as opposed to this textbook…"

> "It's more of an equal alliance and it doesn't feel like a nurse/patient relationship. We are going into their homes and they feel a lot more comfortable and relaxed."

Visiting people in their homes, and the close relationship that develops around the time of crisis, meant that HBT nurses felt that they expanded their understanding of mental illness and its meaning in people's lives.

> "You get more understanding of what that person is actually experiencing. We talk a lot about their experiences and we don't focus a lot on diagnosis and medication. It's about their experiences and how it is for them."

Clients and families were impressed by the good teamwork from HBT. An HBT nurse said:

> "Because you work really closely within a small team, you get to know each other's practice really well, you get to know what the strengths are."

HBT team members also emphasised issues around service user choice and control in their talk about their work. One said that people often do not know what they want or need at first, so things are set up for them and their wishes become clearer as time goes on. In terms of choosing HBT versus hospital, one team member reflected the complexities involved:

> "I think what we try to do is give people a choice. A lot of the time whether that's an informed choice or not…because it can be blurred by the situation, by their experiences and certain stuff like that. …their families are usually pretty burnt out by that stage. And, what we hope to do is to give people an informed choice. Say, look, this is what will happen on the ward. This is what will happen with us. … Give people the option. Talk about it with people."

In terms of treatment:

> "You can disagree on some aspects, but generally you're working towards the same goal in keeping the person well, recovered and move on. As long as the client feels like they're involved in the treatment, that's the important thing."

> "Although we take risks, it's managing that risk but giving some control back to the clients, and with the families. So it's a real plus, I believe that we do that. And there have been some times, even myself, I've had to go 'Ooh, I'm getting overly anxious' – but it's great to talk to the team, it works out. It's like allowing, or letting our clients to have some control, some say, giving that control back to the clients, which is great."

Some clients, most particularly those who have been in hospital previously, are under the Mental Health Act. Their choice may be between having HBT or a longer stay in hospital, but nevertheless, they are free to reject HBT:

> "…if they don't want us involved then there's absolutely no reason for us to be around."

Clients who are still under the Act are usually discharged from it in "a few days... We wouldn't keep them under the Act for any longer than necessary." One person told us how HBT had reduced involuntary admissions for a particular client by dealing at home with the issues that, when left, had got out of hand and resulted in police involvement.

Also, compared to working in an inpatient rehabilitation setting:

> "You're not forcing someone into hospital, the power structure has gone. You do your best to work on that relationship."

Not much was said about exiting, although it was a concern for families and service users. HBT members noted that there were skills involved in rapidly starting and finishing such an intense relationship, and that they enjoyed being part of the move from crisis to resolution.

However, difficulties for clients in stepping down to a less intensive service were acknowledged:

> "We are a team that does see everybody everyday and we are available on the phone … they get a really good service, and sometimes they don't get that when they move along."

Job satisfaction

The nurses we interviewed derived a lot of enjoyment and satisfaction out of belonging to the team. "It's what nursing's about for me" and "It can be stressful as well, it has its good points and its bad points, but generally I love it! I thrive on it."

Someone said it was "refreshing" compared to CATT, where you are "just working on crisis, crisis, crisis". Whereas with HBT there was a longer engagement with people and time management was easier:

> "It's busy here but you can generally manage it yourself, whereas over there you've got no control, you're expected to go to five assessments in one hour so it's full on."

Sometimes it could be fatiguing to be part of an innovation. As one said:

> "I think the biggest drawback [in terms of HBT] is our marketing campaign and the politics that go on in mental health services, and having to sell the service, and continually having to do that becomes quite tiring. Constantly having to defend it, having to put it out there to people, to go over and over again about what it is about. And there are still people out there in the service who really don't understand what we're doing."

Professional issues

The team environment was seen as conducive to good professional work, and the opportunities were compared favourably with acute settings:

> "There's a strong emphasis on working collaboratively. And that's because we have the time. In comparison to working down the acute side."

> "There's more opportunity to reflect and critically discuss things, whereas down the other end, because it's more reactionary in acute and getting through the business."

