Mental Health
and
Independent Housing Needs
Part 2

Expert Voices

A Consultation Report

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Ministry of Social Development

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Mental Health and Independent Housing Needs Research: Part 2
Expert Voices – A Consultation Report

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The twenty consumers/tangata whai ora who agreed to participate provided rich perspectives and depth of knowledge about the issues facing consumers/tangata whai ora seeking to sustain independent housing. Their contribution laid the groundwork for the entire project.

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Lynne Pere, Heather McKay and Kate Marshall (MSP researchers) were responsible for the organisation of the workshop. Their attention to detail also ensured the success of the day.

Mental health and housing needs – outline of the project

In June 2000 the Ad Hoc Cabinet Committee on Mental Health (AMH) established a work programme to address housing needs for people with mental illness. Housing New Zealand Corporation (HNZC) managed this work programme. The Ministries of Housing, Health and Social Development had responsibilities to complete individual items of work in the work programme. The Mental Health and Housing Research comprises two of the items on the work programme.[1]

The research was conducted in response to the Cabinet direction to:

- *quantify independent housing needs for people with mental illness in relation to adequacy of housing, affordability, and sustainability, including the role of support services in the retention of housing;* and
- *identify the extent of homelessness and transience amongst people with mental illness, and to identify housing options to meet their needs, and to consult with Te Puni Kōkiri to ensure a Māori perspective is fully considered*.

The outputs for this project from the Ministry of Social Development (MSD) have a number of components, including a summary report of the research that was delivered to HNZC which comprises Part 1 of the five-part report series published by MSD, and is titled:

- *Mental Health and Independent Housing Need Research: Part 1 A Summary of the Research.*

The other four parts include:

- *Mental Health and Independent Housing Need Research: Part 2 Expert voices – A Consultation Report;*
- *Mental Health and Independent Housing Need Research: Part 3: Affordable, Suitable, Sustainable Housing – A Literature Review;*
- *Mental Health and Independent Housing Need Research: Part 4 "It's the combination of things" – Group Interviews;*
- *Mental Health and Independent Housing Need Research: Part 5 Quantifying Independent Housing Needs – A Survey of Service Providers.*

As Part 2 of the series, this report provides a description of the one-day workshop with 20 consumers/tangata whai ora from around the country, three kaumātua, mātua, two facilitators and five MSD research staff.

[1] Since the research was commissioned, the AMH has been disestablished, the Housing Policy group from the Ministry of Social Policy (MSP) has moved to become part of HNZC, and MSP has been incorporated into the Ministry of Social Development (MSD).

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1. Introduction

This report gives an account of a one-day workshop that was held in February 2001. The then Ministry of Social Policy (MSP)[2] set up the workshop with consumers/ tangata whai ora[3] participants from around the country.

The workshop was a consultation tool developed specifically to ensure that consumers/tangata whai ora voices (the expert voices in relation to housing difficulties for people who experience mental illness) were heard at the outset of the project.

Purpose of workshop

The purpose of the workshop was to give the Ministry researchers an opportunity to:

- listen to consumers/tangata whai ora discussing accommodation-related difficulties
- consult with consumers/tangata whai ora about potential research approaches to be used in later stages in the research (including plans for survey and group interviews work)
- clarify key concepts and definitions in relation t current housing issues
- establish professional networks that would facilitate better access to research participants for interviews.

Background

The consultation workshop was seen as one component of the four-part research strategy.[4] It was planned to take place as early as possible after the initial scoping for the project had occurred so that the ideas, opinions and concerns of consumers/tangata whai ora could be embedded in the subsequent approaches that were to be developed.

The workshop was held with invited individual consumers/tangata whai ora at the Stella Maris Conference Centre in Seatoun, Wellington, and was held on Wednesday, 7 February 2001. The conference centre offered a range of appropriate facilities. There was a relatively large conference room where the participants, kaumātua/mātua, facilitators and MSP staff (29 people) could be seated in one large group or in smaller break–out groups. There were a number of smaller rooms available for separate discussion groups. A cooked lunch was provided as well as morning and afternoon teas and a supply of tea/coffee/water available all day. The privacy and tranquillity of the venue, the harbour outlook, the old wooden buildings staffed by the Sisters and helpers created an ambience that was appreciated by all. The one problem with the venue was stairs between the floors and between the meeting rooms and toilet

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[2] In February 2001, the Ministry of Social Policy (MSP) was a standalone Ministry, not directly affiliated with Work and Income New Zealand (WINZ). Since October 2001, MSP has merged with the Department of Work and Income (DWI, also known as WINZ) to become the Ministry of Social Development (MSD). The former DWI/WINZ function is now known as Work and Income.

[3] During a workshop, a preference was expressed for the term 'consumers/tangata whai ora' when referring to people who experience mental illness. Advice from Te Taura Whiri i te Reo Māori is that 'whai ora' means 'in search of well-being'. This term is used in all the reports in this series.

[4] The other three elements of the research strategy were: a review of relevant literature (see Part 3 of this series); interviews with 190 consumers/tangata whai ora and mental health service providers from around the country (see Part 4 of this series) and a national survey of 800 mental health service providers about their perceptions of housing need (see Part 5 of this series).

facilities that made it difficult for one participant with restricted mobility. It would have been quite inaccessible for anyone in a wheelchair. Mobility access was the one factor overlooked by the organisers, and it was salutary to be faced by the access implications for one of the participants.

The participants included two paid consumer facilitators, 20 consumers/tangata whai ora from all parts of the country, a kaumātua and a Pacific mātua, and four MSP staff. The MSP researchers developed a matrix to identify potential consumers/tangata whai ora from different parts of the country who represented different constituencies (see Appendix 1). The participants who attended the workshop, however, came as individuals rather than as representatives of their constituencies.

This report outlines in some detail what was discussed during the four sessions that took place during the workshop day. The conclusion provides a short summary of main issues. A list of definitions agreed to at the workshop is attached (Appendix 2).

Welcome and introductions/mihimihi

The kaumātua opened the workshop with a karakia.

After the welcome and introductions/mihimihi, participants were assured of their importance as experts in consumer/tangata whai ora issues. Assurances of confidentiality were also expressed by the four research organisers from the MSP, who also outlined the ways in which participants, especially Māori and Pacific participants, would be supported throughout the day.

Participants were told they had been invited to the workshop as individuals, rather than as formal representatives of consumer and tangata whai ora groups. They were reminded that their individual input was important and valued because they were seen as being expert in the field of consumer issues.

2. Session 1: Wāhanga tuatahi – "The research story so far"

To give context to the research the workshop was to address, the MSP staff outlined the mental health and housing work programme to address the independent housing needs of people who experience mental illness. They also explained the role of the Ad Hoc Committee on Mental Health and the Cabinet direction for the research.[5]

The initial timeframe for the research was discussed, as was the negotiation through which a longer time period was secured.

One participant spoke about his concerns regarding the short timeframe. He cited recent comments by the Prime Minister in the press that implied that all people who live in boarding houses or who are transient are former institutionalised patients. The participant believed Government thought they already knew the answers [to the research questions] and because they already knew, were not prepared to offer a longer timeframe.

In response to being asked who else [besides the participants of the workshop] were going to be asked about the independent housing needs of consumers/tangata whai

[5] The Ad Hoc Cabinet Committee on Mental Health (AMH) established a work programme to address housing needs for people with mental illness. Housing New Zealand Corporation (HNZC) is managing this work programme, and the Ministries of Housing, Health and Social Development all have responsibilities to complete individual items in the work programme. The Mental Health and Independent Housing Need research comprises two of the items on the work programme and are the responsibility of MSD. For further details, see p.i.

ora, the MSP staff confirmed that the research would listen to all voices: consumers/tangata whai ora, and providers (including Health and Hospital Services (HHSs)[6] and non-government organisations (NGOs). One participant made the point that in Hawke's Bay, for example, if you asked providers, they would say there is no accommodation (supply) problem – "we (consumers/tangata whai ora) are the experts, however".

