



MENTAL HEALTH COMMISSION RECOVERY SERIES: **four**

**THREE FORENSIC
SERVICE USERS AND
THEIR FAMILIES TALK
ABOUT RECOVERY**

OCTOBER 2000

This is the fourth in a series of publications on recovery gathered and edited by Mary O'Hagan for the Mental Health Commission.

The other three in the series are:

Four Maori korero about their experience of mental illness

Four families of people with mental illness talk about their experiences

Pacific people in New Zealand talk about their experiences with mental illness.

The booklets in this series are available on the Mental Health Commission's website:

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INTRODUCTION ●

This paper is the fourth of the Mental Health Commission's 'recovery series'. The other three papers on recovery for Maori, Pacific people and families have already been published. The 'recovery series' reflects the Commission's commitment to raising the profile of service users and others who do not have much voice. People who use forensic services and their families are not often heard; they are marginalised in the mental health sector as well as in the wider community. This makes their journey of recovery harder.

Three forensic service users and some members of each of their families were interviewed about their experience of recovery for this paper. Each story is told in their own words and has three sections: what happened, what hindered recovery, and what helped recovery. Within each section the service user talks first, followed by member/s of their family or whanau. The service user stories are in normal print and the family stories are in italics. People's names have been changed and other identifying details have been removed, to preserve their anonymity.

Although many people who use forensic services have not harmed others, all three people who tell their stories in this paper did violent or anti-social acts that brought them into the criminal justice system, then into forensic services. They fully recognise the gravity of their behaviour and have had to work hard to come to terms with what they have done, to maintain their self-worth, and to deal with much more intense discrimination than other service users experience. Apart from this, their experiences mirror the experiences of all service users: difficulty in accessing services; the arrogance of some professionals; the paradox of sanctuary and confinement within institutional structures; and cultural insensitivity.

Their families had slightly different stories to tell. They talk of their sense of helplessness, of their desire to do their best for their relative, of feeling blamed or dismissed by professionals, and of their enormous struggle to get information and support from the services.

Both the service users and their families identified the things that contributed to their recovery. People working in the services who treated them with respect and gave them hope. Getting the right help at the right time. Overcoming shame and talking openly. Finding spiritual strength and personal support.

A recovery approach is as vital in a forensic service as any other service, and the 'Blueprint' is clear that forensic services 'must provide education and support for recovery'. Hopefully, this paper will raise discussion on what a recovery approach in forensic services really means.

What happened?

Whētu on what happened

I'm 46 years of age. I live in a rural part of the country with my husband and one daughter. We're on an extended whanau patch of land. It's a lovely, lovely sort of relaxing place to be in. I'm part Maori. Mental illness isn't strange to me, because my husband has been diagnosed with schizophrenia. And it's caused heaps of problems and stress which was a contributing factor for me becoming unwell.

The experiences that got me into the forensic system happened in 1995 when two of my daughters, myself and my grand-daughter went through an experience together that was very mind blowing for everyone concerned. There was a lot of spiritual stuff going on and to this day I don't fully understand it.

By the time I actually got to the nearest psychiatric hospital a week later there weren't any obvious indications of psychotic illness. They gave me the diagnosis of brief psychotic episode. Once I'd come to terms with what had happened I really had to accept the fact that I had been ill, and yes it was very brief, but it was also very traumatic for all the other family members.

When I was first incarcerated my mother and father came down to see me. My Dad just took one look at me and he went through what we call a ritualistic blessing before I went into court. I'm sure for myself that that certainly helped me. There is very much a spiritual element in what happened to me. I maintain that to this day. The psychiatrists don't like me saying it but I keep saying it. I ask the

question, 'Well if I was so very ill, why did it take just a blessing for me to come well?' And then you get the question, 'Are you in fact well?' You know how it goes.

I was charged with wounding with intent to injure, but was acquitted on the grounds of insanity. I was made a special patient. It was just totally amazing to a person who's never been through any of this sort of thing before. I've never broken a law. In fact one of the police officers said to me that he'd never known anyone with such clean skin. I hadn't even had a parking ticket.

I used forensic inpatient services for over two years. Most of that time I was in a psychiatric hospital a long way from my whanau but I was shifted to a forensic unit closer to my home later on.

By the time I reached the community again, I felt I could get out there and conquer whatever came my way. I'd always had a high profile at home and people just wondered where I'd had my holiday because I looked so good. I would tell the people I really wanted to establish a relationship with, exactly what had happened, and they either took a nosedive or decided that this is interesting, let's talk about it. The people who took a nosedive obviously at that stage couldn't really accept what happened with my life. And that's not my problem, it's theirs. It takes you a while to get to that stage.

Whētū's whanau on what happened

When it first happened I got a call from Whētū's mother. I tried to cool her down. Whētū and her daughter were stranded and I had to call an ambulance. Whētū was put in a police cell for a week but we didn't know where she was and we couldn't find out. We rang the hospital and the community worker but no-one was able to help us.

At the time I blamed my daughter for what happened but I wasn't looking at the wider aspect. Mental illness to Maori is not a different thing – it's part of the human aspect. A person is a person, mentally affected or otherwise. Maori don't think you've become another person if you become unwell. Mental illness is not the issue but your attitude to it is.

It took me time to think 'This has happened. How do I handle it?' The only way for us to handle it was to have her near us. It was nearly two years before she was allowed back up here to start the healing process.

You try your best to help but at the end of the day the mental health professionals have the last say. All those meetings we had with them were a waste of time. We didn't resolve anything. My daughter is still under legislation and hasn't been formally released. We were after her to be released to the whanau, so that the healing and nurturing process within the whanau, would allow her to live her life as she lived it before. The system – they don't trust our whanau. No-one else can look after our children as well as we can. We're better at it, no matter how great the system is. We look after our children and they respond in kind.

The two systems don't fit together very well – the whanau system and the mental health system.

What hindered recovery?

Whētu on what hindered recovery

One of the things that I found very, very difficult in the psychiatric hospital was this continual erosion of my own self-worth. When I arrived at that place I was not quite as batty as I had been, and I had skills. So I had to continually say to myself, 'Look it's OK. You are who you are. It really doesn't matter what the staff are saying to you, you know who you are. Just keep that in focus.'

