

**Experiencing A Recovery–Oriented Acute Mental Health Service  
Home Based Treatment from the Perspectives of Service Users, Their  
Families and Mental Health Professionals**

**Detailed Results**

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**with an analysis of the family/whanau interviews by Tess Moeke–Maxwell**

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**Note: This document is a detailed analysis of the Home Based Treatment Study interviews. It is an appendix to the Mental Health Commission publication describing the study, which contains information on the study's context and methodology, a briefer results section and a discussion of the findings.**

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## **INTRODUCTION**

In this report we provide a more detailed analysis of the interviews in our study than it was possible to present in the main report.

The first three sections (pathways to home-based treatment, experience of home-based treatment and life after home-based treatment) are based on analysis of interviews with 12 service users/tangata whaiora and eight of their family/whanau.

More detailed information on participant attributes are given in the main report; suffice it to say that of the service users, eight were women and four were men; there were nine Pakeha/New Zealand European and three Māori; and their average age was 34, ranging from 21–48. Average length of involvement with HBT was 21 days, and ranged from 3 to 44 days.

Of the nine family/whanau members interviewed, four were mothers, three were fathers, one was a husband and one was an aunt. Six were Pakeha/New Zealand European and three Māori.

The second two sections of this report focus on the professionals: firstly, the allied professionals who comment on HBT, and secondly, the HBT team members themselves.

Finally, we have included a separate analysis of the family/whanau interviews.

### **1. PATHWAYS TO HOME BASED TREATMENT: VOICES OF SERVICE USERS AND FAMILIES**

The 12 service users we interviewed had experienced a mental health crisis severe enough for a hospital admission, and this severity qualified them for the home based treatment service.

In this section we focus on service users' and their families' descriptions of events that led to contact with the HBT team.

#### **Before the Onset of Current Difficulties**

##### ***Previous experiences of mental health services***

Most service users (9 out of 12) were known to the mental health services, and those nine had been hospitalised at least once. For two service users, it was their first experience of mental illness.

##### ***Work and family situations***

At the time of mental health crisis, most service users were involved in employment (8 out of 12), studying or parenting, or a range of these activities.

Their family situations ranged from living with partners and children (1), living with parents (4), solo parents living with dependent or adult children (4), living alone (2). One person went to live with relatives for the duration of the crisis.

A few people told us about background stressors that led up to their illness crisis. These included being separated and losing custody of a child, and exam pressure. On the other hand, quite a number of interviewees did not focus on prior stressors, but told us about the lead-up to the crisis experience in terms of increasing symptoms.

## **Describing the Mental Illness Condition**

Service users described themselves as experiencing a range of mental illness conditions, 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 in describing their condition, eg, “things were distorted in my mind”, “trying to hurt myself real bad”, and “I was just so high”. Others gave much fuller descriptions of how they were feeling at the time, emphasising the catastrophic thoughts and emotions they experienced, sometimes accompanied by uncharacteristic behaviour and/or increased use of alcohol and drugs:

“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 over night.”

“I was doing my thing, drugging and drinking again so I slipped back into it but did all sorts of crazy stupid things I shouldn’t have done. I’d been buying lots of jewellery and drinking heaps and stuff, playing on my rush of whatever. And then I think I did come crashing down... I had bulimia, any funny smells or yucky food I didn’t like would just trigger all the horrible feelings of wanting to be sick.... quite a monumental breakdown.”

“I was fitting in quite a lot of different things in my life and probably over a period of months I became spiritually obsessed even though it started off fairly low key...It kind of reached a peak ...and I remember a particularly strong storm outside and it was actually quite frightening...I prayed for the rain to stop and within two seconds the rain stopped. I interpreted that as I was able to change the weather....

I was quite angry with [my friend] because she suggested that we go down to the Hospital just to get me checked over. I thought, of course they want me checked over because I have such an important mission in this world...I was getting more and more talkative and my ideas were really starting to take flight.... I thought I was undergoing some sort of spiritual trial.”

## **Making the Link with Home Based Treatment**

As the person's mental health problems worsened, service users or their family or friends contacted mental health services. Some of those we interviewed had a period in hospital before linking with HBT, either directly afterwards, or as part of a graduated process via day hospital or acute respite:

“Before she was discharged we had a meeting with the staff who had been treating [her] and we talked about where everything was at and how [she] could go home and ...the HBT team would be available to us...”[family member]

“I was only on the ward for two nights...A guy [from HBT] who was visiting the patients there ended up taking me to a Respite Care and he was a lovely person...I can only assume that they felt that the ward was not the appropriate place to have me treated. I stayed in Respite for about a week and we were taken to the Day Programme. I was the only person at the house when I first went there.”

For some, being transferred to the team meant that they were able to leave hospital:

“I got out 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.” (service user)

Others remembered being referred through their contact with the CATT team or day service or respite care. Some were very conscious 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.” (service user)

One or two people remarked about the number of different people they saw during the assessment period. G. and his family, in particular, found it difficult. As one of his family said:

“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 everytime he went to see different people he would start his story again... So by the time he got to them there was a barrier.”

The handover, or initial meeting with HBT was almost always described in favourable terms, with the team members making a good impression, for the most part, on service users and families. Only one interviewee, a family member, complained about lack of promptness in the first linkage with HBT. First meetings took place in the

home or in the hospital or day treatment setting, and often involved a meeting with family and service user together.



## **2. EXPERIENCING HOME BASED TREATMENT: VOICES OF SERVICE USERS AND FAMILIES**

In this section we examine service user and family member accounts of the assistance provided to them by HBT. Firstly, we look at accounts of what kinds of service was delivered, and then we look at service users' and family members' analysis of why HBT was helpful to them. To put it simply, this section focuses on what HBT did and how they were.

### **What They Did: Components of HBT Service Delivery**

Accounts of HBT service delivery described helpful components of HBT service delivery, which are organised under the following themes: practical help; reassuring presence; being available to talk; providing advice; providing information about mental illness; and hook-up with other services.

#### ***Practical help***

Service users said that HBT team members performed a lot of helpful actions for them, ranging from practical things like getting medication and helping someone cook a meal when they were still settling in on their return from hospital, getting a video for someone's son:

“I really needed some help to just get back into managing my household again because it is easy just to give up.”

Family members said that it was helpful when HBT helped service users with things that they were finding difficult, such as being too distracted to complete everyday activities, like taking a shower, and getting them to go to bed. They encouraged people to take their medication, and on occasion they backed up family members by “placing boundaries on him” or in an awkward situation:

“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.”

Family members were also very appreciative about being given a break from the work of caring, whether it was during the visit or by HBT arranging other services (see below). One also mentioned that it was good for the service user to have a break from being cared for by the family.

#### ***Reassuring presence***

Just being there was helpful and comforting in itself:

“Just sort of their presence was what I found so reassuring, they were just solid people.” (family member)

“It was quite nice to have them dropping by. It was sort of like having a district nurse coming round, something like that.... I think they just had a sort of calming effect really.” (service user)

### ***Being available to talk***

Helpful talk was strongly emphasised. Service users found HBT members good to talk things through with. As one said, “They just let me talk about whatever I wanted to talk about. There was no particular thing I had to talk about, it was just what I felt like talking about.”

H. 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.”

G. 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.”

Another person said:

“Mostly I was dealing with women, like my [relatives], so sometimes I just want to speak to a guy for example, so one of them..., I could just take him aside and we’d have a talk and it was just confidential and that’s what I needed.”

Family members spoke with gratitude about talking through problems and issues with the team:

“I found it good just to talk and compare notes sort of thing. Just let them know how we were going as much as anything, because the feedback we got was that “oh well, you’re all fine, and good” no problems, not that they were dismissive or anything, but I guess they had other people they were seeing who were less well or having a problems or whoever they maybe were concentrating on more.”

For one service user, talk didn’t go quite far enough:

“Well I was hoping to resolve some issues but that never happened...they just increased my medication...and it was just like having counselling, just talking my stuff through with them. They were good,...if I asked to see them they came to see me outside of when they normally did and that was helpful. I

don't really know what I expected, I wanted to try and resolve some issues I had but that never actually happened.”

### ***Providing advice***

Both service users and family members reported being given helpful advice about dealing with mental illness, symptoms, medication, services and the outside world. Some comments include:

“I'd quite often ask them questions, ‘What do you think about this?’, and they were quite good at giving that advice.”

“They would try to get me to tell them what I'm thinking – give me answers to that.”

“I had a really good conversation with [team member] and she managed to get me thinking rationally again, not irrationally. Because I've always had problems with my appearance and stuff, and it was nice to feel some people have said to me ‘Oh, you look really attractive and lah lah’, but I've always thought I was ugly and I don't know why, well it started in my teenage years and I think that's when it starts for most women or men sometimes and that sort of progressed. And I had a conversation with T. and she just said you've got to think rationally.”

H. told an HBT member about being in an abusive relationship:

“... and she told me maybe I should move. Not to, sometimes I get mixed messages though, but not to let people tell you what to do.

I: Did you find that helpful, her advice?

H.: I did at the time because I didn't really know what to do.”

They talked to L. about how to manage being back to 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***

HBT was said to be responsive to questions about mental illness, and matters of concern that often came up in general conversation. V. said that he was told:

“...that people were much the same wherever they went and that was interesting and as it came up in the conversation, so I felt that I wasn't the only one sort of thing. So that was, things like that, just what came up in the conversation. They told me little bits and pieces so yeah. It was ok.”

People were mostly satisfied with information they were given:

“They gave us lots of information too you know about bipolar and about medication and treatment options so we could kind of make informed decisions and they also reinforced those information to [him] about keeping on his medication.”