The MSP organisers discussed how they had found very little information on mental health and housing issues apart from material produced by the Ministry of Health and the Mental Health Commission. The MSP research would therefore try to collect information by talking to consumers/tangata whai ora and service providers, and looking at other research.

The research approach

To explain the approach to the research, the proposed methodology was briefly outlined. It was explained that the research would be multi-method in its approach and would have four separate but linked components. The components were described as:

1. a consultation process (that included the workshop with consumers/tangata whai ora, as well as discussion with mental health service providers, other researchers and mental health experts as well as consultation undertaken by housing policy groups on other aspects of the mental health and housing work programme) was a priority
2. a review of literature and existing data (which was currently in progress when the workshop took place)
3. a survey of mental health service providers that would attempt to quantify the extent of consumers/tangata whai ora housing difficulties that were reported by providers
4. interviews and/or focus groups with key consumer and provider groups conducted in priority areas to gather more in-depth qualitative data.

Once the outline of the four components was clear, there was discussion about a number of aspects of the proposal.

Discussion of the research design

Issues with the survey

First, there was discussion about the extent to which service providers would be able to give an accurate picture of what was happening to consumers/tangata whai ora. The MSP staff discussed the survey in more detail and explained that the proposal was to send a postal questionnaire to all HHS mental health providers, all known NGO mental health providers, and all known mental health consumer groups. MSP believe surveying the three populations would provide a better quality of data because:

- the HHSs client base provided the closest fit with the 3 per cent definition[7]

[6] Health and Hospital Boards (HHSs) no longer exist. District Health Boards (DHBs) have replaced them.

[7] Around 3 percent of the New Zealand population have serious, ongoing, and disabling mental illness requiring treatment from specialist mental health and alcohol and drug services. (Mental Health Commission, 1998:7)

- HHSs might give a reasonably confident estimate of the overall numbers of people who experience mental illness who have housing /accommodation-related difficulties. It was noted, however, that the HHSs might not be able to specify the particular difficulties that are most prevalent for their consumers/tangata whai ora
- NGOs and Consumer groups would provide a richer source of data on local differences in housing difficulties and might therefore be able to provide MSP with a picture of the kinds of difficulties that are significant in particular areas
- analysing all three populations separately would minimise double-counting.

MSP staff then asked the group if they would be willing to provide comment on a draft provider survey. Participants agreed to assist and the MSP staff undertook to send the draft out once it had been prepared.

Interview participation

Second, there was discussion about participation in the group interviews. The MSP staff indicated that the focus groups would be with consumers/tangata whai ora who were not at the workshop (and so would expand the number of consumers/tangata whai ora who could be spoken to) and would be held in small settings in particular places. Interviews were designed to collect local information about why/ how housing difficulties affect people who experience mental illness. The staff anticipated that priority areas would include rural, urban, areas of high Māori populations, and areas with high concentrations of deinstitutionalised consumers/tangata whai ora from local mental health institutions.

Provider knowledge

Participants asked further questions about how a survey of providers would be able to shed light on the satisfaction consumers/tangata whai ora have with their accommodation. They reiterated that providers could not tell you anything from a consumer/ tangata whai ora perspective. MSP staff responded that the providers' questionnaire on its own would not be expected to answer these questions, but that some quantification of difficulties could happen through the survey. The researchers were therefore making a pragmatic decision about getting at least some response. The researchers also advised that the consumer focus groups (of which there would be several at places yet to be decided) would be able to record a consumers/tangata whai ora perspective.

The informal support sector

The participants also noted that there were many de facto providers of support for consumers/tangata whai ora, and participants wanted to know how the MSP research team would record the existence of this informal support sector. An example in the Hawke's Bay was cited where a local pub [hotel] provided the most popular residential accommodation for consumers/tangata whai ora (and others) who needed affordable housing. The MSP staff admitted they would value such detail and information from participants about the informal provider networks. However, it was also noted that this local pub was not a service provider *per se*, but rather should be

seen as a resource.[8] It was emphasised that de facto providers are meeting the needs of consumers/tangata whai ora and it would be important for the MSP researchers to be aware of them. It was also suggested, however, that the researchers needed to be careful about the information they would get from such providers, who may have little or no knowledge of mental health. Being aware of the existence of such resources might rather serve to highlight that there is insufficient accommodation in the area. The participants also noted that patterns of informal accommodation vary from place to place and understanding regional variations might be important to the research.

Issues with other people's definitions and information

MSP staff noted that the research focus was on independent housing needs as opposed to supported accommodation or residential accommodation. Participants then warned MSP that the researchers needed to be clear that the focus was not on residential services. The participants reiterated the need to take care with terminology and with being very clear about what they were trying to find out. Some further aspects of the discussion around the definitions are outlined in section 3 on definitions of terminology.

Participants also asked the researchers how transience would be defined and acknowledged the problem of the definition being very wide or too narrow. It was recognised that the concepts of both homelessness and transience would need to be carefully defined and the lack of consensus over the terms would need to be resolved. Participants advised the researchers to be aware of what other researchers had in mind when they talked about homelessness and transience.

Participants stressed the importance of care when analysing information given by providers. For example, in some cases reports that people had to stay in hospital for longer than necessary because there was no accommodation actually reflected lazy providers who would only deal with one or two accommodation providers. One participant suggested it was easy to discharge people into supported accommodation but some providers have an interest in reporting shortages – this was their business. It was important to note that the statistics may be driven by conflicts of interest and consumers/tangata whai ora were commonly in the middle of provider interests.

Another concern consumers/tangata whai ora had was in knowing who would decide what was adequate – different people had different values. Problems of subjectivity in such terms were noted.

Ethical concerns

An even more fundamental concern raised by the participants about the research was the question of ethical assumptions. The consumers/tangata whai ora expressed concern about the philosophical basis for the research and provided examples of their concerns. If, for instance, the researchers felt that it was important that family/whanau were happy that consumers/tangata whai ora were being looked after then what consumers/tangata whai ora wanted could be overlooked. The participants pointed out that there is a long history of the government and people wanting to look after

[8] The discussion of 'resources' as opposed to 'services' that arose in this discussion laid some of the ground work for the conceptualisation of the 'sustainability framework' (see Part 3: a literature review, in this series) which distinguishes between the 'resources' that are available to consumers/tangata whai ora. In the terms of the sustainability framework, the informal accommodation options would be part of the 'material resources' available to consumers/tangata whai ora.

consumers, but the looking after was not always from the consumers/tangata whai ora point of view.

The group wanted to know what the ethical basis for the research was going to be before the research went any further because that would determine where and how this information was interpreted. Participants also wanted to know what the government, and hence those conducting the research, had in mind and what assumptions were being made.

In sum, participants stressed that information from sources other than the consumers/tangata whai ora might lead to different conclusions from those that would be gained if consumers/tangata whai ora were the focus throughout.

Participants also noted that researchers have in the past come in, asked consumers/tangata whai ora questions, taken information, and then changed it to what the government wants to hear. Those present asked that MSP did not do that. The MSP staff assured participants that the researchers had a personal commitment to represent the issues raised by the consumers/tangata whai ora as clearly as possible. It was felt that the group interviews would provide a clear place for consumers/tangata whai ora voices.

Other issues raised

Multiple disabilities

The needs of people with multiple disabilities was noted and it was suggested that it was important the survey was sensitive to their needs. One of the participants gave the example of a person who has a mental illness and physical disabilities but who may not reach thresholds for certain services (either mental health services or physical support services). This person is then not catered for but, with the combination of the two conditions, was actually very much in need of support. It was noted that it is important to be aware of those people with overlapping difficulties – those who experience mental illness and also have physical disabilities.