Also, at the hospital I couldn't believe the things that were being said about my parents. It was so untrue. It's daunting for whanau to get used to going in and visiting. It's often said that Maori families don't give enough support. But it's because it's not a welcoming atmosphere. It's almost as if they're expecting you to make trouble. Even in a locked place you can feel welcome and actively respected. It's all about power and control.

At times I used to get very, very angry at what was happening to us in the psychiatric hospital. I got to the stage where I had to document stuff because I was continually being challenged about what I remembered, what I did, what I said to doctors. In the end I wouldn't go into an interview without someone else coming in with me who I could trust, because there were so many interpretations going on. I had to learn that it was no good just blowing off, because I had to come back with something constructive and show that there were things happening in the service that were continually undermining my confidence and self-esteem.

A major bugbear for me was that the cultural unit on the ward didn't accept that you needed to go back to your turangawaewae and that to me is going back to my home place, to just re-establish those links. I pointed out that it was really important that they used my family as the authority, because I didn't come from the area where

the hospital was, in the tribal sense. I had an aunty who lived in a town near the hospital, and they suggested I sort out the cultural things there. That just blew me away. I began to question the cultural kaumatua's understanding of things Maori. Was this just tokenism?

I remember people questioning the fact that that I became so overtly Christian. I said, 'But surely the principles of Jesus Christ are quite sane? If I want to read my Bible so many times a day, isn't that my choice.' But no it wasn't. If I was telling people they should be reading the Bible too, then that's bizarre behaviour. But reading the Bible was actually helping me, so what was the problem? There were a lot of those sorts of things going on.

One day a nurse had a chat with me and I couldn't believe what she was asking me. She said to me, 'When you pray, who do you pray to?' I thought this is a joke, this is not real. She said, 'Are you calling your ancestors back to you, when you pray? Because we know that you do this sort of thing'. I was thinking what! It was blow your mind material. I said, 'Look do you guys make assumptions about my behaviour without actually asking me what my behaviour is really meaning?' She said, 'Well it has been said, that you do this', and I said 'By whom?' That really made me think about establishing relationships with staff on more than a superficial basis, because it totally blew away the whole trust thing.

One of the things that I found was quite detrimental to recovery was that I was put into the role of the kitchen hand. That was fine. I didn't have a problem with it, but I did have a problem with it when I started asking for things that could stretch my mind. I like to have ideas, I like to exercise my brain. Staff would think that I was being manipulative and had grandiose ideas. They accepted me in the role

of a female carer and cook, but if you start thinking for yourself, you had better look out. This was difficult for someone who had taught and counselled at secondary schools for nearly 20 years.

The forensic ward I was in was part of a larger hospital site. There was great discrimination against our ward by the rest of the hospital. We were seen as not only mad but bad as well. That actually came up quite often and the way the guys in particular, interacted with me, re-emphasised the fact that we were seen as worthless. They would sit on the other side of the fence and make lewd suggestions, and because I was in the forensic ward, I was supposed to be totally enamoured by the fact that they asked me to go for a walk. And of course sex was on the agenda. There was a lot of that sort of thing that went on. I felt it really diminished the status of females, there was no respect and no aroha. Females had become a commodity bought and sold for a packet of cigarettes.

When I finally got out into the community, I went to my nurse and psychiatrist and said I would like to do a study course, which of course gave them the opportunity to say no. My father said to me, 'Why did you even ask them?' But you see that's what happens, you get used to asking people, it's another form of institutionalisation. I suddenly thought, wow! I hadn't realised how much the system had encroached into my life. So the next time I decided to do a course of study, I just told them what I was doing.

My daughter and my husband are on psychiatric medication. Quite often when my husband goes and picks up his Dipixol the guy will say to him, 'Now do you understand how many doses you need and when you have to come back?' I said to my husband 'How can you stand there and take this rubbish?' I'm a different sort of personality to my husband and daughter. I just say, 'Well stuff you, Joe'. I see discrimination happening quite often with my husband and daughter. I get annoyed about it but it actually needs to be them to deal with it, rather than myself.

Whētū's whanau on what hindered recovery

We felt the mental health workers were seeking to keep Whētū down rather than help her.

There was no help coming from the mental health system. I had to seek out my own knowledge. It was very frustrating to not know how to handle it. That's why I have no respect for the system, because the people working in it were so short on information.

When they had taken our daughter to the hospital I went to see her. There was no help with costs for the family to go to the hospital. The costs of toll calls and transport were huge. It was a 7 hour drive to get there. They didn't provide a where or a place for us to be comfortable. We had to go through a locked door. We were made to feel a nuisance. You start off on the back foot if you're not welcomed when you go in a rigid environment.

There was a kaumatua at the hospital doing supportive work but he was controlled. Rather than being a kaumatua, he became part of that system rather than being true to himself. The kaumatua was not on his people's side. He jumped fences when it suited him. Your job as kaumatua is not to mould into the system – you must do it the way you want to do it. That was discrimination against me, my daughter and my family.

The system ignored our kaumatua and our tribal kawa.

At the meetings with the professionals, they didn't take any notice of our whanau. Whatever the family put to them – it was considered worthless. The professionals would say 'Yes, yes, yes', but they had already planned what they would do. What they said to us they didn't mean. I can tell they're not listening to us. I don't believe any of the things they talk about. The way we work – it doesn't come from a book, it comes from the heart. We want to do the best for our families.

One time a nurse assured me she was ninety percent sure my daughter would be released at a tribunal hearing but it didn't happen. They held us there, waiting for over three hours for the hearing, knowing full well they weren't going to release my daughter. There were 22 whanau at the hearing. The tribunal consisted of a psychiatrist, a lawyer and a layperson. They were quite intimidated by our ropu. I felt there was no understanding of what being Maori means.

My big thing is information. We had to seek information rather than being given it. We shouldn't be seeking information, the professionals should be giving it freely. It would ease my mind if they did. I didn't know what was happening and what help I could give my daughter. For instance when they say 'Your daughter is a special patient', what do they mean by special? They use all these fancy names but they don't explain them.

Another example occurred. We had two visits up to our marae from a Maori community worker and cultural kaumatua from the hospital with our daughter. They took notes at the meeting but nothing was relayed back to the clinical team at the hospital, as we'd presented it. All the information we had was given freely. But when we had our next whanau hui the doctor, managers, nurses and cultural worker, expected us to give information to them but they weren't willing to pass on information to us. Everything that went back to the staff was used negatively.