However, one family member said:

“We would have been getting heaps of A4 pages with the effects of various medications. A lot of words and a lot of jargon. And that’s confusing.”

The timing of information was seen by some as problematic. For service users, this could be that it was hard to take in information during a period of crisis, or just because it was new to them:

“I think they gave my family information. I mean there was a lot for me to deal with so I think they didn’t try and if I’d asked they would have given it to me.”

“...because the whole system was so new I don’t think I really took anything in it was just sort of acronyms...I got confused between the CATT team and the HBT team.”

What sort of information was needed was not easy to define. As one family member 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”.

One family found the resources given were depressing:

(Man) “It was supposed to be enlightening but it was....”

(Woman) “I think it was this whole tone of words....”

(Man) “Yeah, you’re doomed but you’ll learn to live with it.”

Information about diagnosis and prognosis was sought, but not necessarily available:

Interviewer: Did they give you enough information and talk to you about what was happening?

SU: 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.

“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.” (family member)

“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.”

### ***Hook-up with other services***

People receiving homebased treatment often received a variety of other services at the same time. Some they were already in contact with, but on the whole, these were services that HBT arranged to assist with the ‘at home’ situation:

Family members, in particular, were very appreciative that HBT could arrange ‘wrapping around’ services:

“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.”

Several of the service users went to one of two day hospital programmes, with HBT visiting in the evenings. Although some did not particularly enjoy the day hospital experience, most seemed to feel that it was useful. Family members appreciated it, as it allowed them to go out to work. One young man, with first experience of mental illness, put it this way:

“I realised where I should be but I didn’t like going there initially. It’s quite a daunting place and it is a secure unit, things over windows and long corridors, and it almost had a feeling to it, that you could almost sense that people didn’t have good times there.... They were really nice people, considering that at the time I didn’t want to be there. ...Coming from a privileged background and going into that place where there is nothing there, it was hard.”

Another 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.”

Another said of day hospital:

“It’s good in respect, but it’s not that good ... you know you can’t ... go to a movie, it’s quite a way away from everything. There’s definitely a lot of things to do out there, it’s mainly arts and crafts and stuff.”

Day hospital was positive in its effects for someone else:

“And while I was at the day hospital there I felt really glad that I was there because I felt safe, I didn’t feel like I wanted to hurt myself anymore.”

Someone else, at a different day programme, felt unsafe rather than safe. She “hated” being at day hospital, although “the nurses were pretty caring”. One of her complaints was that:

“I left there a few times on my own, and went down to the \$2 shop with another guy who was pretty sick, he had ...schizophrenia, and he had ... cuts on his arms and stuff and we were allowed to walk out of the main doors and go down to the street and go down to the shops and I thought that was...crazy. 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.”

Other service users and families coped during the day, assisted by HBT visits and had night staff come in so that they could sleep, or in one case, go away for a few days. One family felt uncomfortable with apparently unprofessional attitudes from the night person that had been arranged, and HBT switched personnel so that a registered nurse came, which the family was much happier with.

Respite care was arranged for some. Again, attitudes to it were mixed, with some feeling it was the right place for them, but one running away after a few nights. For one service user whose family was scarcely coping:

“The psychiatrist was saying to us, ‘Well, we’ll have to admit him,’ and Matt came back in and he said ‘We’ve got an option here, he could go and stay out at respite care, could be another option’, and that’s what I mean they’re so committed to keeping him out. And we thought that was a really good idea. And we took him out there, spent a couple of hours with him and he only stayed one night. I think that one night was enough because we got some sleep and it kind of gave our batteries a bit more of a charge. And then they started talking about him going to the day programme and...it felt like we could live with that”.

Services were ‘tweaked’ so as to find the right mix:

“They kept coming up with different options, ok this isn’t working, what say we put him in respite care for three nights to give us a break because we couldn’t get to sleep because he was up all night.” (family member)

In one instance, though, a family member said that “they perhaps could’ve come in with some of those overnight supports a wee bit earlier”.

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:

“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.” (family member)

Service users also appreciated the contact with other services being facilitated (eg, by a taxi chit to get to day hospital).

Someone else referred to the helpful support organised by HBT, of a woman who would come and get her out of the house for a walk twice a week, which “got me used to doing more and more in public”, encourage her with breathing exercises and got her into driving the car again. Stress management courses were also organised.

On the whole, contact with other services seemed well coordinated and there was not much evidence of systems crossing over. Two service users had contact with the early intervention service and a Māori mental health service at the same time as HBT. Another Māori service user was asked if he would like to have had contact with Māori mental health and his response was: “No! They asked me, like 50 times!”

### **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). In this section we first report on some of the overall evaluative comments on HBT, then look at the following themes that emerged: availability; flexibility; respecting individuality; good teamwork; supportive to the family as well as the service user; including family and service users in decisions; closeness; delivering hope and encouragement about the recovery process; going the extra mile; and dealing sensitively with issues around choice and control.

### ***Overall evaluation***

Overall, the evaluative comments about HBT were strongly positive, with service users and family members making remarks such as “wonderful”, “fantastic” “outstanding” and “just amazing”. The few less positive comments were more luke warm than critical.

Service user comments included:

“They were there when I needed help....If they were not there, I probably wouldn’t be giving this interview.”

“They stepped in, and in a really, really responsible and caring way.”

“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.”

“I think in terms of giving the patient the best care, that they were probably what was needed.”

“It’s heaps more user friendly than anything else I’ve had. And I’ve had quite a bit!”

Someone who was less enthusiastic nevertheless felt that it was not a bad service:

“The visits were good – but because of my frame of mind, I didn’t see any benefit”

In an assessment of what was liked about the way the HBT team was, the following themes emerged.

### ***Availability***

Service users and families were very impressed at how available the team was to them. This was often in marked contrast to their experience of other mental health services.

“[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)

“Sometimes they’d be late ... they’d have other things to do, but ... you could rely on them, they came every day, they gave us a huge amount of time. I remember ringing them...and they were always there, always returned our calls.” (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.”

There was only one family member who complained about not being able to access the service on a particular occasion, which was around Christmas.

### ***Flexibility***

The flexible attitude of the HBT team, which took individual’s needs into account, 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)

“They would see if they could do anything for me.” (service user)

### ***Respecting individuality***

Interviewees appreciated being treated as individuals and in relation to their roles, such as parents or employees – in other words, who they were and where they were coming from. Also, it was important that the team respected the person’s 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.”

### ***Good teamwork***

A number of interviewees commented on how HBT worked well together as a team. Potentially, it could have been stressful relating to several different team members coming to the house. As one service user put it:

“I think one of the things I had trouble with was ... constantly meeting new people when you’re sick, because you’ve got to remember that your brain has trouble processing information because you’re tired and you’re sick and what not... because when you don’t actually have a relationship with them and they start asking you stuff you just start to get a bit annoyed with sharing yourself with all these different people.”

However, there was strong praise for the way in which HBT worked together, and no complaints about lack of continuity:

“They were a really caring, compassionate bunch of nurses that worked well as a team.” (service user)

“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)

One service user said it would have been easier to relate to three people rather than five, and another found it uncomfortable when there were two people from HBT there at the same time:

“It felt slightly strange having two of them here, but I didn’t think they needed to be there in pairs. I felt like one was talking to me and one was watching me.”

### ***Supportive to the family as well as the service user***

HBT came across, in the interviews, as there for the family as well as the service user, Interestingly, for the most part this did not seem to involve conflict in their roles.

Family members were grateful that HBT made home care possible:

“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.”

“Just to allow you to have a bit of peace of mind, just knowing there’s some other support system there.”

“They gave us backup.”

The high levels of family stress during this period is dealt with in more detail in the family analysis at the end of this report. It comes across strongly in the following interview excerpt:

I: If HBT hadn’t been available what would have happened?

FM: God knows, not me. I don’t know. I could have run around with a machine gun and shot everybody!”

Most of the comments were around practical help and stress relief, but some comments referred to improving family’s ability to deal with issues:

“They strengthened her and us.”

One family member indicated that they found it difficult to ask for help, but not because of HBT attitudes:

“ I guess I could have lent on them more but I didn’t, so I don’t know. I presume that, like they say, that they did make it clear that they were there for the family.”

Service users 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.”

“Just to let my family just get some sleep, basically.”

“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.”

“It would just take the pressure off my son.” (service user)

### ***Depth of relationship***

Even though the HBT contact lasted only a few weeks, an atmosphere of closeness rapidly developed with families and service users. Individual HBT members were usually liked, and accepted into the family. Comments on the relationships with team members sometimes indicated a degree of emotional intensity that was perhaps 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.”

“I remember, once they said to me, ‘You know we’re here for you, we’re doing our job but we do care for you.’”

“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, and it was just... I really longed, well not longed, really enjoyed that aspect...”

Not everyone enjoyed the attentions of HBT, though:

“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 brought a lot of themselves to their jobs, so they weren’t just health professionals, they actually built a rapport and a relationship with [service user].”

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

“That really built a bridge with [service user], that was really good that they could do that.”

“We really felt like they had [service user’s] 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.”

“It was quite intense.”

One family member, who did not live with the service user and who was rather lukewarm about the service, explained why she did not develop closeness with the team.

“Interviewer: Did you get a chance to develop a relationship with HBT staff, over the period they visited?”

FM: No.

Interviewer: Would you have liked that?

FM: Not necessarily, I mean I was having time out.”

### ***Delivering hope and encouragement about the recovery process***

HBT was praised by several for helping them understand the process of recovery, with its setbacks, and were grateful for their “positive reinforcement”, help in “seeing the bright side of things” and their faith in recovery.