The nursing involved was challenging and HBT members saw themselves as advanced practitioners:

> "Because we're out there with pretty acute people and we're having to make decisions in the contexts of quite high levels of risk a lot of the time and having to advise people about things like medication, risk assessment, risk benefit analysis that kind of stuff, you're getting pretty advanced. Just because we're round where a lot of other people aren't and we work very independently."

Overall, HBT nursing was seen as a move onwards from traditional mental health nursing, but one that sat compatibly in a nursing framework:

> "I think that nurses don't realise their raw potential, I think they are locked away a lot of the time in what they do. I think nurses have really got it in them. I don't think they go into nursing to be this authoritarian and paternal…, they just tend to slip into it. This kind of unlocks that, this kind of philosophy, this way of working unlocks it."

Relationships with the mental health service

HBT members had a multiplicity of contacts with other mental health professionals. Located in the CATT team, they had assistance from the social worker who could point them in the direction of needed community resources. They also worked in with the CATT psychiatrists (a consultant and a registrar). In terms of other community mental health nurses, roles could be sometimes difficult to work out: "the teasing out who does what". Sometimes a lot of "behind the scenes work" has to be done to "keep things…together".

They had use of a casual pool of people who could be brought in, for example, for overnight stays, and after a "learning curve", they came to be selective about who they used. If medication was a "big issue", then they brought in registered nurses for the overnights.

One HBT member said that the team is "lucky" in that there are such a lot of resources available (such as day hospital, evening cover, respite), so that they can provide wrap-around services.

One area for improvement was that HBT could be more central, rather than functioning as an "add-on" to services, and that it could be expanded to 24 hour availability. HBT staff should be able to offer "advice and input" when community mental health team clients were showing "early warning signs" and if they could take part in assessing for admission:

> "We could be involved in discussion around other alternatives and options."

With an integrated service offering HBT around the clock, and covering pre-crisis and admission periods, it was suggested that HBT could do more to avert hospitalisation.

Overall, HBT nurses would like to see the service continue, grow and become more integrated with the community team. Also, the HBT experience led people to see it as a model of mental health nursing:

> "Interviewer: "Do you think that other teams could adopt the HBT philosophy?"
>
> HBT: "Yes, I do think they should change too, because it's a fantastic service and it shouldn't be a unique service.""

Discussion

THE EXPERIENCE OF HOME BASED TREATMENT

Service users and their families were very positive in the way they recounted their experience of the Home Based Treatment service. What the service delivered to them at a time of crisis was practical help, advice and information, and hook-up with other needed services. Visits, often several times in one day, from team members provided reassurance and meant that needs and issues could be talked through as they arose. Home based treatment worked for service users and their families because the team was readily available (they responded rapidly to phone calls), they worked as a team, they were flexible in the way they worked and they were often seen as going the extra mile for people. The team established strong relationships with, and were supportive to both, service users and families. They treated people as individuals, included them in decisions, conveyed hope and encouragement about the recovery process, and dealt sensitively with the issues around self-determination in the context of a mental health crisis. The team worked so well and established such close bonds with service users and family members that the finish time often provoked anxiety and distress, although it was conceded by some interviewees that the step-down to different and less intensive services was handled well by the team. Although undoubtedly the mental health crisis was a stressful time for family members, as well as service users, nearly all were pleased that hospitalisation was averted.

For HBT team members, the experience of working in this new service was overwhelmingly positive too. Team members enjoyed being part of an innovative service. They liked the teamwork and felt that they had the opportunity to draw on their nursing skills and work as advanced practitioners. They enjoyed working with service users and families in their homes, which enabled them to work more effectively, taking into account service users' life circumstances. They were pleased to establish close alliances with service users and families, involving relationships that were more equal and allowed more flexibility and choice than in some other services they had worked in. There were some areas of frustration in relation to the service's integration in the whole mental health service, and in relation to their roles and functions being understood, particularly around referrals, although this was seen as mainly a function of the newness of the service.

Allied professionals were also impressed by HBT, seeing an enthusiastic team working in well with other services and with a positive impact on clients.