The community workers from the hospital didn't come up to offer support but to look for information. They were seeking ways from me and my wife on how to get easier access to our daughter. That's all they were wanting. They did this with our friends too. They were looking for dysfunctional families, looking for abuse. If you didn't

fall into that category you were 'too good to be true'. My feeling was that we were being blamed. They were suspicious of us. Our mana was being questioned.

In the end as whanau we had to use subterfuge and indulge in back door activity to get information even though Whetu had given her permission.

What helped recovery?

Whētū on what helped recovery

To really even start on the journey of recovery, I had to sort out exactly where I was. I had to identify the issues that are going on for myself. The whole experience was really traumatic but I didn't want to stay stuck there. It was very much my spiritual belief that gave me hope. I also felt I was there for a reason, I had to sort it out, and then move on. I think the hope and faith comes from that. I've learned not to look ahead, in terms of goal setting. I prefer to look at what I want to achieve day by day. Having been denied contact with my whanau, I now appreciate all the blessings and lessons I receive each day. People work in different ways. What suits me, won't suit Joe Bloggs down the road.

I had a doctor who said to me 'Do the walls ever close in on you?' My reply to that was the walls don't exist for me. It's a real spiritual thing, because although you're physically confined, you're never actually mentally confined, particularly if you're on the way to wellness. Institutionalisation can close those walls in, so when things got really tough, I would go outside, sit under a tree, and just day dream.

I think I survived due to a lot of tremendous support from people who were in the same ward as me, and I'm not only talking about staff, I'm talking about support from other residents. There were three other people on the ward who didn't have medication and they could actually think quite logically for themselves. They had gone through horrific experiences and we were able to talk and share things that we didn't necessarily share with the staff, simply because there was no trust factor there. And I really maintain to this day, if that supportive group hadn't been there, we wouldn't have done as well as we have.

The first place I was in was a long way from my family. I missed the family. That was really, really hard. But I had heaps of friends in the area I was staying in because I had taught there for about 12 or 13 years and I'd done heaps of high profile stuff in the community. I had heaps of extended whanau that came and visited me. You can't move on unless you're getting support from somewhere. I was lucky, there were whanau, staff and clients who offered that support. My family were tremendous, they were always there at least once a month. So the support was definitely there for me, and it really made a world of difference.

There were some really good people who could understand at the first place I was in, a psychiatric hospital, but I did have some major concerns with that place. At the forensic unit where I went to next, there was a completely different climate. The staff were really, really supportive. Really pushing to get me further along in the whole system. Very aware that it was necessary for me to spend lots of time with my family.

Maybe part of the reason I had a better time at the forensic unit was because I was able to have more time at home with my whanau. By then I understood how the system worked, which made it a lot easier for me to do things, and say if this is what it takes to get me out, this is what'll do.

I was very lucky that I had two wonderful occupational therapists who I could talk with about the things that were going on with me. Then between us we would instigate recovery programmes. We'd work out exercises that would help and be constructive. For me that was really, really beneficial. One of the other helpful things that comes to mind, was a group session we had at the forensic unit. Learning about the parent, child and adult thing, transactional analysis, this had quite an impact on me because it made me think about things for myself in a different way.

My extended whanau had to come to terms with me, not only being involved with quite a horrific event, they also had to readjust when I went back into the whole family situation. So there was a lot of adjusting that everyone had to do. We needed time together for the healing process to occur. Achieving this took over two years and it didn't happen until I was shifted to the forensic unit nearer home.

It was really important to me to go home. It had to happen for me so I could go on the process of recovery. There were cultural things I had to get home to and learn about. I needed to walk on my own land and that type of thing. There's something intrinsic about it, you can't actually explain it, you just feel it. The tribunal made the recommendation that I should be sent out on community leave because they could see it was really important to my healing process to be back with the family. It took over twelve months before this was actioned.

One of the things that helped was getting back out into the community, and going back home to be able to use all the resources

of my turangawaewae. Healing couldn't occur until I went home. I had a nurse who set up support counselling for me, and one of the guys had a cultural background. It was good to do psycho-dynamic stuff with someone who understood the cultural model in terms of tinana, wairua, hinengaro, whanaungatanga and that type of thing. I wasn't left with that gap that so often occurs. I felt that there was someone there. It was also important for the family to see that there was a support network within the system that they could access at any time, if they felt they needed to. It was a safety net for everyone.

Whētu's whanau on what helped recovery

The mental health system clearly showed its lack of cultural sensitivity to whanaungatanga and to nga whare tapa wha model. This model shows the intrinsic supports for Maori tangata whaiora. It includes taha whanau as well as taha wairua, taha tinana and taha hinengaro. To understand the needs for our daughter's well-being you need to appreciate the importance of these four cornerstones of health.

As a Maori whanau the healing process for us all involves our children being in our care, so that the principles of aroha, awahi and nurturing can occur in an inclusive environment. Within the dynamics of whanaungatanga are the necessary factors to help our children on the pathway of recovery. The way for our whanau to continue to grow in strength is for all members to be near to each other.

It wasn't until our daughter came back to a whanau environment that the kaumatua role was activated. This was to find out what solutions all of us can make together. It's about interdependence, aroha and respect.

What happened?

Joe on what happened

My early history didn't become clear until much later in life. The chain of violence goes back a long way in my family. If we did something wrong, my mother would give us a litany of everything we had done wrong, since day one. So there was this feeling that no matter how hard you tried, you would never be actually be able to walk away from your past or your sins.

My jobs and work and anything I did was never completed. I grew up hugely dependent and obsessed with concepts of betrayal. I didn't know how to forgive. I became inflamed if I felt I was betrayed, but also managed to do very well at betraying others.

I existed in two realities. I honestly did not know which reality to trust. It got to the stage where I could flick from the reality where we see, touch, feel and hear, into one which I could create. In the end I didn't know the difference. When I fell ill I would become manic, hugely manic, very quickly and then I would become emotionally and sometimes physically aggressive. In 1980 a tragic set of incidents came together and I ended up killing my best friend. I thought she was a witch and was trying to control me. But she died trying to get me help, though I didn't perceive this at the time.

I was put into prison in Australia but I fought for my release because a lot of information had been left out of my trial. I was released for deportation back to New Zealand. At that time there was no link up between trans-Tasman services. I had a very difficult time with the media and losing jobs because of who I was. The media would notify

my employers about who I really was, and I would lose my job. Sometimes cruelly.