“At the time 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, and it wouldn’t be, ...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 have had that assistance from them.”

And another said that having “positive reinforcement” from HBT, and being told that down times were “only a setback” was very helpful.

### ***Going the extra mile***

HBT members were seen as putting in more effort than could reasonably have been expected in terms of their professional duties. Two family members said:

“If he didn’t like them or if they hadn’t gone that extra mile for him, I don’t think that could have worked.”

“They went above and beyond.”

“Some just went that extra bit to make you feel even more special.”

### ***Including family and service users in decisions***

The HBT team's willingness to include family and service user opinion was highly valued. They were seen as skilled at consulting.

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.”

“So the HBT team sort of would help negotiate where I was staying, what I was doing, in conjunction with my family. From that point of view they were really, really good.”

“I had the choice, I had the fact that I didn't want to come back to my home and they were very good about letting me stay at the respite place as long as it took. I actually left there and came home of my own volition after about a week and a half, but there was no pressure, I could have stayed there longer there was no pressure from the HBT people to move back to my home or anything like that.”

Family members said:

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

“So they'd kind of take what we were saying and it felt like they valued our opinion and they'd incorporate it into their decisions.”

“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.”

### ***Dealing sensitively with issues around choice and control***

Related to inclusiveness are issues involving choice and control. 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, sometimes using compulsion to control them. In their interviews some service users commented on how they were during their period of crisis, in relation to making good decisions 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.”

“I probably wasn’t well enough to make my own decisions.”

“At the time I really, really pushed and pushed the HBT at times...I pushed my aunties: ‘I want my money, I want my phone’ and they weren’t going to give them back to me.”

Family members sometimes recounted difficulties they experienced with the behaviour of their relatives, particularly with getting them to do things they judged necessary:

“We were a bit concerned about [service user] drinking too much, because one night [service user] came home and he drank a 3 litre bottle of something, and that day he had had 2 litre things of milk and he was buying V drinks, he was just drinking so much and then he’d wet the bed at night.”

“He has to be talked around into things.”

“We were finding it a struggle for him to get his medication down.”

“He was challenging people who came into the house, ‘Who are you, what are your qualifications, what did you do before?’”

Service users, on the whole, felt that HBT had helped with decisions, cajoled them and sometimes made choices for them, without acting in a destructive manner.

Comments on lack of choice included:

Interviewer: Did you feel you really have a choice?

SU: Well, I didn’t have the choice, the choice was made for me.

Interviewer: In terms of the decisions about them coming at 5.15 and another one staying the night, were you involved in that decision making about how that all worked or were you sort of given a plan?

SU: No, they told me what would happen, and that’s the timetable that I think that they’re scheduled to.

But most appreciated the outcome and no one expressed strong resentment at choices made for 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 probably wasn’t well enough to make my own decisions, they probably asked me and thinking back I would say, “I don’t know”, [laughter] and 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.”

“I knew that I was getting better so I knew they were acting in my best interests.”

“They weren’t like prison guards, they were like, they were really lovely.”

The mixture of control and choice is expressed well in the following interview excerpt:

Interviewer: Did you feel you were in control of that process?

SU: No, they were in control of me, because I had no control over my own things so they told me what to do. I did it because I was in no fit condition to make any decisions, and they made the best decisions.

Interviewer: Did you feel consulted about those decisions?

SU: 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 were relieved when HBT helped them persuade their relatives:

“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.”

One family member who was less happy with the HBT service 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.”

Family members 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.”

## **Home versus Hospital**

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 previous experiences of hospital at varying times in the past.

On the whole, highly negative views of hospital were expressed, with service users using terms like “crap”, “terrible” and “scary”, with one describing it as “just the worst experience ever” and another telling us that “obviously, no one wants to go to hospital”.

A couple of service users were in hospital directly before having HBT. One had a negative experience; the other was not negative about the experience, but was pleased to leave with the help of HBT, saying:

“It’s good in its place, but there’s a stage you get to when you’re unwell where you don’t need, the environment is no longer conducive...”

Family members noted their relative’s desire to avoid hospital:

“She was terrified to go to hospital, and we didn’t want her to.”

“Him going into a ward was a last choice for us.”

The reasons for not wanting to go to hospital included being with others experiencing acute mental illness –

“You’re with people who are really sick” (service user)

– less holistic treatment being available in hospital:

“I think you would just be given your pills and that’s it.” (family member)

“There’s nothing to do, they don’t offer you anything.” (service user)

– and being under compulsion:

“They force you, lock you in your room, you can’t make choices there.” (service user)

“The other difference is that he was able to be part of his treatment plan, and his treatment he got, he could have input into what happened to him.” (family member)

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 in people's estimation? Family members were under a lot of stress, indubitably, but on the whole they were pleased to have averted hospitalisation because they felt that being at home was better for the service user.

“The family get very tired, physically and emotionally.”

“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.”

“So, yes, there was a point, ...it nearly came to it, in fact we took him down to the hospital one Sunday ... and I thought they were going to admit him then and I was so tired...It was kind of a thinking like I wanted the problem solved, like I wanted him off my hands, but I didn't really want him to go on the ward.”

“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. I don't know that we'd have him. It was too much..... it was really hard it was probably one of the hardest things I've done in my life, I think.”

But asked if they would have HBT again, another family member said, “Yeah, that would be really good actually.”

Service users appreciated what their families did for them, but one said:

“If I was at hospital I think it could have been a very good thing for the whole family.”

A couple of service users said they would have preferred to go to hospital. One, who had never been to hospital and who said she was “a sad trial case”, even though she appreciated the HBT service, said that:

“I think I would prefer to have a time in hospital and then come home just because, home is terrible when you're here on your own, it's so good to have people around.”

This same person also thought that if she had gone to hospital she would not have developed an “unhealthy and quite draining” dependency on her mother.

And another, who also thought HBT was “pretty good” felt that he would have had time to solve his issues if he had been on the ward, and that the ward “is a safe place to be if you are feeling unsafe.”

## **Finishing with HBT**

Some of those interviewed were very apprehensive 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:

“I felt quite sad because I’d got sort of semi-attached to them.” (service user)

“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)

“I was scared of losing them, like they wouldn’t be there, because I was quite vulnerable.” (service user)

“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)

“At the very end I think [he] kind of felt a bit abandoned and we did too, a little.... he saw them almost as his friends.” (family member)

“It was like a four week ‘meet the rellies then you’re off back to America’ sort of thing.” (service user)

One service user remarked that the short period of HBT availability affected the relationship because he sensed them “pulling back a bit because they knew they didn’t have that much time with us”. This was a minority response, though, since more emphasised the intensity of the relationship.

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 ambivalence, and displeasure that HBT could not continue to see them, was expressed in the following comments, but on the whole people found that they did well afterwards:

“I missed the support initially, but it was ok.” (service user)

“They started cutting me down on days that I went to the day hospital and weaned me off it. Just like a mother weans her babies off her breast, even though you might want to continue doing it.” (service user)

“Well, for that intense time it [the timing] was probably about right, because it’s easy to come dependent on them! (service user)

“I just was annoyed that it didn’t last forever.” (family member)

Those who still needed support, or a slower transition, made comments such as:

“What we got was fine, but we could have had a bit more.” (family member)

“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)

“I think it was really harsh, but it was pretty upsetting at that time. It added stress onto the whole situation rather than, I mean, it might have been easy for them to shift one case on so they could start attention on the next, which is actually what they’re there for, right, to help people at a certain...period, but for us it was, like, almost devastating, it was so, so bad because Dad [was] just starting to get to know the guys, and that was ripped away, and Mum with the women and me with all of them. But for me I actually felt more for them [his parents]. It was just taken away. Because when a person gets diagnosed with an illness and is sick, it’s not just them that’s affected, it’s the whole family. Mum and Dad needed as much support as me.”

One family felt that the discontinuance of HBT, against their wishes, had left them under severe stress and had led to a very unsafe situation for their relative, who disappeared and apparently made a suicide attempt in the period after HBT support had been withdrawn.

Interviewees were questioned about how the actual handover processes went. Some were happy about them, including one who said it was “seamless”. Others said:

“It was very well managed...one of my things was that I was scared of losing them, like they wouldn’t be there, because I was quite vulnerable, but they’d be good and they’d call me.” (service user)

“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)

“They introduced me to the people there [a community mental health centre], and so we had a meeting so it was a transfer I guess, so they didn’t sort of just leave you sitting there, thinking ‘Oh God, these people have gone’.” (service user)

One family member expressed disappointment that the HBT team was not available for the handover:

“They actually needed to have made more of an effort to have been there and to have done it with us.”

Overall, only a couple of service users initiated the exit themselves, one who had another support worker and decided “I just didn’t really need her [HBT team member]” and another who decided to go back to work, asked HBT to come around in the evenings at first, and emphasised that it was “my decision” to end.

Some interviewees expressed disappointment at lack of followup 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.”

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

#### **Services After HBT**

In the last section we examined exiting from HBT and the handover process, establishing that many HBT clients feared that they would not manage without continued intensive support, and were sad that the team was leaving since they had developed an attachment to them.

In this section we look at what families and service users had to say about the services they received after HBT. Firstly, we look at their experiences with community mental health teams (mostly, handovers were to community mental health teams) and secondly, at their experiences with other mental health services.

Service users' experiences with community mental health teams, in terms of satisfaction, 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 who liaised with the doctors on her behalf. Another, who said she is recovering well, had counselling from a psychologist via the CMH team, as well as getting her "meds" there. She was just about to be referred to a GP and will cease using their services. Another found the clinic "good", seeing a psychiatrist there but with less frequency, since he is recovering, and another said services were "cool".