Categorising people

Following on from this point, another participant stated that the mental health arena creates boxes that you need to fit in but the boxes do not work – they are just categories. Another responded by saying that the use of categories was a trap – people are very different and do not fall neatly into categories. It is critical that the whole person is seen, not just the disability. One participant suggested that it was the people who did not fit into boxes who sometimes ended up on the street. He stressed that if MSP had one underpinning value for this process it should be to "focus on the needs of the individual … then we wouldn't fall into the trap of having to fit categories".

Supported accommodation

This in turn led to a discussion about the lack of supported accommodation (residential rehabilitation) for people (men and women) with children. Consumers/tangata whai ora suggested there is no supported accommodation available, not even a category, for someone who has a child/ children. The participants indicated that this issue has been raised many times before to the Ministry of Health but no one was sure what the Ministry of Health was doing about it.

One participant suggested that relationship break-ups occur alongside episodes of illness on many occasions. Another stated that some mental health workers use access to children as a punishment – if you break the rules then you will be prevented from

seeing your child this weekend. It was noted with some vehemence that the issue of accommodation for someone with dependants was not a women's issue. It was a custodial and access issue that was non-gendered.

One participant made the point that he thought community care was an assumption. Community care had never really been there fully, and there was not enough support at home. However, he believed Section 11 could be served at home.

Population-based approach

There was extended discussion about the population-based approach of mental health services. The participants explained that this approach meant that services tended to go where there was seen to be a major need so services ended up being in urban areas. The result from this is that consumers/tangata whai ora drift to the cities to get the services they need and then end up being "stuck there".

One participant noted that the HFA had researched population-based funding and had shown that because there is a small population base outside of the cities rural consumers/tangata whai ora miss out.[9] Raglan was given as an example of a small town where there is no supported accommodation. The participants questioned the population-based model used by government that results in too few services in rural areas. Participants argued that this needs to change or rural consumers/tangata whai ora will always miss out. They suggested this was an important equity issue that needs to be addressed. It was acknowledged that there needs to be some balance. People in very isolated places may need to take some responsibility for getting to services, but there do need to be more services in the smaller towns. The view that the needs of 20 were more important than the needs of one was challenged, and participants stressed this was important to note when analysing the results of the research.

The lack of services is not just in relation to rural consumers/tangata whai ora. Participants noted that there is no supported accommodation for Pacific peoples outside of Auckland and there is no supported accommodation available that includes accommodation for partners.

"Where do you live?"

After the discussion session, the facilitators began the next phase of the workshop with a warm-up exercise. Participants were asked to think about where they lived at present and to imagine themselves in relation to the other participants by placing themselves on an imagined map of New Zealand. Northland was indicated at one end of the long conference room and Bluff at the other.

Once spread on the map it was obvious that there was a good spread across the country. People were then asked to say something about where they lived. Comments centred mainly on the weather rather than on the actual place/house that they lived in. One participant noted the importance of his land, which was his home, rather than the dwelling on it. The facilitator then asked the participants to move to a place they would like to live in, if it was not where they already were. There was a clear drift to the North, along with comments about needing to get where it was warmer.

Participants were then asked to sort themselves into groups according to the type of housing they lived in: people who lived in their own home, those who lived in rental

[9] It was not clear from the discussion which research was referred to here. Note that the Health Funding Authority (HFA) is now included in the Ministry of Health.

accommodation, those who lived with family, and those who lived alone. Once everyone had moved there appeared to be an even spread amongst the four groups. Comments at this stage reflected surprise at the outcome, especially the numbers of people who were living in their own homes.

This warm-up exercise then led into a wide-ranging discussion about aspects of housing and being at home. A number of themes emerged during the discussion.

Choice of housing is important

Participants noted that different things were important to them and that their different needs were reflected in where they lived. Some liked living alone as it provided a refuge and a haven from the hassles of daily life (even though where they live may be rented and small), including noise. The consumers/tangata whai ora suggested that the effect of noise on recovery and maintenance of well being was significant. Some were adamant that they did not like/could not manage being in noisy places.

Some participants suggested they needed to live alone for their wellness and saw it as a choice in that respect; some thought living alone provided them with the flexibility to do what they liked when they were unwell, like staying in bed all day if they wanted. Others found it difficult because of their illness to live with others.

Proximity to support

Still others noted how important it was to live with, or near, family and partners. Being close to support was more important than the physical adequacy of the house they were in. Being separated from this support, even if in a beautiful house, would not be good (or adequate) for their well-being. One participant lived in a residential facility and described it as "a beautiful home" because support was immediately accessible.

Renting versus owning

Some of the participants noted that paying rent was "wasting money". For some, the onset of illness had meant they had lost their home many years ago and it was difficult to get back to home ownership. Several did own their own home, or in the case of one renter, owned a property elsewhere. One participant had moved frequently since losing his home – two and a half years was the longest he had remained in one place since. Another who had lost his own home due to illness doubted he could ever own again, and found it encouraging to see many other participants who did own their own home. Māori participants raised the issue that home ownership was important for Māori: "Māori must have their own whare for their well-being", and noted with concern the paradox that there was a high rate of renting among Māori consumers/tangata whai ora.

One person who owned the place he lived in did not see his house as his home – rather his home was his marae. For some, home was a place where you cared for others that came to see you – just like on the marae.

House versus home

It was notable that comments relating to where people lived centred more on who people did or did not live with, rather than what the home was like physically. Participants discussed the idea that a house was not always a home – rented houses, for example, could be homes while houses that were owned might not feel like a home. Choice in relation to where you lived, what kind of house, and who you lived

with was described as being very important. Some participants suggested that where they lived was part of their identity, but others in the group did not support this idea.

Employment

Participants also discussed the role of employment on where consumers/tangata whai ora chose to live. Employment was seen to be a very important influence. One participant noted, "you have to go where the work is, and the services, to be able to afford housing." Another noted that if support services came into your home, you were able "to call the shots", in contrast with what happened in residential facilities where you had much less control.

DWI perceptions

Consumers/tangata whai ora also noted that the Department of Work and Income (DWI) had perceptions about people on the invalid's benefit. The perception was seen to be that DWI staff expected consumers/tangata whai ora to live in certain places if they were on an invalid's benefit. Participants discussed the perception that consumers/tangata whai ora could not be an invalid and live on their own. As a result, some participants noted that they did not tell DWI where they really lived. Once again, the participants emphasised that it was important that the individual was recognised – their abilities as well as needs.

Transience versus being mobile

Another point of discussion made was that 'the average kiwi' moved every three to four years and is not called a transient because of this. But when consumers/tangata whai ora move frequently, they are called 'transients' and their mobility is seen to be a negative thing. The participants suggested that care needed to be taken with the research not to make something (transience) an issue when it is actually "normal kiwi behaviour".

Role of boarding houses

It was noted that a lot of boarding houses were halfway homes for consumers/tangata whai ora. One participant said that where he was from there were "a lot of halfway houses, boarding houses and rural pubs filled up with consumers" – yet all these services had nothing to do with mental health. They provided a place to stay but no other support, such as for budgeting. These other supports were critical needs for many consumers/tangata whai ora in boarding houses. There was some speculation that being used to communal living arrangements in institutions may influence consumers/tangata whai ora in their choice of boarding houses and pubs for their accommodation.

Forensic discharge

The participants spoke with concern about consumers/tangata whai ora who left prisons. Often consumers/tangata whai ora discharged from prisons were very nomadic. No specific support was given to them on their release other than the standard $400 given to assist in setting up their lives. In the group's experience many homeless and transient consumers/tangata whai ora had come from prisons. The gap in service delivery to consumers/tangata whai ora being discharged from prisons was identified by the participants as huge.