I wobbled on. I ended up a project manager for a large construction company. I had a relationship and a period of wellness for about 13 years. But I decompensated very badly through sleep deprivation when my mother became ill. Within five months I was seriously ill, and for the second time caused a car accident which nearly killed someone. I was found guilty of grievous bodily harm and incarcerated in a forensic psychiatric unit.

I'm now 52 years old, and possibly for the first time in my life, have achieved what feels like a sense of stability and balance. I guess society invested a lot of money in me, to try and get me back when I hit the bottom of the cliff. I believe they did get me back.

Joe's brother and sister on what happened

Joe was always different. We grew up in the country where boys are boys but he was more like a girl than a boy. He was interested in knitting and sewing and things like that. We were competitive as male siblings are. I was a sportsman and physically able but that was denied Joe. We both went to boarding school but boarding school was a terrible thing for him. He come home in the holidays and his bum would be black and blue from the beatings.

Joe went to hospital for the first time at 17. He was having visions – he saw huge spinning lights in the sky. They doped him until he was completely insensible.

When it first happened to Joe I was 18 and busy doing my own thing. Dad told me before he died that I had to be responsible for Joe. Sometimes I feel guilty that I haven't given him enough support but at other times I think, 'What more can I do?' But Joe's never complained about it. My support has been minimal but he's always

appreciated it. It makes me think he must have been getting very little support from anyone else some of the time. Joe being gay has been another thing we've had to come to terms with. I've had some guilt feelings over that too. Still, Joe has had a lot of support from the gay community. And some from the heterosexual community as well, which has given him some credibility. It's easy to like him because he's an articulate and intelligent person.

We didn't feel the stigma much. People don't pick up a mental illness and do it deliberately. We only got snide comments from one Christian family in the neighbourhood. The rest of the farming community were very supportive. My parents never hid it from people.

Dad was an extremely good stockman with an ability to breed good animals. I suppose in a way, when Joe became mentally ill, it brought into question his ability to breed good children. There's almost a blame thing – that as a parent you must have done something wrong with your child. There's more information about those things now. It happens in the best of families. Politicians get up and talk about their kids committing suicide.

When we heard that Joe had killed Liz we couldn't believe it. It was like a nightmare, it wasn't real. We thought they must have got the wrong person because he had always been so non-violent. It was devastating for Joe once he became well again. He's deeply conscious of some of the terrible things he's done.

The media pestered Mum after Joe killed Liz. They were on the doorstep all the time. She stopped answering the door after a while and she had to change her phone number. It was very, very stressful for her. But we're fortunate it didn't hit the press as much as it does with some families. Liz's family didn't contact the press at all. Perhaps it was because our family set up a trust fund for Liz's three children.

Mental illness drains everyone's resources. You're dealing with someone who comes from a different point on the compass, even

when he's reasonably well. Joe phones me regularly. He has got no other dependents. It's a blessing in disguise. He's tried so hard to be normal. One huge sorrow is that he doesn't feel he's going to have a life partner. I think he's lonely.

What hindered recovery?

Joe on what hindered recovery

There is always a price to pay for our actions, but when you've paid that price, then you also have to pay the price of everybody else's judgmental attitudes towards you. It makes it even more difficult. To ostracise, stigmatise or alienate people are not the behaviours of bad or ignorant people. They are the reactions of all of us to fears bred on ignorance and misunderstanding. I assert we all know enough about being out of control to want to shrink away from the spectre of mental illness.

I think the labelling that goes on is really limiting. Once you get a person to accept a label you also get them to accept the behaviour which is attached to that label. To be called a schizophrenic or a bipolar, or hoosie whatsit, turns you into just that.

I think the services gave me a new learning process. They gave me enough of the good stuff to get around the bad. But the process would have been much more rapid with better communication and some better ideas and ideals. But the respect I got in the services came and went. Sometimes it was just a reward for good behaviour.

In the forensic unit I was hamstrung frequently by the fact that authority figures presented themselves as being God. I really believe

it's time for the professionals to get off their high horses. One of the reasons the rehabilitation hostel I went to, succeeds so well is that the professionals sit down and eat with the patients. There isn't that division.

I believe a lot of the staff are actually entrenched in a system, which claimed them at a very young age. Not many people learn beyond their twenties so you've got people who are 60 working in the system, and they've been promoting the same values for 40 years.

I'm homosexual. Once in group therapy the professional was describing relationships, but the only relationships mentioned were heterosexual relationships, so I stuck up my hand and said what about homosexual relationships? On other occasions staff said things that was quite derogatory, and I would get up and say I was offended by that. The interesting thing is that some of the professionals are so rigid and so fragile they couldn't even apologise. Rather than apologise or correct or change, they would just ignore.

It's important to have consultation in services. It reassures the person, who is always upset when they get into the hands of a whole lot of powerful strangers. Your personal power has gone and you're shunted around like a child's block or rolled around like a marble. It's very unsettling. If you're going to stick a horse needle in someone's arse, let them know what's in it. Talk to them. Let them know what's happening.

We are well when we're fully integrated back into the community, when there is no way of distinguishing us from anyone else. Often we get shunted out onto the street, given some pills, told to go and see our local GP, put in a half-way house and then we're supposed to be well. We're not, we're only part of the way there.

I came into the unit, and they said to me they wanted me to be part of the decision making. Then I would ask 'Where's so and so?' 'Oh she's off in the office writing up reports.' 'What reports?' 'Daily reports

about you.’ ‘But I thought you said I was a part of this process? A few more days go down the track and they say, ‘You guys just do what you like because the staff will be all down at the end of the unit, we’re having a meeting from 1 till 3’. ‘What are you talking about?’ ‘It’s your weekly assessment, we’re assessing how you are.’ ‘Hold on, shouldn’t I be there?’ ‘Oh, no’. So down the tube goes all my trust again. Sadly enough it discounted their credibility for me. So I believed less in what they were doing because they didn’t have the manners or the honesty to talk in front of me. It took me a long time to grow through that.

Everybody should be at the assessment meetings, every single person in the unit. And the books need to be open. Everybody hears, everybody talks, everybody writes. I think if you’re a cohesive family unit, there are no secrets within the unit. We can be part of each other’s healing. Forget the names, forget the titles. Sure we’ve got different skills, we’ve got different levels of learning, we’ve got different input, but let’s make the place a living entity, rather than all of a sudden, the head disconnects itself, goes into the next room and writes up all these reports, then comes back and joins itself to the body again. That creates mistrust.