One service user, who referred to "my social worker who looks after me", said that she had missed the intensive HBT support initially, but:

"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."

Another said that "the different aspects of the health system just seemed to blend together."

A family member said that because their relative "bounced back quickly" they did not need much contact with the community team, but:

"I was certainly made aware that they were there and if I needed them I had all the contact numbers."

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

"When [he] went back to his flat and back to work there was ... a time when he needed a lot of support ... but a different kind of support, not the intensive wrapping around, like the HBT team gave him, not the intense personal but more strategising, how to cope with going back to work (he was very anxious about 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...Also he was really open to receiving help at that time, whereas I think he's probably maybe not [now]."

Another family member said that they missed the HBT involvement with them as family, and they were worried about how to cope with the move from daily to weekly or fortnightly consultations:

"There began to be a bit of a demarcation between people saying 'We are here for [service user]' and 'We are not so much here for you.'" There is a person

[at CMH] who has on a number of occasions seen that we were emotionally affected and I'm pretty sure ... she had skills to deal with people who had those sorts of imbalances but she said on more than one occasion, 'My primary task was [service user], and that's fair enough, but [it] was really frustrating to be in the presence of a health professional who might have been able to address some of our reactions ... as well.'

One service user said she did not like her case manager and was unable to change. Initially she had felt supported ("she's been good to me"), but increasingly, she was feeling "a bit let down", especially because of cancelled appointments. 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 followup:

"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."

Another service user felt that it was hard to establish trust with the CMH team: "It's really a whole different feeling." She needed to "know that they're going to be there for me, because they weren't in the end, were they?" This person had stopped going regularly and had "slipped back" and was not followed up. The team were about to put her off their books when she rang for help.

One or two referred to reluctance to seek help, and several said they would like to have been followed up more. One family member spoke of feeling that she was "imposing" if she rung, but "huge gaps" in the system meant that there wasn't a person for her daughter to ring after hours. Consequently:

"Weekends, I've got to be constantly available to take her out and do things with her, and evenings I've got to be constantly there on the telephone, and if there's a crisis I've got to be constantly there to keep her company and stay the night."

People were asked if they knew how to seek help in a crisis, and most seemed to understand, more or less, the relationship between crisis services, case workers and HBT. They referred to information they had been given.

There were comments about case managers not being available out of hours, but people also spoke of phoning the CATT team or the Mental Health Line, and found that "chat" on the phone was helpful.

One person, under the Mental Health Act, felt that that was beneficial in that they would be able to go "straight to hospital", or else to their GP, psychologist or psychiatrist.

The other service referred to by several service users, in addition to community teams, was the Early Intervention Service. One family member felt that early intervention, although providing social support, did not give him the right kinds of things to do, and another family member referred to their daughter as not fitting into the EIS. Another service user found the range of activities and support from the service was very good, particularly the youth groups (she was about to go off skiing with one of them), and the case managers were “very supportive”.

One person found that it took a bit of time to get organised with EIS after the HBT team finished, but that now “they’re very good”. She has help from a psychologist via them and was referred to a “living without violence” group to deal with an abusive relationship. Overall, “the mental health system is really great for me.”

Services referred to by only one or two interviewees included Māori mental health services and the eating disorder service.

## **Recovery: Strategies for Getting Well and Staying Well**

We asked service users (and their family members) how they were doing now, and what had helped with recovery. The previous section of this report, on experiences of home based treatment, made it clear how aspects of HBT helped with recovery. In this section we look at some more general aspects.

### ***How are they doing now?***

People were interviewed more than six weeks after HBT had been terminated. Some had longer to recover than others, so this section is in no way a thorough examination of outcomes. However, what they said about how they are doing is interesting, in terms of service provision issues, as well as in 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”:

“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 were well, but spoke of residual symptoms. G said that now he feels “pretty good” but noted that when his medication was being changed, “a little bit of psychosis seemed to occur for a day. Nevertheless:

“Even on the medication I still get the feeling that people can read my thoughts but I now know that’s not true but it’s almost like how a car gets stuck in gear and it’s hard to get it out of that gear.”

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

“Sometimes I feel a wee bit like things are distorted in my mind.”

“I have a bit more stability now.”

“I think I’m a lot better than I’ve been but I’m not nearly 100%.”

“At the moment I don’t feel too positive about it because I’ve had a stressful week, but basically I think I’m doing really well.”

“Once the medication had been increased, I guess I became a bit clearer in my head and was able to handle the situation better. I wanted to try and resolve some issues I had, but that never actually happened.”

A couple still seemed to be having mental health difficulties to the extent that they felt they may need crisis help again soon. 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 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...”

### ***Back into life***

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:

“I really had to get back to work, that was my priority.”

“I’ve been working since May and it’s been an interesting job but one that I haven’t been completely happy in, so I’ve just been accepted for another position which I start in about a week’s time, which I’m really thrilled about it, that I got it.”

Others put some of the credit for their being able to find and hold down a job to the help they received from 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....”

Someone who was not currently working was still feeling positive:



“I just picked up something someone offered me and it wasn’t actually very good, but I did it for a while and decided that was no good for me so I stopped....I don’t work any more, but yeah, work is definitely something in the future I’d like to... soon. I’m seeing ...my social worker next Tuesday to talk about work.”

V. had left hospital early, with the help of HBT, to take up parenting again, allowing mother and son to “have a normal relationship”.

### ***Strategies for managing recovery***

People spoke of having learnt more about themselves from the illness experience. 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.”

“More inclined to ask to get help before it got too late.”

Someone also spoke of making a personal decision to try to stay well, assisted by help from HBT, and motivated by an inpatient nurse who had said to her:

“You can choose to be a normal, happy, healthy ... girl, or you can choose to be a bulimic and anxiety disorder ... kind of girl.”

### ***Understanding and interpreting one’s mental illness, diagnosis and prognosis***

People sometimes felt quite shocked about having their mental illness experience given a label. H. said:

“It was really really, big scale, big September 11th.... a big blow.”

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:

“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.”

G. had researched his diagnosis, and that made him wary of the diagnosis he had been given:

“You get enough information that you sort of become quite sceptical of things sometimes, but ... I’m not certain that anyone knows what causes it or how it comes about... People could say, ‘You’ve got XY chromosome and that triggers this, and that might be why it happens but it’s not the underlying step back, the trigger I guess... History says people under a lot of stress can have a breakdown, so did I have a breakdown? It’s all up in the air, I mean, shit.

I just feel like the whole thing has been about me knowing who I am and my position is ... I guess, [I] have come to accept myself in certain ways.... My line is, if I take my meds everything is fine, and just carry on with life... because otherwise I could think too much about it and think, ‘Oh well, I’m bipolar, and sort of feel sorry for myself a bit.’”

The idea of having had mental illness was difficult for some to embrace, partly because of the stigma surrounding madness. G. said, “If you had told me six months ago that I would go through a psychotic episode, I would have said ‘No way!’” W. suggested that HBT had been particularly helpful in reinforcing 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.

Being given a diagnosis naturally raises questions about future recurrence, and that was an area that was deeply worrying for some people. As mentioned in the discussion of providing information about mental illness, some were frustrated that they could not be told more definitely what was the matter and what the outlook was for them, but at the same time, understood something about medical uncertainties. Queries such as, “can you grow out of this sort of thing?” and “how long will I be on this medication” expressed uncertainty.

Talking about the future, people said:

“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.”

“The Community guy down there, ... he’s like, ‘If it happens once, you’ve got a 50% chance of it happening again, if it happens twice you’ve got an 80% chance, if it happens three times you’ve got a 90% chance that it will come back”, so he was talking about my medication, having to be on it long term. He said that even so, you still might get depressed again.”

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.”

People on the whole said they knew how to contact services again.

#### **4. ALLIED PROFESSIONALS: REFLECTIONS ON HOME BASED TREATMENT**

We interviewed four allied mental health professionals, including a social worker with another service, an inpatient staff nurse, a community mental health nurse, and a psychiatric registrar. The inpatient nurse had regular weekly contact with HBT and each of the others had referred clients or worked alongside the HBT service.

##### **Accessing HBT: Professionals and Their Clients**

The professionals were pleased at how easy it had been to access the HBT team when they needed to. One said:

“The thing that stood out in contact with the HBT is their willingness to get involved rather than barriers....I think that we work in a system where everyone tries to protect themselves and often there are barriers going from the ward to the community team; or going from the community team to the ward; whereas the HBT team have at times been canvassing for people...Whenever we have rung I personally haven’t had any problem with accessing.”

Another said that it was “brilliant” that HBT would get back within half an hour and arrange for an appointment the same day, and:

“...you know that it’s not going to be a lot of argy bargy for a few hours...but that you are going to get on the phone, get a plan...It certainly makes it smooth for us, but also ... you can give the family and the person a definite about what is happening, there’s not that kind of uncertainty that escalates people’s anxieties.”

Suitability is determined by a number of factors, including risk management, acuity, and level of family support. The inpatient professional admitted that “pressure on beds” sometimes influenced decisions, especially because another service had closed at the same time as HBT had begun, meaning that pressure had not decreased as expected. However, the HBT team could reject referrals, and had done so at times if the person was “too well”.

An issue for referral from the inpatient service was family readiness:

“One thing you have to appreciate when patients get admitted is families are exhausted and they need some respite as well before they think about taking someone home and continuing that care in their own home.”

The busyness of the ward also affected referral processes. The inpatient nurse believed that it would be helpful for team members to spend time in different acute areas – HBT in the inpatient ward and inpatient nurses in the HBT team – so that the conditions such as high turnover and demands for paperwork could be appreciated.