3. Session 2: Wāhanga tuarua – "Definitions of terminology"

The two discussion sessions that were to follow the lunch break were designed to cover debates over terminology and a general discussion about accommodation issues. The debates about terms ended up as a discussion about accommodation issues as well and the second part of the agenda was never separately addressed. The researchers had a set of terms that they wanted to discuss, and these were tabled at the start of the session. The group broke into smaller groups to discuss the terms; key ideas were recorded on poster sheets and then considered by the whole group at the end. The general tenor of the discussions around each term is recorded below, and the final definitions agreed to by the group are included as Appendix 2.

People with mental illness

There was discussion over the term 'people with mental illness' used by MSP in correspondence with the workshop participants. An alternative of 'people who experience mental illness' was suggested. Participants felt this would be a more acceptable term to use in the research, as it did not imply that a mental illness was forever. It was noted, however, that the Mental Health Commission used 'people with mental illness' to reflect the fact that the focus of *The Blueprint*[10] was on the 3 per cent of the population who used mental health services. Another workshop attended by participants recently came up with the term 'people who' which was then asterisked to a footnote that explained this referred to people who experience mental illness. However, the group in general did not favour this because when written in sentences it didn't really make sense. While participants did not really like being referred to as 'consumers' because it sounds depersonalised – "sounds like a supermarket shopper, or that all we do is 'consume'", it was recognised by everybody.

One participant suggested the term 'tangata whai ora' should not be used to mean Māori only because many people in the mental health community interpret tangata whai ora more broadly. Although many do interpret tangata whai ora to mean Māori only, the participant felt that such a narrow definition disenfranchised Māori service users because it "it should not be used to split Māori off". The participant saw herself as 'tangata whai ora' and a 'service user' and proposed the terminology 'service users/ tangata whai ora' to identify people who used mental health services. Others in the group, however, did not favour this suggestion.

There was some discussion about the use the term 'turoro', which is used commonly on the East Coast of the North Island. Participants discussed the implication of disability in the phrase because 'turoro' literally means 'lying on the floor like a plank staring into space'.[11]

The term 'consumers/tangata whai ora' was decided as the best to use as a combination, not specific to Māori. It was agreed that the term may be used interchangeably – the slash mark (solidus) being an indication of an alternative, not a separation between the consumers and tangata whai ora. Although it was suggested by one participant that the research should refer to 'Māori' rather than 'tangata whai ora',

[10] Mental Health Commission (1998) *Blueprint for Mental Health Services in New Zealand: how things need to be.* Mental Health Commission, Wellington. (see the References attached to Part 3 in this series: a literature review).
[11] In the group interviews (see Part 4 in this series: group interviews) the phrase turoro was used by consumers/tangata whai ora from the East Coast.

when surveying about Māori specifically, the research will use the term 'tangata whai ora' on its own when referring to Māori only.

The group noted that a whole day could be spent debating the terminology – it was a frequent debate and was never agreed on. What was important was that the research got quality information to inform government, and the terminology was secondary – not withstanding that language can be very powerful in its effect on consumers/tangata whai ora. It was critical to change language but it was not the purpose here. It was agreed that people choose their own label personally, but in the context of the research, wherever possible MSP should just use 'people who experience mental illness', and where it is necessary to be explicit use consumers/tangata whai ora as interchangeable terms. It was noted however, that there needed to be a good definition to accompany consumers/tangata whai ora.

Adequate housing

The next definition to be discussed was 'adequate housing'[12], which, according to the proposed MSP definition, refers to *the physical condition of a dwelling – that is, housing that is of good quality; does not cause discomfort because of a poor state of repair, dampness, dilapidation and pest infestations; is not overcrowded; and/or has secure tenure. Adequate housing also refers to housing that contributes to mental health recovery through being suitably located to support services and/or family/whanau. Inadequate housing includes homelessness.*

It was agreed that adequacy is very much in the eye of the beholder. For example providers may say the particular housing of a consumer/ tangata whai ora is more than adequate, but the consumer/ tangata whai ora may disagree. Someone may say "this house was condemned – it is inadequate – you can't live there" whilst another person may be OK with that. The dilemma is that everyone has his or her own individual perception of adequacy, and choice is the critical variable. What someone considers adequate is very individualistic. The research answers will therefore depend on who is being asked.

Participants emphasised the point, therefore, of adequate housing needing to be defined by the consumer/ tangata whai ora– that is "adequate to me, adequate to my needs". An example given by one of the participants was of one of their friends who lived out the back in a shed and loved it (would describe it as adequate).

What was clear was that adequate housing is very much based on individual need and thus is very hard for a third party to judge. "It is critical that the judgements of others aren't imposed" or else as one participant suggested MSP may have a big fight on their hands. "Adequacy should not be used as a stick to beat us with."

Participants acknowledged that the researchers had an ethical obligation to be clear about the definitions of terms when they were developing the survey, but that should not get in the way of consumers/tangata whai ora having their own understanding of what is considered adequate housing. The participants noted that a definition of

[12] In the final publication of the 5 Parts of this Mental Health and Independent Housing Need research, the housing concepts that were debated in the one day workshop underwent further change. The concept of 'suitable housing' is used to indicate this subjective notion of housing adequacy and the idea of 'adequacy' has been restricted to refer to the physical condition of the housing stock: "adequacy refers to the physical condition of a dwelling. Housing can be regarded as adequate when it is of good quality, does not cause discomfort because of a poor state of repair, dampness, dilapidation and pest infestations and is not overcrowded; suitability refers to the appropriateness of housing for the mental health recovery of consumers/tangata whai ora. Suitable housing needs to be physically adequate and located near sources of support …" (see Part 1 Summary, p2).

whether or not a house was adequate "is down to the individual", and "some may be happy to live in a culvert – that's OK". Participants felt that what was important was that there is a good standard of accommodation available if consumers/tangata whai ora wanted it – but that housing was not to be enforced if their view of what is adequate is different.

While the group generally accepted the proposed definition of adequate housing, some participants had an issue with the part of the definition that said '…through being suitably located to support services and/or family/whanau'. They felt that this implied control was being taken away from them and being given to the family/whanau and support services. Being 'suitably located to support services' was interpreted by some to mean the consumer/ tangata whai ora needed to live near support services, for the convenience of the mental health services. The participants felt this needed to be clarified: support services, which include mental health services and social services agencies, need to be suitably located in areas where consumers/tangata whai ora are able to access them easily.

One participant suggested rewriting the definition to focus on the basic structure and necessities of housing, while others felt that 'adequate housing' should cover only those physical aspects of housing. Access to support and other very individualistic things should be covered under a separate definition of 'suitable housing'. Still others, however, did not like the suggestion of not including family/whanau. They felt that it was important to acknowledge the support of families/whanau.

It was noted that there was nothing in the definition that acknowledged that Pacific people who experience mental illness mostly live with their families and that families/ whanau also require support. In Pacific people's cultures, families must be considered at every level and support must come to the whole family. Not all Pacific people attribute the clinical diagnosis of symptoms to 'mental illness', and it is important that families have access to support that recognises this different approach to diagnosis and labelling.

The discussion highlighted that a more holistic view of mental health and adequacy needed to be considered in the research. "Support is not just about professional support but also about family and friends." A participant echoed this thought, stating "we need to support the community because they are the ones who try and meet the needs of the clients."

For some consumers/tangata whai ora, it may be more important to live with family/ whanau in inadequate physical conditions, than to be separated from them in a more physically adequate house– "I would rather experience a little bit of dampness". One participant stated. "I've lived in holes, but was very happy because I was with people I loved".

The comment was made that there is already legislation[13] that defines adequate housing in terms of the physical things, and it was suggested that a definition focused on physical adequacy be the one used in the research. It was also acknowledged, however, an element needs to be added to this for mental health consumers, that includes reference to the role of support, which may or may not be in the form of family/whanau support.