Joe’s brother and sister on what hindered recovery

If services had been better back then, when Joe was young, he wouldn’t have got as bad as he did. Back then the services were paternalistic. They just said, ‘You know nothing’. Whatever Joe said wouldn’t have any validity. Joe is an adult but sometimes he’s been regarded as a non-person who can’t make a decision for himself. But he can make some decisions. Professionals need to understand this.

There have been people who persuaded Joe to stop taking his drugs and move away from tried and true procedures. This has happened

a few times. His GP said to him that if he went on a special diet and stopped his drugs he would get well. But he became unwell and killed Liz. Another time a landlady said to him that he was so well he didn't need to be on drugs. Joe really felt the stigma of taking drugs and the side-effects. He would never, ever go off his drugs now.

Quite often, there doesn't appear to be anyone out there listening. The system has been so slow to pick up problems. The Police are too busy. The psychologists just say, 'He's not as bad as you think'. If Joe starts to get manic he's articulate, intelligent and physically able – he's extremely plausible.

The last time he had an attack, his partner tried to get hold of the mental health services all weekend. He left messages on the answer phone but no-one got back to him. After the weekend Joe crashed his car. That was only two or three years ago.

The ability of his illness to resurface is a continuing worry. We're hopeful for a complete recovery but we're sceptical. We were warned that Joe's regressions would become deeper and more violent every time it happened. We have real fears for the family when Joe has an attack. Once his psychiatrist actually said we were in danger. We don't just fear he can do physical damage, we have the knowledge that he has done it.

What helped recovery?

Joe on what helped recovery

I started to learn through trust, confidence and forgiveness, that I had some real power in my life. That power was really the ability to understand that although I was always interconnected with other people, I wasn't other people. What my mother said about me, was about me, it wasn't me. Once I learned that my behaviour was actually a different entity from myself, my behaviour was a product of myself, but it wasn't me, I could start moving on.

Once I could see there was a spark of hope, I would practice being nice because it felt good. If I did something wrong, I wouldn't beat up on myself any more.

My mother was part of the healing of my journey, she was also part of the illness. She taught me some very basic skills about how to feel better. She taught me to keep myself clean and well groomed. She taught me to look for things that were beautiful, to smell, and to look for things that were nice. To listen to beautiful music. All the things that actually make me feel better.

When I went to the forensic unit I was just seething inside with a cold anger. The Police had me severely beaten up while I was in custody. It cost me \$5000 in remedial dental work to save my teeth. My family and almost all of my friends had dumped me. I felt I'd been betrayed by society that had elected to look after me. I felt that I'd been betrayed by the system that had taken responsibility for me.

For eight months I tried to destroy what the forensic service was holding for me. I fired almost every shot that I had in my armoury to

disrupt and destabilise. I threatened and I did all sorts of things. Wrote letters to management and the whole bit. At the end of that eight months, I was losing my battle because I had no armament left. But by then I was able to capitulate because I knew I was secure with the staff there who were not going to betray me. Perhaps understanding me better than I understood myself, they refused to buy into my games and anger.

At the forensic unit we were taught the basic emotional responses we learn in our first years. Our programme was based loosely on Maslow's hierarchy of needs. Apparently in my first years I didn't learn how to trust. When I first went to the forensic unit I was going back to that state where I couldn't trust people, but this time it didn't get played out the same old way. For the first time in my life somebody responded without trying to bash me back down. After eight months the staff really were friendly. They disclosed later that some disliked me intensely over that period. They didn't actually want to have anything to do with me but they were professional enough to keep staying and showing a very stable, very consistent attitude.

The easiest way for an authority figure, like a mental health worker to earn my trust is for them to say to me straight up, 'I am human, I'm going to make mistakes, some days I'm going to come with a headache, and some days straight after a row. I'm not any different from you in that respect. I'm holding a different position in society but I'm still a human being, I still hurt.' And for them to allow themselves to say 'ouch' when I say something which is really unfair or cutting.

I lived in a rehabilitation hostel attached to the forensic unit. I became part of a surrogate family. You have new brothers and sisters. You have new parents. It's like being placed in a petrie dish and put in an environment where you can re-grow. I learned to trust. But even more important, I got confidence back. I also learned to forgive.

I think that if everybody knows there's a mad dog in the neighbourhood, it's a hell of a lot easier if you know which dog it is. I have no trouble at all in talking to people about my experiences. But friends of mine say that my story blows people apart. But I say if they handle it, fine. If they don't it saves me a lot of hassle down the track. Most of the time though, I get into deep conversations with people who want to understand. The bigwigs at the forensic unit told me I must never disclose who I am. But how can I beat discrimination if I buy into it and don't disclose who I am?

I've managed to balance my reality. Balancing your reality is like a cat grooming itself, you're doing it constantly. Constantly checking if you've got it right and how you're presenting to others.

Joe's brother and sister on what helped recovery

The services have improved so much since the first time Joe went to hospital back in the 60s. The environment is much better for a start – it's safer and more welcoming. The staff are more positive, outgoing and reassuring. Their communication with the patient is much better – about where they are in their own recovery. And they've tried different things with Joe like the psychoanalysis.

When Joe last went to the forensic unit, for the first time the professionals informed us of what was going on. They asked us to come and see them. They were concerned about his immediate future. Joe has agreed for them to send us copies of his assessments. We wanted him to stay in longer because once we know he's being looked after, we can get on with our own lives. But they were right to let him out when they did.

He still gets support from the forensic unit and he doesn't have trouble telling them when he's not getting enough help. He has no hesitation going back there. He goes back socially and he feels he can contribute.

It's a safety net for him. If Joe gets another attack he might be able to do something about it himself. We're now more confident that we could put pressure on the various agencies and they would do something about it.

One time when Joe had an attack, the Police looked up his file and rang us to ask us what to do. We told the Police to ask Joe to let go of the person. They did that and Joe let the person go. Then he let the Police take him away. The time before that six Police had swooped on him. Joe fought back. He got some broken bones and all the Police had bruises. Later Joe said if the Police had just asked him he would have complied.

Joe is as well now as he's ever been. The black dog on his back has gone. He can't get over how wonderful it is to feel as well as he does.

There's an air of contentment and peacefulness about him now. I think it's because he found someone with the ability to tap into the core reason for his problems.