The psychiatrist interviewed admitted to “surprise” at how much he had found that HBT could be used:

“I thought there would only be a small number of people we could manage in the home, but that the rest would come into hospital.”

He noted that colleagues had sometimes found it difficult to get HBT referrals, but he felt that was because they had not come “on board with the treatment” and established an alliance with the team. He felt that he had been clearly informed about acceptance criteria and that if others may have felt less clear, this was not because of HBT policies but because of their unfamiliarity with them.

## **Communication and Relationships Between Teams**

People were asked about their relationship with the HBT service, and generally responded that communication and relationships were good. The inpatient nurse thought that there could be a little more communication, including feedback about outcomes:

“Generally when you have successes, you don’t hear back. They go out and get back to their lives, then maybe they don’t come back in for six months or we don’t see them again.”

Initially, some staff at the unit had reacted to HBT less than favourably, in terms of “fear of the unknown” and feeling “left out of the loop”, but that had changed, in this person’s opinion, although there were still some things to be ironed out. Some staff do not seem to see HBT as an acute service, and some are concerned about risk, but “when you are managing risk, sometimes you have to take risks to enable people to succeed.” However, “it’s not going to be too long before it’s second nature for all the staff here” to be thinking about suitability for HBT.

The issue of people treated by HBT returning to inpatient care was raised, and the comment was made that “if people need to come to hospital they need to come to hospital”. Even though there had been occasional “joshing”, due to the newness of HBT, someone returning is not seriously seen as a failure of HBT.

A social worker with another team thought that there was sometimes a problem with overlap in care:

“I think those guidelines, between how it fits together, is a bit blurry, and maybe needs some more work around that. About where each of those boundaries start and how we work together with someone, because often at those times those teams are working really intensely with that person, it’s not like HBT comes in and community team steps back, you’re often both working, you know, you guys maybe in the evening, or popping in during the day and we’d still pop in at times during the day to see that person.”

Good communication, she felt, “gives reassurance to families that one team’s talking to the other team.”

## **Philosophies**

The issue of HBT philosophy also was canvassed – was it a cause for clashes or do the different services work co-operatively? The reply from the inpatient nurse was that people working on the ward understand why HBT is needed, as well as why the ward is needed:

“Most people recognise when you are unwell (and I’m not talking about just mentally unwell), all the things that you crave are things that give you comfort and the things that you know and are familiar to you. These are things that give you some kind of security and I don’t think that there is a nurse here who doesn’t realise that this is an alien environment and it’s totally foreign and artificial, and if you lose sight of that you shouldn’t be working in an acute unit. This isn’t people’s norm, this isn’t what people normally do, they don’t live in an area which has 20 other people in it, and they don’t take their meals each day with 20 other people. [The ward] environment is different, [but] I think that the staff here realise that there are things that are good for people that aid recovery, but how do you facilitate that?”

One professional noted that the HBT approach was particularly compatible with Māori mental health models, with their emphasis on family and on “getting alongside” with people so that they do not feel that “their rights have been taken away.”

An early intervention service worker believed that their two models fitted “really well” together as they also emphasised working with families and fitting the service to the person’s needs.

Once person noted that, because HBT is a new team:

“...it has attracted to people who want to work proactively – they have more enthusiasm and are more committed to what they are doing. ...They are far more committed to their philosophy as opposed to the team clinicians.”

## **Benefits for Service Users**

Professionals mentioned having had positive feedback on the service and noted various benefits to service users from having access to HBT, both in general terms and by reference to ‘success stories’. The greatest benefit, some suggested, was avoiding admission to hospital, with its associated trauma and stigma. Others points mentioned included: the team getting on well with a variety of people; a patient-centred approach “bringing the person alongside”; continuity around treatment; being able to be seen outside normal working hours; family support; and family education.

One negative aspect for a particular client was mentioned:

[On the other hand, there was] one that wasn't so successful and I think it was because of the change of people, too much change of people, and she never felt she could really disclose what was going on. It just didn't work."

Someone told of a woman who had given birth nine weeks earlier and came into the intensive care unit "quite disorganised and obviously her mood was quite elevated....and doing very odd things. She had to give up breastfeeding because she was put on a mood stabilizer. For her husband, "it was a very new experience for him having anything to do with mental health services, not a positive one, because his wife had been committed, she ended up in ICU for a couple of days, she wasn't the woman he fell in love with or the woman who had his child ." He was very reluctant to bring the baby into ICU, but with the help of HBT she was able to go home:

"...and spend time in a supervised way initially with her child and they continued to bond, and there was less stress on the family because her husband didn't have to try and find child care, trying to pay bills, coming to see his wife every night."

A community mental health nurse spoke of:

"...a client with a partner who was very controlling and the client was also very resistant to hospital. She knew that when she goes in she collapses and it takes her a long time to get back her level of functioning. Every time she does that she loses a part of herself....The HBT team worked really hard with her and her partner, helping him to understand what was going on.

...[T]here was a regular time when she started to get unwell, and the HBT would just step in at that time and give her what she required, so she had more control over that. Just recently she came to a time when she would have normally got unwell and she didn't have HBT. So it was a great discovery for her to find that she could actually manage her own illness."

Another person had a client

"...who was incredibly isolated....very unwell and ...had had very long admissions...They didn't want to go back...You guys took him out, you know, and that was kind of neat for him to be able to get out of that environment where he was feeling so enclosed...It doesn't sound that important, but it was very important for him. And for him to know that ok, at this time I'm going to have somebody come round, so I can last until then, and then I can last until I go to sleep, and then I can last for the morning or I see my community worker. So it really made it manageable for that person. 'Ok I'm not alone here and I don't have to be alone, this is not something I have to deal with alone', and just that sense of relief that gave them,...it gave them a sense of freedom."

This client said that:

"...it was at their pace, it was in their home, it made them actually feel as though they were in charge and that they had choice and they had options."

Another, whose:

...client prefers using the HBT as it fits with where she is in trying to manage her own illness and gives her the flexibility of support but also the independence, which is something that has really progressed her. She doesn't feel that dependent upon the hospital anymore, but knows she can ask for HBT whenever she gets unwell and she is able to maintain her own environment."

## **5. THE HOME BASED TREATMENT TEAM: REFLECTIONS ON PRACTICE**

All five members of the Home Based Treatment team were interviewed for the study. They are all registered nurses who joined the team through their association with other mental health services in Capital and Coast, particularly the CATT team. Some had been involved since the beginning of HBT, others had come on more recently. Length of service ranged from six months to two years, with average time on the team being 12.8 months.

### **Nursing Background and Joining the Team**

We asked them about their previous nursing experience, why they had joined HBT, what their HBT work involved, their opinions about the effectiveness of HBT and how they related to other mental health professionals and teams, as well as about professional and administrative issues in relation to HBT.

All were experienced nurses, [three female and two male] with between seven and 20 plus years of experience. Only one had trained in the Wellington region, two were from other parts of New Zealand and the other two were from the United Kingdom. All had experience on inpatient wards and in acute settings; only one had not worked in an acute inpatient ward. All had experience in community settings, including a UK home based treatment team, early intervention, CATT and forensic. Together, the team had a wealth of clinical experience.

When invited to join HBT from the CATT team, people accepted for a number of reasons, including that they wanted to extend their experience and be part of a new initiative that had an interesting philosophy and was client-focused:

"The concept of HBT was going round for a while. I've always shown an interest in moving forward and developing services and stuff, that's a bit of a passion of mine."

People also mentioned enjoying acute work and wanting to provide people with constructive help:



“I wanted to broaden my experience, just draw in on all the nursing that I’ve already been able to work effectively with and enhance that, and prevent people from going into hospital and making it a good experience.”

Two mentioned the hours of work – HBT were working 12 hour shifts with four days on and two off – and for one this was a plus after a 9–5 community job, whereas for another, it was not possible to accept the initial invitation to join HBT until certain things had changed in her life making the 12 hour shifts possible.

## **Delivering Home Based Treatment**

### ***Referrals***

HBT has relied on other teams to make referrals to it. Receiving inappropriate referrals, and sometimes not having an appropriate client referred, were sources of frustration. It was felt that when colleagues had a good idea of what HBT involved, they were more likely to make appropriate referrals, but some “don’t or won’t understand what we’re all about”, “some of them think we’re just there to do the medication run in the evening”, and therefore “we spend a lot of time saying no”.

Not being involved in the initial assessment of the client was part of the referral problem. 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”. In relation to referrals involving discharge from hospital, they should be done “the right way” by:

“...ringing through first and offering an appointment for HBT to be involved rather than making a decision at the hospital...”

More recently there has been a “resource coordinator” who manages the referrals, and team members seemed more satisfied with this process.

As part of the referral process, appropriate locations for treatment needed to be established, and 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 services to someone who is home alone or with their relatives or in respite care:

“You do meet the person who actually wants to be on the ward, but most people would much prefer to stay in their own environment with their own familiar things and people around them. We can offer that..., the chance to stay at home basically and get some treatment there.”

### ***What the work involved***

In terms of the tasks involved in the services provided, HBT members gave much the same picture as service users and family members: 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 with clients, liaising 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. When asked if they practiced outside the usual range of nursing care, though, people tended to disagree. Although “some things seem that way to an outsider” in fact 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:

“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.”

In terms of flexibility, which service users and families had praised, HBT emphasised that they were a “needs-led” service, using an “experience based model” that involved “teasing people’s needs out of them – What’s going to help you through this? What do you know about yourself?”

### ***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.”

“There is a lot more family work and you are not just working with the client and it affects a lot of people...You build up a lot more of a relationship because you are involved with them, sometimes for two months.”