IMPLICATIONS FOR SERVICE PROVIDERS

This research shows, via the experiences of service users and their families, that Capital and Coast's home based treatment service is providing a worthwhile, indeed outstanding, service in relation to the provision of acute mental health care. It should be seen as a preferred alternative to inpatient care for those who meet its selection criteria.

As part of the research process, initial findings from the research were discussed on two occasions with the current HBT team, staff and management involved in the wider Crisis Assessment and Treatment (CATT) team. These discussions covered issues raised in the research, and also raised some further issues about some changes in arrangements that were occurring for the team.

The team was pleased and heartened by the ways in which service users, their families and allied professionals evaluated their efforts. One of the

areas for discussion was the finding that the exit process was anxiety-provoking and distressing for many clients and families. HBT members were aware of how intensive contact during a period of crisis can lead to rapid development of a strong alliance, but they were both surprised and moved at the intensity of feeling expressed around the team's exit. Transition was a process that they felt they should discuss further. The range of views on services encountered in "life after HBT" suggest that more could be done to improve other community mental health services, even though some service users continued to have access to excellent services.

Another topic for further discussion was the degree of stress expressed by families during the treatment episode, even though HBT was appreciated and preferred over hospitalisation.

It was also recognised that HBT had an ongoing role in educating other mental health services about its work, and continue to clarify its role and admission criteria, so that it worked well in the continuum of acute services.

HBT team members, in the discussions, emphasised the importance of the composition of the team, its commitment to the work and its adherence to team philosophy. They discussed frustrations, which had started to become evident in the team, and raised concerns, one example of which was team members being rotated off the team and replaced by members of other services who had not necessarily chosen to work in HBT and who were not necessarily tuned into its approach. This raised the issue of training needs for team members. Also, it was acknowledged that working with crisis could become wearying, and that the team needed to retain high quality, committed and experienced staff.

Training needs were not a focus of the discussion, but the recent experience of team rotation should make this an area for development.

Overall, team members felt that HBT approaches should be recognised for their success. It should not be seen as a competitor to other forms of acute provision, but it should be seen as a valuable part of the spectrum of services, and its recovery philosophy should become incorporated into the whole service.

CONTRIBUTIONS FROM THIS STUDY TO HOME BASED TREATMENT RESEARCH

From the international literature on home based treatment, discussed in the introduction to this report, a number of factors emerge as important to the success of a home based treatment service. Comparing these factors with against the structure and operations of the team this research focused on, we note:

- ***The importance of a clearly articulated model of home based treatment:*** Team members were able to clearly articulate recovery philosophy and nursing practice behind their work, and service users and families described, in their own words, receiving a service based on these principles.

- ***Home based treatment needs to be part of a whole system of care and supported by a satisfactory infrastructure of services:*** It was clear from the research that the team was able to put people in contact with a variety of other services during the acute period, including acute day services, respite care, overnight care in the home, and psychiatry and social worker input.

- ***The team needs adequate training and preparation for their roles:*** There was little emphasis on training and preparation, but the maturity of the team, its self-selection, and the challenge of the innovation meant that people were able to easily work in new ways. They did use core nursing skills, but also went beyond the boundaries of the traditional nursing role.

- ***Successful crisis resolution services are responsive, flexible and creative:*** This was strongly indicated as featuring in the service we examined.

- ***HBT involves a collaboration between service user, family members and the service:*** This was very evident in talk around consultation, involvement and choice.

- ***HBT reduces hospital admissions and enhances continuity of care:*** Statistics bearing on this issue were not available for the current service at the time the research was carried out. However, retrospectively it was established that although there was an 18% increase in unique clients for acute services over that time, there was also a 25% decrease in hospital admissions.

- **HBT, despite its challenges, enhances staff satisfaction and does not lead to burnout:** Team members were clearly satisfied with their work, but the discussion following the research suggested that it could be difficult to constantly work with crises and acute mental illness.

- **HBT programmes should be designed with local populations in mind:** Although there are services in this DHB area specifically designed for Māori and Pacific populations, HBT works across the spectrum. Because of the small size of the research project, and the correspondingly small number of Māori interviewees, it is not possible to say how well the team met specific cultural needs.