They took him back to infancy and it was a huge revelation for him. It gave him a truth that works for him. Joe is well informed about his illness – he has a great ability to absorb stuff. He knows as much as some of the professionals who treat him.

Joe is quite happy where he is. He does a bit of work and has time for his interests. He recognises that he can't get too tired or stressed and that he needs to have a healthy lifestyle. At this last job the boss left him in charge for the day with just one other person. He found that too stressful and decided to leave. That was really good.

Since this story was written Joe has informed the Commission that "he has entered full-time employment and is for the first time in many years free of the benefit and direct financial support from the system".

What happened?

Keith on what happened

I'm 36 years old. When I left school I went into a seminary because I wanted to become a priest. After I left the seminary, before my training was completed, I trained as an enrolled nurse. I then worked for a short period of time in a large psychiatric hospital. Mental health had always been something that had interested me.

My introduction to forensic services was early 1990s resulting from a severe trauma I suffered when I was in England. I went on a rampage when I came back from England with post-traumatic psychosis which lasted about four or five years. Paranoid schizophrenia was my diagnosis but they couldn't really put me into a specific pigeon hole.

My post traumatic psychosis was not officially acknowledged until I was in Australia some years after the forensic unit. The chemical and sexual abuse I received in England precipitated my problems but this didn't come out until I went to private counseling. The forensic unit failed to pick it up; they diagnosed and treated my symptoms but not my core issues. This has left me with a profound sense of injustice.

I manifested as very delusional, very paranoid. I was continually making a nuisance of myself, writing letters to authorities and so forth. It culminated in a situation in which I was prepared to go and kill someone. I felt it was something I had to do, like it was a spiritual thing. But when I went to the person's place they weren't there. I had a moment of absolute terror, looking at myself and seeing the reality of where I was at. And I knew I needed help.

I didn't want anything to do with the system, because I always had distaste for it, and I had seen the injustices done to people in the psychiatric hospital where I had worked. I had a fear of having to do things on the system's terms rather than on my terms. But at the end of the day I couldn't access help. If the general mental health system had been functional and accessible I would never have been charged and directed to the forensic services in the first place.

I was arrested and charged with trespass, and as a result I went to a forensic unit. I went before the judge and everything. I was resigned to spending the rest of my life in the forensic unit, perceiving that it was something like the old psychiatric hospitals where people just spent 30 years or 40 years and that was the end of their life.

My parents had best of intentions but were totally ignorant. They were of the generation where everything was swept under the carpet. They didn't really perceive what was really happening for me. They sided with the doctors, and the doctors thought, 'Oh goody, we'll use them'.

I was really very antagonistic when I went to the forensic unit. When things started evening out for me, it bought the doctors very much on side, and they saw the merit of me getting through the system as quickly as possible. So I consider I was very lucky to spend only nine months in the forensic unit.

Keith's mother on what happened

He went over to England and when he came back from there, it wasn't Keith. I knew in my head that something happened over in England, something we don't know about.

In the early stages it was very difficult, because Keith didn't want to know about it, and it went on like that for a long time. We used to ring and try and keep in touch with him, but he would go off and we wouldn't be too sure where he was. We'd be worried sick about where he was because we just knew he wasn't thinking straight. We were never in the actual position of being in crisis with him because when Keith wasn't well, he didn't seem to want to have anything to do with us, but we would go and see him whether we were welcome or not.

You can't actually do anything. That's the frustrating part. You know something's not right but you really don't know what is wrong and you are caught right in the middle. Until the person wants something done you just can't do a thing. You're so helpless. That's what I found. It was just the absolute helplessness.

Keith did some strange things and he was taken into custody. And then at one time, he went into hospital for a while. He was discharged from there and he was better. But he looked like a zombie going round, doped out of his head. He walked very straight and stiff. Then he went off medication again, and got into another hassle. That was when he went to the forensic service. But what I found dreadful, was the way the drugs affected him. He wasn't him, he wasn't functioning as our son. It was dreadful.

He never talked about what he was going through, and now at times we start to talk a bit and I just know what hell that poor kid went through in himself. He had enough awareness to know what was going on. He's always been such a kind considerate person but there was something inside that wouldn't let that come through.

As he got into working life, he lived away from home which I thought was good because we didn't want to take his independence away. And at the moment he's nursing and he does it very well. But I say to him 'Don't do it full time, have days off for rest.' A lot of Keith's problems did begin with frustration which gets him stressed, and it sets him off on the downward spiral.

He is such a different person now, he's functioning again.

What hindered recovery?

Keith on what hindered recovery

'Recovered' is not a word in the true vocabulary of the people working in the psychiatric system. No-one is going to turn around to you in a position of authority and officially say you are recovered. It's really a crime against humanity because it is only keeping people in a job rather than bringing about wellness and recovery. That's where I have a big problem with the system. To my way of thinking, my recovery has been despite the system.

The quality of care at the forensic unit was the best the system could offer in the old way of thinking. But there is a huge gulf between the all-on care in the forensic unit where you've got key workers, social workers, people coming out your ears wanting to blow your nose, and wipe your bum and all the rest of it. You end up on the other hand, having escaped this gulag structure, to the great no-man's land in the community. There are not enough normalised environments for people to come into.

If I had listened to the doctor who was keeping me under compulsory treatment, I would still be on injections, in a half-way house and on a benefit. My doctor refused to sign the piece of paper releasing me

from compulsory treatment. So I got another psychiatrist to give a second opinion. I was in his office five minutes when he said 'What the hell are you on this for?' He signed it and gave it back to me but the other doctor still wouldn't accept it. At that point the lawyer on the tribunal said, 'This doctor won't accept the recommendation of the top psychiatrist in this city? Get off the grass, or we'll do it for you'. So the doctor had to sign.

One of my greatest experiences of prejudice from the people working in the system was to do with my own religion as a practicing Catholic. Suddenly you were thrust upon with a Freudian model of spirituality. That didn't work for me.

There was a fundamental ignorance of my Catholicism. I felt I was tolerated for being a Catholic but I didn't feel accepted. I felt quite alienated. To give them their credit though, I did go to mass on Sunday and I was very good friends with the chaplain who used to come in and bring me communion.

Initially there was no respect for my personal beliefs. I suddenly had to be reformed, reshaped, 'We're going to change you'. They didn't respect the fact that I had lived for over 30 years. I remember telling one of the psychiatrists that I thought her science was in its primacy, and how dare she in one hour assert to tell me what over 30 years of living had given me. There was all sorts of shit and ructions as a result of that. I was given an extra pill and told to be quiet.