One person contrasted the HBT client relationship with relationships on the ward and in community mental health teams:

“We have to form a good therapeutic relationship with some people in a very short space of time and then maintain it for short spaces of time. On the ward, things are contained, and it feels like people aren’t too interested in getting to know the clients, or they haven’t got time to. We have got time and space to do that, get to know people, get to know their families, get to know their support systems, get to know their world, really. CMHT’s also do that as well, but in office hours. We get to see people at different times of the day in different situations, which gives us a wider perspective.

But we have to be able to get into people pretty quickly and they have to be able to relate to us pretty intensely, pretty quickly, which is not always easy for the client to do.... it’s the acuteness and the short period of time that we see people, it creates a different form of relationships in a short space of time.”

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...so you are able to allocate clients with a primary nurse as such and ...because you’re two on two off, there was always a person crossing over to the following day

to work with someone different. So it was quite refreshing as well, to work with not the same person all the time, even though I liked all the people in HBT. And that's helpful because you get a different perspective on clients as well."

### ***Issues around choice and control***

Issues around choice and control were referred to in the service user and family accounts. HBT team members also emphasised these issues 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 nurse reflected the complexities involved in choice:

"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. If there is a carer's burden there, then maybe it's an idea that they go on respite or on the ward, for a while before coming out, being discharged or something. It's kind of hard really, because when we're working with clinical health teams, we're working on selling this idea of homebased treatment, try really hard to get it in people's minds. Give people the option. Talk about it with people. Advanced directives, things like that, but I think people really do choose. You see the people who have the experience of hospital before. They know. That's even more of an informed choice. Perhaps someone [for whom] it's their first presentation. Their family's really anxious about what they've heard about psych wards, mental health patients and things like that, they will come to us. Whether that's the informed choice or not can be freely argued really."

It was seldom that service users stated a preference of hospital over home, but if they did and their family wanted them at home, HBT:

"...would look at the needs really...If there was no immediate reason for them to go to hospital, we would probably be more likely to want to keep them out of hospital and rationalise as to why. So we would sit down with the client and talk it through and say 'These are the reasons why we want to do it this way, and your family are also in support of that, let's try this out first.'"

In terms of what needs to happen during treatment:

"We aren't enforcing treatment on them, it's more of an equal alliance."

"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.”

A story was told about how HBT involvement had reduced involuntary admissions for a particular client:

“[She] was having several admissions per year to the unit under the Mental Health Act, and when we became involved it was the first time she didn’t have to go into the unit and have the trauma of being dragged off by the police....There was a bit of a process: we were asked to be involved twice with her. The first time still resulted in a hospital admission, but she went informally, and that was a change for her in that she wasn’t taken in the middle of the night and that started sowing the seeds for her. The second time we were involved earlier on when she became unwell. Her team contacted us, and a lot of it was just practical stuff like having someone in the house over night so that she knew when she got up she could chat rather than open a bottle of wine, which is what she had been doing in the past and it had impacted on her state also. So it was really putting in place some practical stuff and she wanted to stay at home.”

### **Relationships with Other Mental Health Teams and Professionals, Within and Outside the CATT Team**

HBT members had a multiplicity of contacts with other mental health professionals during their clients’ time with them. Located in the CATT team, they had assistance from the social worker who can come to meetings and is able to point them in the direction of needed community resources. They also worked in with the CATT psychiatrists (a consultant and a registrar). Someone commented that they worked well with the psychiatrists who “take into account our recommendations”.

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 have use of a casual pool of people who can be brought in, for example, for overnight stays, and after a “learning curve”, they have come to be selective about who they use. If medication is a “big issue”, then they bring in registered nurses for the overnights.

## **Exiting**

Not very much was said in interviews with team members about exiting, although it was of concern for families and service users. HBT members referred to the skills involved in rapidly starting and finishing such an intense relationship. They enjoyed being part of the move from crisis to resolution. Someone mentioned a concern about over-involvement sometimes. The impression was given that it was professionally satisfying to achieve a speedy resolution of crisis.

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

“We are 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.”

## **Assessment of Impact of HBT on Service Users**

HBT interviewees were asked about the impact of HBT on their clients. All thought that HBT provide a very good service that was well received by clients and families and had positive outcomes.

The high level of time and support provided was emphasised, as well as the focus on meeting needs in a flexible way (“fitting the service around them”), choice and inclusive decision-making. The quality of relationship, with client involvement, honesty, trust on both sides and not being judgmental, was often mentioned, as well as taking clients' lives into account and “going through it with them”. Also mentioned as important were information and education.

Averting hospital stays, with their associated trauma, was seen as a big reason for client satisfaction with the service, too. Someone suggested that crises often resolved faster with HBT help, as compared to an inpatient situation:

“People, from my experience, have responded quicker to treatment...People would be on the ward for four or five weeks, people would be at home two weeks average turnaround.”

However, two weeks was said by another team member to be “not long enough at all” for the team to be involved.

Another mentioned a client who the team saw for 2½ months, but this was someone who had historically long inpatient admissions and HBT had speeded up the process of recovery.

## **Administrative Issues**

As mentioned, HBT is located within the CATT team. In terms of administrative procedures, there was little complaint, just:

“...a few systems and processes we do that could be smartened up a wee bit, and we could probably be given a bit more support around supervision, I think, but we kind of do that amongst ourselves.”

However, HBT members felt that there could be improvements in the way the whole service worked together. In particular, it was suggested that HBT could be more central, rather than functioning as an “add-on” to services. It could be expanded to 24 hour availability, and it would be an improvement if HBT staff were able to offer “advice and input” when community mental health team clients were showing “early warning signs” and, as mentioned earlier, if they could take part in assessing for admission:

“We could be involved in discussion around other alternatives and options and if they know they are going to see someone that day and hospital is likely, then we get invited along then rather than they have already made a decision and then having to try and undo that decision.”

With HBT functioning as an “add-on”, there were some frustrations about how it was perceived. There was the feeling that some perceived it, as mentioned earlier, as a medication run in the evening. Others “think that HBT is a dumping point for when their patients get too acute for them.”

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.

One way in which integration was working was that CATT team staff sometimes rotate into the HBT team (“though they need to be there six months”) and this means that increasingly, CATT team staff have better knowledge of HBT, although:

“There’s a big hangover from institutions there as well, and that’s 10 or 15 years ago that they were closed down, so I think there’s a lot of people that are still institutionalised in their mind about things.”

Entry criteria have relaxed too:

“We were quite inflexible in the beginning, that it was only going to be those people who should be hospitalised, and now it can be that they are heading that way.”

Also, the team seemed to be more relaxed about the occasional longer need for the service.

Sometimes it could be fatiguing to be part of an innovation:

“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.”

## **Job Satisfaction**

The nurses we interviewed seemed to derive a lot of enjoyment and satisfaction out of belonging to the team. 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.”

Very few negative things were said – one of the few was about 12 hour shifts seeming very long, especially when one finished late. Otherwise, they made comments such as:

“It's a really good way to work.”

“It's what nursing's about for me.”

“Personally and professionally it's very rewarding to do that, because you get real contact with people.”

And finally:

Interviewer: Would you ever go back to a ward?

HBT member: No, I couldn't stand it, couldn't stand it!...It's good, I mean it can be stressful as well, it has its good points and its bad points, but generally I love it! I thrive on it.

## **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.”

“I think that what makes an advanced practitioner is about the way you think. I think that might sort of make a difference, we’re not comfortable with saying we’re advanced practitioners, but what we’re doing is certainly moving boundaries around and so that’s advanced in the area I think we do. Reflection has been bandied around for many years, but I think we truly do, subjectively and objectively, we’re really into that.”

The impact of working in HBT was emphasised by a nurse with slightly less experience than the others. When asked if her practice was enhanced by working with HBT, she replied “100%” and went on to elaborate:

“At this level you have to be very very knowledgeable in MH presentations and diagnoses and treatment packages and you have to have a good communication skill, written and verbal, so that you can communicate effectively with families and clients. And there’s such a different range of clients coming through so you have to be very knowledgeable in how to work with them.”

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.”

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.”

## **Future**

HBT nurses would like to see the service continue, grow and become more integrated with the community team. In being seen as an “add-on”, it was seen as vulnerable:

“There’s always a danger that the pressure on beds and things like that, that this could be lost, or it probably could happen. Something negative could happen and it would all shut down and that would be a shame.”

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.

## **6. FAMILY/WHANAU EVALUATION OF HOME BASED TREATMENT**

*(This section of the report was prepared by Tess Moeke–Maxwell, independently of the research team and therefore sometimes repeats points and quotations appearing earlier in the report. However, it is a fuller analysis of the family member experience.)*

This report provides an analysis of family/whanau experience of Home Based Treatment (HBT). Of the nine family/whanau interviewed, four were mothers, three were fathers, one was a husband and one was an aunt.

Two main reasons are identified by family/whanau as contributing to the success of HBT. The first concerns the variety of practical services HBT provides to enable the family to care for the mental health consumer at home, while the second reason is attributed to the high standard of interpersonal skills exhibited by HBT staff. Presented in four parts, the first section 'Assessment and Referral', presents an overview of whanau perceptions of the HBT referral process. The second section 'HBT – Practical Support', highlights the practical services that families/whanau claimed made HBT successful while the third section 'HBT Staff – Quality Resource' demonstrates the value families/whanau place on HBT staff interpersonal skills and explores why this is seen as a prime factor in the success of HBT. The final section 'Critical Comments' identifies where family/whanau were dissatisfied with HBT and makes recommendations for an improved service.