[13] Housing Improvement Regulations 1947 that forms part of the Health Act 1956.

The participants cautioned the researchers "to be very careful when lumping many things together." In the end, to dispel any confusion, it was agreed to take 'services' out of the sentence. It was suggested that support services and support networks were different things. A suggestion was also made to remove 'mental health' from the sentence – 'Adequate housing' also refers to housing that contributes to mental health recovery through being suitably located to support and/or family/whanau'. However, this was not generally supported.

One participant suggested that the state could do more to support and help consumers/tangata whai ora to stay recovered. Along these lines, it was agreed to add maintenance to the definition, so that the sentence reads, 'Adequate housing also refers to housing that contributes to mental health recovery and maintenance of well-being through being suitably located to support and/or family/whanau.'

Even at the end of this lengthy discussion, it was not clear whether adequacy should relate only to those things specific to mental health recovery or to the general adequacy of housing that could impact on anyone's well-being. It was suggested that the researchers make sure those things that are specific to mental health and are important to the wellbeing of consumers/tangata whai ora are made clear in the survey.

One participant suggested that a preference for living in the central city may be about the wellbeing of a consumer/tangata whai ora because it places them nearer to people they know. Another participant noted the difference between right and wrong locations when he said, "I've been places that are physically fine but you want to kill yourself, because it's not really right."

Participants also suggested that the right to privacy needed to be included in the definition of adequate housing. There was a discussion about recent moves by the Manukau City Council to insist that neighbours of proposed residential accommodation be supplied with phone numbers of the accommodation facility. "Being able to have some private space" is critical, and the consumer/ tangata whai ora needs to be able to control the level of social contact and interaction they have. 'Adequate housing' therefore should encompass both support and privacy.

It was noted in the discussion that the effect of community views also had a real impact on the housing of consumers/tangata whai ora. For example, in one case a Level IV[14] house was built in the grounds of a hospital because the community objected to it being located in a residential suburb. From the point of view of consumers/tangata whai ora, however, there sometimes needs to be distance from services.

For consumers/tangata whai ora, an acceptable noise level and adequate sunlight is very important. It was agreed that these two things needed to be added into the definition of adequate housing.

There was discussion regarding being able to live in the area of your choice. One participant suggested that the housing you are able to afford depends on the benefit you receive. Some consumers/tangata whai ora are on an Unemployment Benefit, some are on ACC and some are on an Invalid's Benefit. Different benefit levels

[14] The Residential Support Service, funded by the Health Funding Authority (HFA), provides accommodation and clinical support and is funded at different levels. A Level I residential service is funded for people assessed to have lower support needs associated with the effects of mental illness. Level IV services are for people assessed as having higher support needs.

influence how much you can afford to pay for accommodation and where you will live.

Another participant responded to this statement, saying that the term 'benefit' is not synonymous with income. There are others who are not receiving a benefit but are also on very low incomes. His suggestion was that there is a need to look at the minimum wage as well as benefit levels.

In Hawke's Bay there is only one Level III supported accommodation facility and one Level IV supported accommodation facility. This lack of choice means there really is a lack of adequate accommodation – "if we don't like that place or the people there, there is no choice."

Some participants cited problems arising from those who want to "assist us". The example was given of one social worker who decided a certain consumer needed to be in supported accommodation and would only help them into this accommodation, no other kind.

A further element in the discussion between the researchers and the consumers/tangata whai ora at the workshop was the discussion about the 'accommodation related difficulties'(ARDs) [15] related to housing adequacy. The ARDs paper defined a possible adequacy accommodation-related difficulty as 'lack of basic facilities and amenities/ access to utilities and amenities (i.e. sharing kitchen and bathroom facilities)". One participant commented that sharing facilities should not necessarily be seen as a bad thing – e.g. in a rooming house you have to share. "Some people want to have communal living". The researchers were again reminded not to make assumptions about what constituted adequate conditions.

Sustainable housing

The next definition to be discussed was 'sustainable housing', which, according to the proposed MSP definition, refers to *housing that allows people who experience mental illness and tangata whai ora to live within their means, to maintain their independent housing options including during episodes of acute care or hospitalisation and to have security of tenure. People who experience mental illness and tangata whai ora may need varying degrees of support to sustain housing. Some people who experience mental illness or are tangata whai ora may need long-term help with household affairs.*

One participant stated that he did not think consumers/tangata whai ora should be asking for anything different from the community at large. He suggested therefore that the sustainability ARD associated with insecurity of tenure (i.e. landlords being able to sell properties to reap capital gain) be taken out of the definition. He felt the researchers needed to be very careful not to breach the Human Rights Act 1993 by implying there has to be anything different for consumers/tangata whai ora. Individual needs have to be the reason behind anything different.

The lack of protection for consumers/tangata whai ora in some places was noted. The example was given of a consumer who moved into a flat, used his non-recoverable

[15] A paper on Accommodation-Related Difficulty (ARDs) had been prepared by the researchers prior to the workshop and this had been used to promote various aspects of the discussion. The researchers had coined the phrase 'accommodation-related difficulties' (ARDs) as a way of talking about housing difficulties in the broadest possible way. Although much of the workshop discussion was in relation to ARDs, the term did not persist into the final version of the survey where it was replaced by the phrase 'housing difficulties'.

needs grant (re-establishment money) to buy furniture. Another person then moved into the room that had been set up, and the consumer was left on the couch. This consumer was "led to expect a + b, but ended up getting c + d". The participant who highlighted the example suggested this was a discrimination issue and a rights issue. Another participant wanted the consumer's rights spelt out more explicitly because she had also heard of many situations where landlords and other tenants used stand-over tactics. Many of the participants agreed that consumers/tangata whai ora should not sign tenancy agreements in situations where their rights were unclear.

Another participant felt that lack of tenancy protection could apply to anyone and was therefore not just a consumer issue. Although the group was talking about consumers/tangata whai ora in a positive way he warned that highlighting tenancy problems might be used by politicians to prescribe legislation against consumers/tangata whai ora. "We need to be very careful with the research – the politicians may take the results and legislate as to where we should live."

Some participants thought that by deleting the sustainability ARD associated with insecurity of tenure (i.e. landlords being able to sell properties to reap capital gain) there would be no move to regulate so landlords could not give notice. The fear was that regulation could have a lot of negative spin-offs in the rental market. It is important to acknowledge this as an issue for all tenants, but also to note that it is not recommended that there be regulation to make it harder for landlords.

The only suggestion made in regard to changing the definition of sustainable housing, apart from the terminology used to describe people who experience mental illness, was that the last sentence be changed to 'a deinstitutionalised person, for example, may need long-term…'

In response to the sustainability ARD associated with environment (i.e. satisfaction and appropriateness of the environment, and the neighbourhood and community), one participant suggested this may be more about discrimination issues.

In response to the sustainability ARD associated with proximity, accessibility and availability of support, it was suggested that MSP find out what services were available in the first place. MSP noted it was difficult to assess what was available. It was also noted that the availability of mobile support needs to be included in the sustainability ARDs instead of consumers/tangata whai ora being required to live in close proximity to services.

Advocacy and consumer rights

The discussion about sustainability led into a long digression about rights and advocacy. As one participant noted, the MSP definitions were fine, but the only thing missing was advocacy – "I just think there's a big gap in advocacy for people [consumers/tangata whai ora]. They have rights – who dare defend them. There is legislation to protect consumers/tangata whai ora but not all know how to use them." As one participant noted, a lot of consumers/tangata whai ora only see the Mental Health Act 1969 as applying to them. They don't realise that the Residential Tenancies Act 1986 and other laws are also for them. But another participant pointed out that sometimes people just are not well enough to go through the necessary process to stand up for their rights, or they do not know what their rights are. "When you need them, you're too damn tired. You need more advocacy to work on your behalf." It was also noted that the advocacy that health services supply may not

necessarily always be the most appropriate service for people who experience mental illness.