When I was in the seminary, despite it being institutional, we did a lot of human development work and we were very clued up on group dynamics and all that sort of stuff. There's not enough emphasis on interpersonal stuff in the mental health system. People in the system shut down to survive – the staff as well as the clients. I was appalled at the old system and it's interpersonal destruction of people and

their lives, when I worked in it. That's part of the nature of over-institutionalisation.

I was lucky, I had an understanding of the system, but for a lot of consumers out there who don't have the nous or the help to find their way to wellness – what hope is there for them? The legal system is just another nail in their coffin.

Keith's mother on what hindered recovery

I don't think he was really correctly diagnosed in the first place. They put labels like 'schizophrenic' on to him, but it seemed superficial, they didn't get down to the depth of what it was. I don't know what the cause of it was or anything like that, but I honestly felt it wasn't him, it just all happened so quickly.

Some of the people in the services gave him support but there were some who seemed to try and block everything or didn't give him the necessary encouragement. I think they just saw the illness. Yes I'm sure of that because they didn't look at the potential of the person they just looked at the illness. If they had seen the potential of Keith they would have seen just under the surface that he wasn't as bad as they thought.

I can't put it into words but I just know that they looked at the mental problem, instead of seeing a whole person with a mental problem.

They could have got to the bottom of what caused this mental problem instead of shoving dope into him and once that was working, saying 'Oh he's fine now, he's coming right'. The whole system seems to be that if you drug them and they are quiet, that's enough. I do think medication is necessary but I just feel that it could be monitored

more to make sure they're not on too much so they don't live a half-life or end up like some zombie.

I didn't like it when my husband and I sat there with the staff and were put through the whole drill and Keith wasn't there. I thought at the time, 'Why haven't they got him here, surely he's well enough. Why is it all so secretive?' If it's our fault, he should have his say about it. We didn't really think it was our fault, but the point is that's the impression you could get. We'd done the best we could and if we were to blame for anything, well, we would like to have discussed it with Keith present.

With some of the staff you'd think you were going through a grilling or the third degree or something. I can see their faces. I can see them sitting around that table down there and I was wondering what we were there for. And we were just about out of our own minds worrying about Keith.

You bare your soul to them about all your family history. There didn't seem to be any feedback as to whether this was helpful or not. It was like banging your head against a stone wall. Keith may have told them the underlying factors for it all but we never got the feedback that would've have been of help to us. They could have said to us 'Keith thinks this of that particular thing. How do you view what Keith thinks of it?'

I don't know about the Privacy Act. In some cases it is necessary but in a real family situation like this, where the parents are really concerned I didn't see the point of it. I could ask 'Is Keith sitting up a tree?' and they would say 'We can't tell you because of the Privacy Act'. I just found this just so frustrating. You would ring up, and oh dear, dear, it was like a brick wall. They would just say 'Oh, yes, he's alright'. That's a great one, when you are sitting at home, and he's down there in the forensic unit. Keith has since written a note, which I've got, to say we can have information about him if he has a breakdown again.

What helped recovery?

Keith on what helped recovery

One thing that I have found in my own reading of psychology is that sanity is fundamentally a choice. It's certainly been my experience of it. A person either chooses to go 'la la', and remain 'la la' or they choose to take responsibility for their actions and its implications.

A long time ago I learned how to receive love, to love myself, and to accept that no matter what I have done, that I'm still loved by God, the God of my understanding. That's probably the best way of putting it. And I feel blessed by my family, because there was never any sort of abnormal violence or abuse or anything like that. I attribute my recovery to my friends and family and people I knew in Catholic circles.

The other thing that helped was that I'd had a life before my problems started. When you look at the kids in the forensic unit who have had nothing but wacky baccy and everything else, they have absolutely no perception that there is a future out there and there is something to strive towards. That's really where I feel, the whole key to my recovery lay. I was also in a system that I was familiar with because I'd worked in it. It was an enemy I knew.

The forensic unit nailed my tail to the carpet. It got me out of circulation. It created four walls whereby I felt safe. It was an absolute necessity, considering where I was at. I was on the road to nowhere and I would have ended up on the end of a rope or something. I was getting that low and distraught. To me, the forensic unit was a watershed experience. I spent three months in the lock up and then the rest of the time waiting for the section to be changed, in a rehabilitation hostel. It would have been counter-productive if I had been in lock-up for any longer. I would have just become a system junkie. I would have ceased to want to take responsibility for myself.

My room became a cell, and I always wanted to be a monk. There is a lot of similarity in any kind of institutionalised living, and I had been a part of religious life in the past. What I learned in religious life was to work on the philosophy that the only person in life I can change is me. The other bastards are all going to be the same. But my perception of them can change and how that changes, affects the way they relate to me.

There needs to be a recognition of the trauma created by being in an institution, and being locked up for those few months. Everything revolves around the ash tray and smoke butts and the whole culture that goes with living in hospital.

I went on a journey to de-programme myself against the institutional experience through mediational prayer, through the grace and friendship of others on the outside, and with my gradual release into the community. I'd experienced the same thing when I left the seminary. Again, it was very enclosed.

The rehabilitation hostel was the first step to normalisation. They let me have a car which meant that I could go up to my parents on weekend leave. When I got out and went into supported accommodation, I was able to go to meetings and look for part-time work. They were important factors for me in my recovery.

I'd say there's some very fine, good people in the system. I think though that like everything, unless someone has experienced something, they might have an empathy but not necessarily understanding.

I belong to SA or AA and they talk about a surrender of self to the God of your understanding. This has been helpful for me, to maintain a sense of wellness in my life, in a holistic sense.

Keith's mother on what helped recovery

I don't know what helped him, I really can't answer that.

Our family, and Keith's sister, we all supported each other. We didn't have counseling or anything, because it's just not my cup of tea. My husband and I supported each other, and then as things evolved and time went on, more of the family, and other people, got involved.

I never went to any of the Schizophrenia Fellowship meetings because I'd read up about schizophrenia and I was getting more and more confused about the different types. I thought if I went along there I would only get more confused. We felt we had to work through things ourselves in our own time.

I felt that if the lad had cancer or something like that, we would have got all the help in the world, everybody would know about it. I think with mental health, you're inclined to keep it covered up for a while, for your relative's sake. Then when you come to terms with the whole thing, you think 'This is ridiculous, it's an illness, and that is all there is to it'.