### **Assessment And Referral To HBT**

In some instances, families were introduced to HBT as part of the mental health service user’s acute assessment process. Whanau state that the referral process often evolved out of a confusing series of assessments by a variety of mental health professionals. One family member stated:

“[My daughter's] doctor made an appointment with the CATT team because she was showing signs of serious mental disturbance... we had an appointment a couple of days after we saw the doctor to see the CATT team's psychiatrist, and at that point we were introduced I think to, or maybe she was assessed first, and then they might have made the decision to put her with the HBT? I think at that point we were introduced to one or two, yeah two nurses, because there were two at a time. And so we didn't know anything about it before that... we were basically in turmoil with this unexpected situation in our family and so it was a completely new thing to us, and so that's how we first came in contact with them.”

A protracted assessment process and transfer to HBT can create problems for the service user:

“... it seemed to be 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, because he told them he was manic, he told them all this stuff about himself that he had never told anybody before because he is manic... a whole lot of family secrets and very difficult things.... things that were quite difficult... And then every time he went to see different people he would start his story again because he was quite manic. So he was seeing all these different people and by the time we came in contact with the HBT team he was quite negative. And we were actually quite tired of seeing different people and we were like ‘are you going to be the last, are you going to be the final people, are we going to be dealing with you?’”

At other times HBT was put in place as a follow-up to hospital treatment:

“Well before she was discharged we had a meeting with the staff who had been treating [her]... and we talked about where everything was at and how [she] could go home and that we could make use [of], or the HBT team would be available to us. [She] was in hospital for about four days or so, and so after that, I mean she was considerably better.... I guess that people at the hospital thought it would be a good idea to have somebody come in fairly regularly just to see how she was getting on. And that was all set up before she was discharged as I recall. [She] came out on a Friday afternoon, and it may well have been that weekend or the Monday or something, within a few days after which we had our first visit which was good.”

### ***Consultation And Informed Consent***

Whanau reported that HBT was chosen in consultation with mental health practitioners who believed the family would benefit from the team's support during either an episode of mental illness, or during the recovery process. As one whanau member put it: "(T)here was too much pressure for me to be there for (service user)... so I think we had consultation about what we could do to relieve the stress on me, and that's what we came up with". Families agreed that the concept of HBT was explained in detail which made it appealing and accessible. They appreciated the way that HBT

staff avoided the use of jargon or labels and resisted defining the client's experience of mental illness. One explained it this way:

"... (T)heir spin on things was quite different to the psychiatrist's, they were a bit more mellow about [mental illness] saying "these are the boxes but people are people and they fall where they fall" kind of thing. So they were quite nice in that way".

### ***HBT – Better Than Hospital!***

Family agreed to HBT as they were concerned about their ability to manage caring for their family member on their own, or they were resistant to their family member being hospitalised. Whanau reported that HBT provided a welcome alternative to hospitalisation, or having to cope with the family member in isolation, as they believed that the kainga (family home) was the most appropriate environment for the client to stabilise and recover in. One family member states: "Oh, I think it's great, I like the idea a lot, being at home, I mean that's what we've wanted all the time, and to be in your own home is nicer than being anywhere foreign". Families/Whanau generally agree that HBT was a worthwhile alternative mental health programme and would use it again. One of the benefits is that families can maintain normal relationships with whanau while being cared for by mental health professionals. One family member states:

... It was just a very positive experience. [She] was just so thrilled with it all that she wrote each one of them a card to say thank you when she was feeling a bit better which was an indication of how much she had got fond of them and how much she felt they had supported her.

### **HBT – Practical Support**

Two main areas of practical support are significant in family' narratives and are highlighted in this section. The first concerns the families' experiences of HBT as an *inclusive* recovery model while the second area reflects the value families place on HBT model providing *respite* for the family.

### ***HBT Inclusive Of Consumer And Family/Whanau***

Families observed HBT team commitment to keeping the consumer at home. One person describes the flexibility of the staff in their attempts to keep their family member out of hospital:

“And it got to a point that I thought me and my partner, we couldn't look after him unless he gave us his telephone, gave us his money card because it was just too hard to manage him and he was reluctant to do it. But when the HBT team came and we talked about it with them, they kind of backed us up... they said "Well how about if [we] hold onto the phone?", and [Son] gave them the phone and things like that. So because of the relationship they had with him... if he didn't like them or if they hadn't gone that extra mile for him, I don't think that could have worked. And I think they had a real commitment to

keeping him out of Inpatient care... they really had a commitment to keeping him at home, and that kind of showed through... they kept coming up with different options, "Ok this isn't working, what say we put him in respite care for three nights to give [family] a break" because we couldn't get to sleep because he was up all night... So they kind of kept coming up with different options, they were really flexible; they had a real commitment to keeping him out of inpatient care."

HBT provides an inclusive service which families appreciated. Families commented that the family member was involved in their treatment plan and was consulted about their recovery process. Families appreciated that the service user had the opportunity to be a part of their recovery process which contrasted with inpatient processes. One parent states:

"And I think the other difference is that he was able to be part of his treatment plan, and his treatment he got, he could have input into what happened to him. Whereas I think on a ward I think you would just be given your pills and that's it. And you would just be told where to go or when to do it. You're not allowed to do this, you're not allowed to do that, I mean that's what we were doing to [him] but we were kind of having to negotiate with him. You know, "We don't think you should do blah blah at the moment because at the moment you're not thinking very clearly blah blah", it took a lot of talking to him... I don't think they'd bother on a ward, they'd just say "No, if you don't like it..." and lock you in your room or something."

### ***Respite For Whanau: 'Time-Out' and 'Space'***

One whanau member welcomed HBT because she understood they provided respite care by allowing her time away from the home and the service user. 'Time-out' or 'space' was seen as central to this mother's ability to cope with the demands placed on her by her unwell family member. A parent said that they requested HBT because they needed to put some "distance" between them and the mental health consumer in an effort to reduce stress levels and prevent burn-out as they were the primary caregiver:

"Yes, I'm pretty sure, they either came or rang or took [daughter] out which was great because it was like having a very small child that was totally needy, so just having a break, it was like having a child taken to creche, to give us a break. It was just wonderful. So it was very intense for three weeks. I think we may have petered off a little bit towards the end of that three weeks, but we couldn't possibly have managed to have her at home had we not had that support, it would have been completely impossible."

The success of HBT is largely attributable to the way staff take responsibility for the service user when needed. For many families, caring for the mentally unwell person produced stress and can cause safety issues for the family. Families were overwhelmed by the amount of attention the service user required and they expressed difficulties managing the individual and their illness. To "keep an eye on" the service user when wakeful and restless, some found themselves trying to keep going around the clock. Efforts to contain non-compliant members of the family could prove

disruptive and stressful. Families appreciated the professionalism of HBT staff when it came to supporting them to manage the mental health consumer at home:

“And they gave us backup on placing boundaries on him. That's right, at the start [he]... was unwell and they were seeing a lot [of] him, he was *challenging* people who came into the house, "Who are you, what are your qualifications, what did you do before?" He did that to [HBT staff], "What was your previous job, what was your qualification?" And [HBT staff] says "I used to sell insurance" ... professionals would say "That's not relevant, that's none of your business," but [HBT staff] didn't. But they said this to him (and I think that really built a bridge with [him]), that was really good that they could do that. Yeah, I think they were non-judgemental in their attitude towards [him] they just accepted him as he was, and us as we were. Yeah, 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! Yeah, we just thought that they functioned under a rehabilitation model rather than a sickness model, they used a holistic approach. They considered his family, his friends, his work relationships.”

Families emphasised that caring for a whanau member at home could have been impossible without HBT support. One mother said "... I could have run around with a machine gun and shot everybody! I would have been very stressed.”

### **HBT Staff – Quality Resource**

Families/whanau attributed the success of HBT to the high standard of HBT human resources. Family/whanau expressed deep gratitude and appreciation for the exceptional interpersonal skills displayed towards the mental health consumer as well as the family/whanau. These skills, when combined with the practical model of recovery administered by HBT staff, in conjunction with consultation with the consumer and their family, provided the key ingredients which made HBT a success.

### ***Integration Of HBT Into Family/Whanau***

Families generally thought that HBT staff possessed exceptional qualities that contributed to them gaining the trust of the service user as well as the family:

Yeah, I trusted basically they seemed like good people and sensible and knew what they were talking about and I think if we'd needed more help they would have been there... without being too formal I thought they were good, sort of casual, friendly, I mean I took to them straight away all of them.

When a service user is in crisis the family is often confused. They often need questions answered as well as an opportunity to *process* thoughts and feelings in order to come to terms with the mental illness. Whanau pointed out that HBT staff had the ability to put families at ease and provided answers to questions, allowing them time to process thoughts and feelings. One family states that staff were "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". Another family found HBT invaluable for their ability to reassure the family:

“Just sort of their presence was what I found so reassuring, they were just solid people who would sit down and talk, they'd sit around this table and we'd talk for ages. He [staff] was just such a lovely guy. But they were all such nice people, and caring people and really focused on trying to get the best.”

Staff integrated into each family culture with ease enabling the families to feel comfortable with HBT. One participant states:

“... there were obviously people you had a stronger association with than others but that is quite normal. But we never had a problem with them coming to the house. I use to like them coming as it was good for me.”

One of the skills commented on involved the HBT team's consultative process. Using a recovery model, staff included the service user as well as whanau in discussions about the service user's treatment. One person said, "I feel they just embraced us as part of the team, I think they really respected our judgement. I think they were consultative and worked as a team, they took our concerns seriously."