The issue of consumer/tangata whai ora rights was discussed. It was suggested that consumers/tangata whai ora must police their rights – "These are civil issues. But it's not enough to be given your rights – you also have to take them." There are loopholes in fighting for your rights, however. If a landlord doesn't lodge a bond given by the consumer/ tangata whai ora, for example, that consumer/ tangata whai ora will have to take the landlord to court to retrieve it – "There are costs and you have to take the case on."

There was also discussion of the idea that rights can also imply duties and just as the consumer/ tangata whai ora has rights, so the government has a duty to provide accommodation. There should also be an obligation on behalf of the provider who supplies the accommodation. But there are dangers – the Residential Tenancies Act[16] protections do not [currently] apply in supported accommodation, and sometimes "even if you stand up for your rights, you can be got back at later."

There was much discussion about the issue of losing supported accommodation while in hospital. "When you have lived in supported accommodation and then go into the ward, the supported accommodation will only keep your bed for 21 days 'cos that's all they've got the health dollar for – you lose your place and right to be in a supported accommodation – you lose everything."

The discussion highlighted that there are times when consumers/tangata whai ora cannot stand up for themselves and need much more than minimum levels of support to counter the vulnerability they experience. "We are disadvantaged by our experience of mental illness – there are times when we need much more to help us." For example, consumers/tangata whai ora do not need minimum accommodation, rather they need more or better accommodation than those who are mentally well. Because they are trying to aid and maintain recovery, consumers/tangata whai ora may need more money, more advocacy or more support to be on the same level as others. Having said this, however, the participants also noted, "These standards shouldn't be dictated …they should be there if you want them to be equal … at times we need more than others."

One participant suggested it might be better to get rid of supported accommodation and replace it with Club Med. His suggestion was that it may be better to spend the money (the health dollar) on allowing consumers/tangata whai ora who were unwell to spend time in five star accommodation. His point was that the needs of consumers/tangata whai ora should not be specified on the basis of the minimum – "for recovery people need sometime nice." What consumers/tangata whai ora need however, may differ for individuals.

Affordable housing

The next definition to be discussed was 'affordable housing', which, according to the proposed MSP definition, refers to *housing for people who experience mental illness and tangata whai ora that takes a proportion of income while leaving enough money for other basic necessities and medical costs.*

[16] The Residential Tenancies Act 1986 defines the rights and obligations of landlords and tenants, and establishes a dispute resolution service, including a tribunal, to determine disputes between them. The Act also establishes a fund in which tenants' bonds are held. The Residential Tenancies Amendment Bill 2001 is expected to come into force late 2002 or early 2003

It was noted that not only consumers/tangata whai ora have affordability problems – other low income people also do. The participant discussion, however, highlighted that many consumers/tangata whai ora had lost their state housing when market rents were introduced on the one hand and mortgages increased significantly on the other.

The researchers asked the group what the return to income related rents has meant for consumers/tangata whai ora. Some participants said it meant more food; some were $40 a week better off and some said it meant they could "buy more smokes".

The group was also asked it could be argued that rent should be limited to 25 per cent of income for someone who has a mental illness. The overall response from the participants to this suggestion was "no". Participants said this would mean that people would have to say they had a mental illness. One participant also noted that people who experience mental illness should not "have to live in a state house".

The facilitators asked if there was anything specific about having a mental illness in regard to affordability. Participants noted the additional costs of medication and doctor's visits.

There was a view that to address housing affordability, a few things needed to happen– there needed to be a move to measures that create an equitable society, that were not means tested:

- There needs to be an increase in housing stock until it brings the private rental market down. The return to income related rents should have meant that private rentals would come down but more HNZ properties were also needed to bring rents down;
- There needs to be a return to state advances on mortgages – this was seen as one way of ensuring people on low incomes should have the right to buy their own piece of planet;
- The Accommodation Supplement needs to be reworked – it should be sufficient so that consumers/tangata whai ora could live in private rentals too;
- There need to be cheaper rentals for those below the poverty threshold;
- There needs to be an increase in the minimum wage so that consumers/ tangata whai ora are not excluded from home ownership.

It was noted that the exercise earlier where participants stood in groups depending on if they live own their own, in their own home etc illustrated that many do own their own homes – consumers/tangata whai ora are not all poor. This exercise challenged the perceptions of otherwise.

One participant spoke about the need for asset protection during episodes of acute illness. In these times of crisis when consumers/tangata whai ora need help, it is critical that those who have assets and houses do not lose them. It was suggested that it might be more important to get assistance with asset protection during acute illness than getting a mortgage, because the impact of losing your house can still be going on twenty years later. Discharge planning was also a very critical component.

Participants also stressed the importance of being cognisant that the '3 per cent' was not a static group who are severely ill all the time, or poor all the time. People move in and out of this 3 per cent group, it is very fluid, and people change – "I was a 3 per cent once."

Overall the definition for affordable housing proposed by the research team was agreed to.

Residential rehabilitation and supported accommodation

The final two items discussed in the main afternoon session related to the concept of supported accommodation. It was evident in discussions the researchers had with consumers/tangata whai ora prior to the workshop that this was a term that was open to widely different interpretations. On the one hand it seemed that mental health service providers used the term quite narrowly to refer to support that was provided in the context of residential care facilities. Consumers/tangata whai ora, on the other hand, seemed to suggest that the term could refer to any kind of support that could enable them to sustain independent living. The researchers therefore proposed two interpretations.

According to the proposed MSP definitions, 'residential rehabilitation (supported accommodation)' refers to *the residential support services currently funded by the Health Funding Authority (HFA). These services provide accommodation and support and are funded through Levels I through to IV. A Level I residential service is funded for people assessed to have lower support needs associated with the effects of mental illness, whilst Level IV services are for people assessed as having higher support needs. Most of these services are provided in the community.*

Home-based support (supported accommodation) is an ambiguous term. For the purposes of this research, it refers to any accommodation that is supported by clinical and social services and thus includes privately owned homes, rental properties, groups of units or apartments designated hostels and boarding houses. However, support services are separate from the actual dwelling and is thus distinct from residential rehabilitation.

Participants agreed to accept these definitions of residential and supported accommodation. However, there was discussion regarding their different regional interpretations. The term 'home-based' support was offered as one to get over the confusion created by the term 'supported accommodation' (which sometimes referred to 'residential rehabilitation services' and other times referred to 'support in one's own home').

MSP commented that 'independent housing (living independently in the community)', which according to the proposed MSP definitions refers to *people who experience mental illness and tangata whai ora living in accommodation that is not residential/supported accommodation. A person with mental illness living independently may still be in receipt of clinical and social services on a regular basis and may receive financial support for their accommodation, including being able to choose support services*.

However, participants questioned whether home-based support really offered people the scope to choose the level of support they wanted. It was suggested that MSP needed to look at small towns and rural areas to find out these differences in supply of support services. Participants also had different interpretations of what the term 'support services' might include – some interpreted it to mean only mental health services; others thought it included either community type services (such as assistance with household management), and others saw it as including family, partners and friends.

4. Including "consumer/tangata whai ora in research"

Project support

After the final tea break, the group came together for the closing session. The researchers were hopeful that some of the participants would be willing to stay involved with the research in an advisory capacity and some time was spent establishing the feasibility of this.

Most participants said they were willing to participate in the project further. In particular, they were willing to give advice on questionnaires and methodology. All the group members wished to be included in ongoing feedback.

Participants also indicated a willingness to assist in providing networks/facilitation for focus groups/group interviews if needed.