Other findings from international research, in comparison with the current study

- **Service users prefer HBT and do just as well with this form of service:** The research did not examine outcomes systematically, but service users expressed a clear preference for HBT, and their accounts of their recovery processes were encouraging, overall.

- **Research usually shows that family stress is not increased, in the long term by HBT as opposed to hospital admission:** This research clarifies the point that, while families were under intense stress at the time HBT began, the HBT process allayed their anxieties and they found that they were better able to understand and cope with their family member's period of acute mental illness. This was the trade-off for staying in there with the situation, as was the belief that their relative was better off for remaining in the home. It was also pointed out that the hospitalisation period does not necessarily alleviate stress to families.

The current study, with its qualitative nature leads to some suggestions for further research around HBT. In particular, the transition from the intensive focus of the service to other less intensive services could be investigated further, in order to devise strategies that might allay distress and anxiety on the part of service users and families. Workforce issues also need more investigation, in particular training and development, and working in sustainable ways in acute alternatives. Qualitative studies focusing on family resilience and enhancing coping skills during periods of acute unwellness among service users could illuminate some useful processes and provide a corrective to research focus on family burden. Finally, it is always useful to research service user views of mental health services, for the relationship between service users and services is at the heart of successful services.

MATCHING UP AGAINST RECOVERY DIMENSIONS: TO WHAT EXTENT DID THE HOME BASED TREATMENT SERVICE MODEL A RECOVERY-ORIENTED SERVICE?

The context for this research is the revolution in mental health services known as the recovery approach, which places the service user at the centre of services, and services in the context of whole of the service user's life. Recovery research is a growing field that investigates the processes of recovery from the point of view of service users, and inquires into how services can be designed to facilitate those processes. It seems that recovery concepts have been aligned more closely to the field of psychiatric rehabilitation than to acute care provision, but nothing about recovery writings suggest that their coverage should be limited in that way. So, in terms of a recovery-oriented mental health service, how did acute care provision in the form of a home based treatment service rate?

We compared our research findings with the dimensions of recovery-oriented services listed in the introduction to this report. The home based treatment service performed well, and sometimes extremely well, on most of these recovery dimensions. It had *a recovery philosophy*, it provided services *at home*, and it was offered as a choice and it was seen as a service that resulted in less *stigma*. The team was very *accessible* and they were *flexible* in terms of the services they provided. Their interactions with service users and families were characterised by *respectful two-way communication*, they provided *reassurance and safety*, they took *a collaborative approach*, *provided information* and *conveyed hopefulness* in relation to overcoming the immediate crisis. They took a *whole of life approach*, dealing with the crisis in context, they fostered *support from families*, and provided *good linkages with other services and supports*.

Not much was said by service users about whether *treatments were effective*, but on the whole people did not give voice to complaints about pharmaceutical treatments, which were prescribed by a psychiatrist who serviced the team. Not much was said about *physical health care*, but the community location would mean easier access to general practitioners.

In terms of avoidance of *force* and maximising *choices*, we found that the HBT team dealt sensitively with issues of choice and compulsion, and service users recognised the difficulties involved in making choices at the time of acute unwellness. HBT policies make it clear that it is a choice to receive their services, but the element of compulsion was not absent, given that for several, choosing HBT was a way of leaving the hospital.

A notable lack in this (and other) home based treatment services is the lack of opportunity for *peer support* and the *involvement and advocacy of other service users*. With treatment taking place in the home, service users do not meet others, although they may do in the services they are hooked up with, such as the acute day services programme, though this is not service-user run. There is no service user expertise integrated into the team, although there was in the initial phases, and although service user advocacy is available through the DHB, it is not part of the home based treatment service.

This research described a home based treatment service from the perspectives of service users and family members, and those engaged in service delivery. It established that this particular HBT team was providing an excellent service. The project also makes a contribution to the qualitative literature on home based treatment, emphasising several interesting issues that could be further explored. This research has also engaged in a process of matching the features of this particular service with emerging general understandings of features of recovery-oriented services. As such, it stands as an early example of research on mental health services and how they go about incorporating recovery approaches. In conclusion, the research shows that recovery concepts can align well with acute service provision and it supports the development of recovery-oriented home based treatment services as an alternative to inpatient acute care provision.

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