### ***HBT – Recovery Model***

Whanau applauded staff treating the service user as a 'whole person' by refusing to define them by their mental illness as it made a difference to how the person viewed themselves. One family member comments:

“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 *fruit-loop*, or I'm *mad*"... a ward would kind of give you that message whereas he never got it. He got a message that he needed help and he got it. Which I think is good. So, it is more of a wellness model. [He] would think "Ok I wasn't coping, I wasn't functioning, but that was only part of my life", he wasn't kind of like [saying] "I went mad" or "I am mad".”

HBT staff treated the mental illness as an "episode", allowing staff to educate the service user about future encounters by developing a relationship with their mental illness. Staff enabled the person to explore ways to manage health and maintain significant relationships. One participant states:

“... (T)hey were kind of looking at him and his life and his future. So they weren't just looking at who he was but how his life might plan out. Kind of got him thinking about sowing some seeds [and] dealing with some issues he needed to deal with in his life.”

### ***Skilled Communication***

Whanau commented on the excellent communication skills staff exhibited which enabled them to contain the service user and administer medication. Families often struggled with non-compliant family members and were at times stressed, fatigued and afraid. One parent states:

“We didn't know who we were meeting, but the psychologist said there would be two people coming to see us. But we were having problems with a child who has never been in hospital and never taken medication, we were finding it a struggle for him to get his medication down. He responded better to the male, and *he* convinced him to take his medication... 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.”

Families relied on HBT staff expertise during crisis periods and they appreciated the way the staff used their communication skills to manage the service user's mental illness. One family member states:

“[He] has to be talked around into things, and he could be. They were quite good at doing that, and we had to do our degree of talking him into things, getting him to agree to things. But I think that, yeah. [Consumer] was involved. I mean when they came to the house we all sit round a table all of us, and that's how it went.”

### ***Caring For Whole Family***

Staff embodied the entire whanau and provided care and respite to younger members of the family when needed. In one example staff spent quality time with a child during the course of a home visit:

“... I recall, I think they were like reading stories with him, and things like that, but he was really the main reason why we needed it because if [Child] wasn't there [Child's Mother] would have stayed in hospital more likely. But because he wanted his mum and she wanted him she got out possibly a little bit sooner than she could have, so overall having him there, allowed [Child] and [Mother] to have a normal relationship. Because they were supporting [Mother], it was also supporting [Child].”

HBT staff were generally available and accommodating. Their responsiveness and support provided whanau with a valuable resource and enabled them to care for the family member at home. One person states:

“...the HBT team, sometimes they'd be late... they'd have other things to do, but... you could rely on them, they came every day, they gave us a huge amount of time. I mean I remember ringing them at one point and they were always there, always returned our calls. They were very available, very supportive to us.”



## **Critical Comments**

Some families/whanau commented that the effectiveness of HBT was compromised in several areas. Their points related to quality of service, structure of HBT and the duration of treatment time, as well as issues around the period of transition.

## ***Suggested Improvements***

One whanau member was concerned because she could not make contact with HBT staff stating that she had "tried one night and couldn't get them because [service user] played up after they left." At times whanau felt as though they would have liked more contact with HBT staff:

“Yeah, just to touch base with [Staff]. There were no problems, everyone was fine. I found it good just to talk and compare notes... Just let them know how we were going as much as anything, because the feedback we got was that "Oh well, you're all fine" and "Good, no problems." Not that they were dismissive or anything, but I guess they had other people they were seeing who were less well or having a problems or whoever they were concentrating on more. So they didn't feel the need to be 'round here terribly often and when they were here I don't think they spent terribly long here. I think the first couple of visits they might have been here for an hour or so, but the last couple would have been quarter [hour], more like half an hour. Just a general chat.”

Some would like to see the service extended. One parent commented that HBT should link service users with positive role models as a way of supporting them. Some parents also wanted HBT to provide an educative role by supplying appropriate literature about mental health. Families would benefit by HBT staff acting as educational interlocutors in the family's introduction to, and awareness of, mental illness and recovery processes. Further, there is room for HBT to provide ongoing follow-up to ensure that whanau members are coping sufficiently.

Further one family member suggested that HBT could provide service users with constructive recreation to eliminate their involvement in unhealthy pastimes and practices:

“Well I would have thought that there was a big risk there. Once again he has moved in to two new groups and apart from going to EIS they were drinking with him and that wasn't really what he needed. He needed someone to play golf with him, someone to go to the gym with him and just sit while he reads.”

These improvements suggest that extending HBT services (treatment hours and resources) is important if the service is to meet the needs of its client base. These changes could go some way to supporting families cope with the service user's recovery. Further, the service could be improved by providing more recreational support for service users as whanau recognise that fostering healthy activities will benefit the service user's recovery process.

Families generally praised the HBT staff but one family questioned the appropriateness of one of the caregivers employed to do night duties:

“... (T)hey had one guy come and stay in the house overnight so that we could sleep....he stayed a couple of times; one of the times we actually left the house and stayed at a friend's place. And we had a number of concerns about this guy... there was a cigarette scorch mark on the inside of the windowsill of the bedroom so he has obviously let [our son] smoke. We don't [allow smoking] inside ...we were quite worried that he could burn the house down. And he was taking [him] into town shopping but [he] was coming home with all these things, he was buying; sports shoes, CDs, gear. And then he was saying to me "Oh why can't [he] just go back to his flat?...and "This medication's not working for [him]." Oh, I was beside myself because we were desperate for help, we didn't need someone who was going to be undermining treatment. Oh that's right, and then the guy was asking how much do we rent the house, do we have burglars come in our area... and I felt very uneasy... He wasn't a registered nurse.”

HBT did change their policy so that registered nurses were employed for night duties.

### ***Transition Difficulties***

One theme that recurred concerned the difficulty experienced when the service users ended HBT and were transferred to another treatment provider. Also, some families/whanau described their dissatisfaction over the length of HBT hours provided and the short duration of the service. One participant states that they were disappointed because HBT staff were "... only available for a set period of time, I think two weeks, three weeks" and the family needed the service for longer. Another whanau participant states that they would like HBT to be:

“(a) bit more structured and funded so it happens regularly and is reliable, I found it sort of unreliable. I couldn't rely on that support, I didn't know when it was happening ... I'd like to use them all the time to be honest, who supports me? That's it. I'd like [HBT] to be available all the time but there's no funding for it.”

One participant felt as though treatment ended too quickly:

“No it wasn't the time – the time wasn't right as far as we were concerned and we still had great issues with our son. He disappeared for a week. If we had had the HBT team he wouldn't have gone. But he was gone in Hastings for a week and tried to commit suicide. Someone who knew him and was concerned about his welfare, rung the police and then finally he turned up here and his sister rung. If she didn't see him across the road, and didn't bring him over, he wouldn't have come over. It was the wrong time to finish it as we still didn't have any support.”

Meanwhile, another family member expressed their concerns over transition this way:

"I'll speak for myself – I relied pretty heavily on them and I was pretty disturbed at the thought that we would have to move on from them to a new set of people. And having said that I can see that they were set up for more urgent rather than less urgent cases so we couldn't stick with them indefinitely but the transition from them to the next lot was something that... sticks in my mind."

Families can easily come to rely on the support of HBT and can find the referral process difficult to cope with. Transitional periods need to be handled with care to avoid trauma to the service user and their family. One family member describes her fear of HBT services ending:

"We felt bereft actually, we were absolutely terrified... I remember feeling terrified when we went to the Tory Street clinic and we had that final meeting with members of the HBT, of handing over to the Tory Street, thinking "How are we going to cope without these guys?"... Well for that intense time it was probably about right, because it's easy to come dependent on them!"

HBT would be improved if the service was reduced gradually as some whanau felt as though the service user (and the family), were left to cope on their own too soon after forming a trusting relationship with staff. One person states:

"At the very end I think [Son] kind of felt a bit abandoned and we did too a little at the end because they told us it was coming up for referral across to the Community Mental Health Team and how it would work, and I had wanted a hand over, that we'd get the four of them and [Son] would do a farewell. Or I kind of thought we'd have them home and do some food or something and talk to them about what was, and do a closing but it didn't happen like that. And on the day that we had the hand over at the CMHT none of them were available they were either on leave or something. So we had a guy... [at] the very first presentation [Son] made. He was there representing [HBT] which was ok because he was someone [Son] had a connection... but we never actually had the hand over which was a shame."

The deep level of trust and sense of safety in the HBT staff warrant more care in ending HBT and referring clients during transitional periods. Another family member described their experience:

"... As I say, the handover never really happened which was a shame, yeah, I think it might have been getting towards the end and there was two of them...[HBT Staff] came to our house and we sort of said "This may be the last time we see you" and we kind of said an informal "Goodbye" sort of thing. But, we hadn't imagined that it was going to happen so quickly... "Oh, I think [Son] felt a bit abandoned. He really saw [HBT Staff], maybe it was a bit inappropriate for him because he was unwell, but he saw them almost as his friends."

## **Conclusions From Families/Whanau Evaluation**

In general, families made favourable comments about their introduction to HBT and the service they provided during periods of crisis, as well as basic day to day care. As an additional treatment option, whanau endorsed the HBT as an alternative to their family member being hospitalised or to caring for the individual themselves during acute periods of illness. Whanau demonstrated that HBT was a welcome contribution to the mental health strategies that were currently in place in that it complemented existing mental health care initiatives. Family narratives suggest that HBT is a useful treatment option in that this model of recovery accommodates the specific needs of the mental health service user as well as their whanau. Whanau were generally supportive of HBT because treatment is situated within the context of the whanau/family lifestyle and environment and is based on the client's need in consultation with the whanau. However, more attention to the service user's transition to subsequent mental health organisations needs to occur if families/whanau are to have complete confidence in the HBT model of recovery.