The researchers indicated that they would welcome more feedback on issues that had not been able to be covered in the workshop. There was some discussion about the need for more understanding of the circumstances of consumers/tangata whai ora living in rural issues and for the homeless and transient. Given the impact of mental illness as the population ages, networks of those who knew about the issues for older people who experience mental illness were seen as particularly important.

Key issues

Finally, the group went over items noted throughout the day as items not to be missed. These were:

Home ownership: This was covered to some extent during the day. Homeownership was seen as a good option for some consumers/tangata whai ora. More importantly however, those who achieved it must not lose their homes due to illness. There needs to be protection and mortgage finance for consumers/tangata whai ora (including those on benefits) to make home ownership available.

Needs of those with drug and alcohol addictions: It was noted that people with alcohol and drug addictions had specific needs because of their environments, and therefore required specific focus groups to identify their needs. Participants agreed to supply the names of some people with expertise in the drug and alcohol field.

Equity: This was also covered during the day as a justifying principle. Participants noted that consumers/tangata whai ora did not just require the minimum – "We need to be compensated for our bad luck."

Stigma and discrimination: A basic agreed principle was that everyone in the community must take responsibility for putting into place the mechanisms to ensure people who experience mental illness do not encounter stigma. This is especially important in supported accommodation (residential rehabilitation) situations. "There needs to be education out there for people about stigma and discrimination of consumers/tangata whai ora." Participants were also cautious to ensure that privacy of individuals was protected. "Stigma is everyone's responsibility."

Prisons: This was also covered earlier. It was again noted that it is important to remember the needs of those leaving, and in, prison. The lack of clear discharge planning for consumers/tangata whai ora being released from forensic institutions was a matter of concern to the group members.

Closing

At the end of the long day the researchers felt that they had been part of a privileged experience. The participants had spoken honestly and openly about their suspicions, anxieties and concerns and had offered their expertise to the project. The lengthy debates about the appropriateness or otherwise of key terms had provided a forum for the "real stories" about people's lives and the frustrations and obstacles that are faced on a daily basis by many consumers/tangata whai ora were brought to the fore.

The offers of ongoing support for the project gave the researchers some confidence that their approach and methodology was likely to gain a positive response. The expert knowledge of the participants gave an insight into how consumers/tangata whai ora were often forced to live their lives through the circumstances of poverty, poor housing and stigma and discrimination.

The participants were also able to provide links back into local communities and so facilitate the setting up and running of group interviews in the later stage of the project.

The workshop, therefore, met its two principal aims: clarifying definitions and establishing networks. For the researchers, the workshop also laid a basis for kanohi ki te kanohi (face to face) relationships with consumers/tangata whai ora and mental health service providers that was to be a great asset in the overall project.

The two facilitators closed the day in the late afternoon – in time for the participants who had come long distances to catch their return flights to Kaikohe and Dunedin. The participants were warmly thanked for their commitment and engagement. The kaumatua closed the day with karakia.

What followed

The researchers returned to work the following day with screeds of handwritten notes to collate and transcribe as well as with a pressing agenda to begin work on the national survey of providers, to set up the group interviews around the country and to complete the review of New Zealand and international literature. Resourcing issues meant that all of these aspects of the project were progressed simultaneously in the months that followed.

The draft write-up of the one-day consultation was eventually sent out to the participants in late April 2001. The material in that draft document has been changed very little in this present form.

The participants in the workshop were able to provide the links into the local communities where the group interviews subsequently took place. In several instances, participants the one-day workshop acted as facilitators for the interviews. The researchers were quite clear in their own minds that the workshop played a significant part in the overall project over and beyond being a first opportunity to listen to the expert voices of consumers/tangata whai ora.

Appendix 1: Methodology

Identifying participants

The development of a matrix of consumers/tangata whai ora constituencies used in the selection of workshop participants.

There were four key concerns in terms of representation at the workshop:

- geographical representation from Māori and Pacific people nationally (taking into consideration population-spread, e.g. 70 per cent of Pacific people reside in Auckland and 15 per cent in Wellington);
- geographical representation of non-Māori/non Pacific consumers.
- national representation from those involved in alcohol and drug) related mental health issues; and
- representation of rural and small town communities.

These four elements were plotted in a matrix diagram and the names that were identified by key informants were then checked into the matrix. This produced the following ethnic/geographical representation with a few consumers/tangata whai ora with A&D awareness and experience included overall:

- Tangata whai ora and Māori provider representation: Gisborne/East Coast (2), Auckland (2), Northland (1), Nelson (1), Christchurch (1) and Wellington (1)
- Pacific people's representation: Auckland (2), Christchurch (1) and Wellington (2)
- Non-Māori/non-Pacific consumer and provider representation: Christchurch (1), Dunedin (1), Southland (1), Hamilton (1), Wellington (2), Auckland (2), New Plymouth (1), Napier (1), Taupo (1).

Contacting consumers/tangata whai ora

Key informants, either service providers or consumers/tangata whai ora known to the researchers, gained consent from prospective participants prior to forwarding their names and contact details to the researchers. The researchers then telephoned potential participants.

The nature and purpose of the workshop was explained in the phone call and participants invited to attend. A letter, designed to complement telephone contact, was also sent out to potential participants. The potential participants therefore had two telephone contacts, either from the researchers directly or from the group facilitators, and the invitation letter. The wording of documents to be sent out to consumers/tangata whai ora was pre-tested with facilitators and consumers/tangata whai ora, advisory groups and consultancy groups.

The initial telephone call establishing contact with respondents secured initial consent to participating in the discussion, but they would be free to withdraw consent and leave at any time. The initial phone call also to include a request for consent to participants' names being made available to other participants, and assurance that no names or other personally identifying information would be included in the workshop notes or research report. A transcript of the notes taken by MSP staff and the summary of the transcript to be forwarded to the participants for comment and

verification. All original notes taken by MSP staff at the workshop to be kept in a secure place, to be seen only by MSP staff involved in compiling the notes and summary of the workshop, and to be destroyed by shredding at the end of the project.

Workshop facilitators

The workshop was facilitated by two mental health consumers who are known to have the confidence of consumers/tangata whai ora groups, through their previous activities in similar settings.

The facilitators established ground rules for the day (including confirmation of consent) at the beginning of the workshop, and confidentiality was assured as part of this process

The workshop facilitators were both Pākehā but a Māori kaumātua from Healthlink South and two Pacific mātua were present at the invitation of the workshop participants and co-ordinators. One of the researchers for the project was also Māori. Issues of protocol and iwi representation were discussed at length with Māori advisors in MSD and in the mental health community.

Size of the group

The workshop size was agreed to in a series of discussions with consumers/tangata whai ora representatives and workshop facilitators. The workshop was understood to be an exploratory discussion amongst people who had some clear views about housing issues for consumers/tangata whai ora and were willing and able to articulate these views. The purpose of the workshop was to identify the kinds of questions that need to be explored in some kind of national survey and in more detail in locally based, small-group interviews.

It was agreed that the workshop would break out into Pacific, Māori and Other groups for part of the discussion time. This was agreed to by the consumers/tangata whai ora who were consulted about the format for the day.

Format for the day

The format for the day was developed by the facilitators in consultation with the research team. Two forms of the agenda were then developed. The first provided a more detailed guideline for the facilitators and researchers, while the second was given to the participants in their handouts and displayed at the venue.

The agenda included a large number of breaks (every half hour) to accommodate the needs of the participants and to ensure that people stayed in for the sessions rather than drifting outside for less formal discussion. Some of these breaks were not taken when they fell in the middle of very focused discussions but there were always invitations for people to get a drink or move around.

The presence of kaumātua facilitated elements of taha Māori protocol to be incorporated in the day – in particular, attention was given to opening karakia, mihimihi, blessing of food and the closure for the day.

Proposed Agenda [detail for facilitators]

Note: Cold water, tea and coffee facilities to be available throughout the day

9.30: *Welcome* (MOSP and facilitators), Karakia, (Kaumatua), Te Mihi

Housekeeping + Blank paper to put some issues on hold for the afternoon as they arise during the morning.