I don't know whether Keith felt stigma and discrimination. But once we accepted Keith's illness, which didn't take us very long to do, we realised it was an illness and we were quite frank about it. I think you've got to be open. As far as I'm concerned there's no use in shielding it. It's happened. I found too that when we spoke about it people would start to talk about members of their families who had had problems. And it's amazing the number of friends who ask me how Keith's keeping.

Some of the people in the services treated us with respect. Some of them were very good and very supportive. Our GP understood and he gave us very great support and he even rang to say 'If there's anything I can do to help, get in touch'.

There was one doctor in the forensic unit who was really great. He spoke to us as though we were normal, as though we had an idea of what was going on. And he didn't make us feel like we were prying people wanting to know something they couldn't tell us because of the Privacy Act. We could talk to him and come out with hope.

The majority of the forensic unit staff helped get him back by letting him realise that he'd be able to get back into a working life again. I've tried to encourage him not to over do it for the simple reason of stress and strain. I'm trying to keep him on an even keel. I say to him 'I don't want you ill again'.

My husband saw a letter in the paper about a mental health supported housing provider and he thought that might be a good thing for Keith. We had a talk to Keith about it and he got in touch with them. When he came out of the forensic unit he went to stay there. I think he helped some of the people there. He was more aware than a lot of them. The chap who's running it is a wonderful person. He is still in touch with Keith occasionally. When they saw that he could cope with things, he gave him encouragement to go out and do them. Keith got a voluntary job in a nursing home and he seemed to progress from there.

I never lost hope for Keith. You see I've got a deep faith which helped me. It's given me someone to talk to apart from my husband and he had a deep faith too. Just having that and the support of priests and others was wonderful. But it wasn't faith alone, it was support too. Keith had such a deep faith too and I thought 'Oh well something's going to get through to him'.

The Blueprint on Recovery and Forensic Services

What is Recovery?

Recovery is a journey as much as a destination. It is different for everyone. For some people with mental illness, recovery is a road they travel on only once or twice, to a destination that is relatively easy to find. For others, recovery is a maze with an elusive destination, a maze that takes a lifetime to navigate.

Recovery is happening when people can live well in the presence or absence of their mental illness and the many losses that may come in its wake, such as isolation, poverty, unemployment, and discrimination. Recovery does not always mean that people will return to full health or retrieve all their losses, but it does mean that people can live well in spite of them.

Historically, mental health services have failed to use a recovery approach. Recovery could never take place in an environment where people were isolated from their communities, where power was used to coerce people and deny them choices, and where people with mental illness were expected to never get better.

Some people have experienced recovery without using mental health services. Others have experienced recovery in spite of them. But most will do much better if services are designed and delivered to facilitate their recovery. Virtually everything the mental health sector does can either assist or impede recovery.¹

¹ Blueprint pp 1-2

Forensic service Components

Forensic services meet the needs of those people with a mental disorder, or a suspected mental disorder, who are:

- referred from the criminal justice system and/or
- exhibiting very violent or dangerous behaviour, likely to offend, and requiring specialised assessment and management.

Mental illness often remains undetected for many Maori until a crisis occurs. This is true for Pacific people too. Because of this, many come to the attention of mental health services once they have offended, and therefore both groups are presently over-represented in forensic services.

Secure Inpatient Services

Services providing full psychiatric and mental health services, within a secure inpatient environment. These services must be effective for Maori. They must cover the following levels of security and acuity:

1. Acute inpatient (medium secure)
2. Minimum secure
3. Long stay (maximum secure)

All levels must provide education and support for recovery.

Community-based Residential Recovery Support and Education

Specialist supported accommodation and support and education for recovery services for those who no longer require secure inpatient services, but whose risk management and safety needs indicate a further period of intensive supervision in a community setting is required.

Court Liaison

Attendance at court by forensic services staff to provide advice, assessment, reports, and recommendations to court judges.

Prison Services and Liaison

Specialist psychiatric services for people within prisons, and consultation and support for prison service staff (based on 1 FTE per 200 prison muster).

Forensic Community Services and Liaison

Forensic service community assessment, treatment, and follow-up, for forensic service users in the community, incorporating consultation and liaison with, and assessments and advice for, general mental health services.

Forensic inpatient services should be delivered on a regional basis with close working relationships with local general mental health services. It must be ensured that people in rural areas receive forensic services equivalent to the resource guideline level. This may require a flexible approach with some resourcing from the general mental health team. Where this occurs, the division of roles and responsibilities between the local service and forensic services must be well defined.

The forensic services' skills in the prevention and management of behaviour disturbance and violence should also be available to general adult mental health services, through consultation and liaison, and as a back-up service.

Prison treatment and liaison has a growing role, partly due to an apparent increase in the number of people with mental illness within the prison system, and partly due to the better recognition of mental illness within prisons. Forensic services should provide regular clinics in prisons and those experiencing severe mental health problems who require inpatient services should be transferred to a secure forensic service for treatment. Follow-up treatment when the service user has returned to prison should continue for as long as is necessary. Forensic services have a key liaison role working with prison staff (including medical, nursing and psychology staff) to assist with the

treatment and support of prisoners showing behavioural disturbance.

There should be explicit criteria for the movement of patients between general mental health services and forensic services. Former patients of forensic services should not automatically be treated as forensic service users when they require further mental health services.²

Anti Discrimination Resources

A Gift of Stories: discovering how to deal with mental illness (1999) is a book in which people who have at some point in their lives been diagnosed with a mental illness tell their stories.

The Mental Health Commission is committed to getting rid of the discrimination towards people who experience mental illness that exists throughout our society. It believes that sometimes stories, rather than facts, figures, and case studies, are the best way to tell “the truth”. Stories make ideas real, and personal stories go one step further; they fill ideas with meaning.

The book has been produced as part of the work of the Commission's Anti Discrimination Action Plan Team. The Commission hopes that it will be a powerful resource – a source of inspiration for people with a mental illness and those who are close to them and a special teaching tool for people who work in the mental health area. *Available from book stores or University of Otago Press, P O Box 56 Dunedin.*

Map of the Journeys Towards Equality Respect and Rights for People Who Experience Mental Illness is the plan the Commission developed for countering discrimination, after extensively researching the nature and persuasiveness of discrimination in our society. *Available from the Mental Health Commission.*

² Blueprint pp 47-48