Warm up (facilitator). How participants feel being in workshops – discuss with those nearby then further away.

10.30 Cup of tea

Research background (MOSP) The story so far, including: ministerial directive, elements of research process, including literature review, workshop, questionnaire (to HHSs, NGOs, consumers) with Maori, Pacific Nations, Older People focuses.

Time for questions

11.00 *Break* followed by

Warm up: (facilitator) Participants position themselves on part of NZ. Some describe the place, then move to a part of NZ where they would like to live – why?

Session 1: - Terminology – To reach common understanding. Outline how the current terminology has been arrived at. (Terms are on large pieces of paper already on the wall.) In large group (MOSP – scribes)

11.30 *Break* leading into ***Session 2*** - Building on Session 1

Describe the Questionnaire, who it is going to and why. What is important for MOSP to ask? Important not to miss the point/s! Copies of draft Questionnaire around the room for written comments on layout, colour, font, user-friendly, its size etc. Accommodation issues with particular impact on those with mental illness. (Participants consulted as to the best way of work-shopping this. Our option is: In 4 groups - separate foci - Maori, Pacific Nations, Older people, Other. Participants can choose a group and then move once later.) (MOSP – scribes)

12.45 *lunch –Blessing of food (Kaumatua/Matua)*

1.30 Afternoon sessions begin Re-cap from morning's work. Walk around written sheets. (MOSP scribes available to answer any questions on what is written)

1.45 ***Warm up*** (facilitator). Where do participants live? House, flat, room. Who with? Etc. Discuss with those nearby, some to share with larger group.

Session 3 Consumer Research What are the issues for participants? Follow up on any morning's issues put on hold. In large group (MOSP – scribes)

Break / Session 3 continues

3.00 ***Closure***

Overview of outcomes, final recap. Any unfinished business or unanswered questions? Debate-Where to from here? More participation? How? Who? Reference group? Feedback on the day. Informal evaluation in the large group. What worked? Didn't? Best/worst parts? Thoughts/Suggestions? (facilitator)

3.30 Closing Karakia (Kaumatua/Matua) Farewells and thanks.

The agenda, as presented to participants

Workshop Agenda

Tea, coffee and water will be available prior to the start of workshop from 9am for those participants on earlier flights, as well as throughout the day

9.30am	**Welcome and introductions / Mihimihi**
10.30am	**Morning tea / Kapu tī**
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10.45am	**Session 1 / Wāhanga tuatahi**
	"The research story so far" (MSP)
11.35am	**Break / Wā whakatā**
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11.45am	**Session 2 / Wāhanga tuarua**
	"Definitions of terminology"
12.35pm	**Lunch / Kai**
- - - - - -	- - - - - -
1.20pm	**Session 3 / Wāhanga tuatoru**
	"Accommodation issues"
2.10pm	**Break / Wā whakatā**
- - - - - -	- - - - - -
2.20pm	**Re-cap of day's work**
2.35pm	**"Consumer Research"**
3.10pm	**Wrap Up / Ka mutu**
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3.30pm	**Afternoon tea / Kapu tī**

Appendix 2: Definitions

The definitions listed below were agreed to during the workshop and were confirmed in e-mail follow-up with the participants. It is important to note that these definitions were not carried through into all the other aspects of the research although the original intention was that they would be used verbatim throughout. Differences were notable in three areas:

1. **Supported accommodation**:

Problems arose when the survey (see Report 5 this series) was piloted and it became obvious that mental health service providers viewed 'supported accommodation' in quite a different way from the consumers/tangata whai ora at the workshop. Most providers understood supported accommodation to refer to residential rehabilitation only, whereas consumers/tangata whai ora tended to view the concept more broadly.

2. Sustainable housing:

The development of the 'sustainability framework' in the course of this research required stepping back from the definition agreed to at the workshop at accepting a more broadly conceived definition of sustainability where:

- *sustainability refers to consumers'/ tangata whai ora capacity to sustain independent living in the long term. Sustainability depends on the existence of an array of accessible material, service and social resources and a well-developed and monitored regulatory environment. These various supports need to be well configured to allow consumers/tangata whai ora not only to manage independently on a daily/weekly basis, but also to retain their housing arrangements during episodes of acute care, respite care or hospitalisation* (See Report 1 this series, p 3).

3. Suitability:

Definitions for 'suitable housing' and 'accommodation related difficulties' were not explicitly covered in the discussions but were discussed in follow-up emails. In addition to these definitions, it was agreed that there needed to be definitions for 'support services', 'homelessness' and 'transience'.

It was suggested that any definition of 'support services' recognised tohunga and kaumatua as having equivalent skills to psychiatrists. Discussion followed regarding the need to pay them accordingly, whilst not "pricing the skills" of kaumatua in particular. It was also noted that there needs to be adequate training for Māori workers.

It was also suggested that a person described as homeless or transient may in fact be someone who chooses to move from whanau to whanau.

Definitions from the workshop

Accommodation related difficulties is a phrase used in this research to refer to the whole range of housing and service access issues that people who experience mental illness face. It refers to more than the physical availability of a house or the material state of the house. Accommodation related difficulties exist across the whole range of housing options (including residential rehabilitation).

Adequate housing refers to the physical condition of a dwelling- that is housing that is of good quality; does not cause discomfort because of a poor state of repair, dampness, dilapidation, inadequate sunlight, and/or pest infestations; is not overcrowded; does not have excessive noise; and has secure tenure. Adequate housing also refers to housing that contributes to mental health recovery and maintenance of wellbeing through the provision of privacy and choice, and being suitably located to support and/or family/whanau. Inadequate housing includes homelessness.

Affordable housing refers to housing for people who experience mental illness that takes a proportion of income while leaving enough money for other basic necessities and medical costs.

Home-based support (supported accommodation) is an ambiguous term. For the purposes of this research, it refers to any accommodation that is supported by clinical and social services and thus includes privately owned homes, rental properties, groups of units or apartments designated hostels and boarding houses. However, support services are separate from the actual dwelling and is thus distinct from residential rehabilitation.

Independent housing (living independently in the community) refers to people who experience mental illness living in accommodation that is not residential/supported accommodation. A person who experiences mental illness living independently may still be in receipt of clinical and social services on a regular basis and may receive financial support for their accommodation.

People who experience mental illness refers to consumers/tangata whai ora, clients, customers and patients of mental health services who experience mental illness.

Residential rehabilitation (supported accommodation) refers to the Residential Support services currently funded by the Health Funding Authority (HFA). These services provide accommodation and support and are funded through levels one through to four. A level one residential service is funded for people who experience mental illness, who are assessed to have lower support needs associated with the effects of their mental illness, whilst level four services are for those assessed as having higher support needs. Most of these services are provided in the community.

Suitable housing refers to both the physical condition of a dwelling but also its appropriateness for people who experience mental illness. Thus, housing that is physically adequate and contributes to the mental health recovery requirements of a person is suitable

Sustainable housing refers to housing that allows people who experience mental illness to live within their means, to maintain their independent housing options including during episodes of acute care or hospitalisation and to have security of tenure. People who experience mental illness may need varying degrees of support to sustain housing. Some de-institutionalised people who experience mental illness may need long term help with household affairs.

Tangata whai ora refers to Māori people who experience mental illness who access mental health services. It is intended that when referring to tangata whai ora, that whanau are included. The term ‘Tangata whai ora’- frequently written as ‘Tangata whai ora’- means ‘a person seeking health’ (Durie 1994, Whaiora: Māori health development). Advice from Te Taura Whiri i te Reo Māori suggests that whai ora means ‘in search of well being’, whereas whaiora means ‘who has well being’. ‘The former is more appropriate in this research.