

# **Te Āiotanga**

**Report of the Confidential Forum for  
Former In-Patients of Psychiatric Hospitals**

**June 2007**

## **Confidential Forum for Former In-Patients of Psychiatric Hospitals**

### **Wānanga (Te Āiotanga) Noho Tapu mō ngā Tūroro i noho ki ngā Hōhipera Mate Hinengaro**

#### **Panel members:**

Judge Anand Satyanand, *Chair (December 2004 to April 2006)*

Judge Patrick Mahony, *Chair (from April 2006)*

Jan Dowland *(from April 2005)*

Anne Helm *(from April 2005)*

Katharine Greig *(from March 2006)*

#### **Secretariat:**

Katharine Greig, *Executive Officer*

Sandra Forsyth, *Executive Assistant*

Adrienne Mitchell, *Forum Support Facilitator*

### **Te Āiotanga: Report of the Confidential Forum for Former In-Patients of Psychiatric Hospitals**

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## ACKNOWLEDGMENT

**This report acknowledges the voices of people who had experiences in psychiatric hospitals that deeply affected their lives. The Confidential Forum was set up in the belief that the experience of being heard would be helpful for participants. Our hope is that the Forum has assisted those who participated in their quest to make peace with the past and to move towards an internal place of resolution and calmness ...**

**that place called *Te Āiotanga*.<sup>1</sup>**

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<sup>1</sup> The Māori name for the Forum is Wānanga (Te Āiotanga) Noho Tapu mō ngā Tūroro i noho ki ngā Hōhipera Mate Hinengaro. Te Āiotanga means tranquillity, calm, peace in English.

## PREFACE

The Confidential Forum was a new initiative for New Zealand, set up by the Government to provide an opportunity for former in-patients of psychiatric hospitals, their families, and staff members to formally speak about their experiences of psychiatric institutions in the period before November 1992.

The Forum's hearings were held in private and were confidential. The value of the process lay in the benefits of talking to a body officially set up to listen.

The Forum was not an attempt to sidestep the formal legal process for pursuing a civil remedy such as compensation through the court system, which remains an option for people. Nor was it sitting as a Commission of Inquiry with power to test and evaluate evidence and make findings, and it was not within the Forum's mandate to make recommendations.

Participants came knowing that the purpose of the Forum was for them to speak in confidence to a Government-appointed panel. They were aware the Forum was not dealing with issues of compensation or liability. They came because they wished to relate their experiences and they wished to be taken seriously.

Participants spoke openly and with dignity and sincerity about their experiences of psychiatric hospitals, including the conditions, treatment, and the impact their experience has had on their lives.

This report summarises the general themes emerging from individual experiences recounted to the Forum. It does not refer to individual stories, which remain confidential. Inevitably something is lost where summaries are relied on without the reinforcement of illustrative individual experiences. However, there is a potency about common themes emerging from the experiences of unconnected persons from different places at different times.

*Judge Patrick Mahony, Chair*

*Jan Dowland*

*Anne Helm*

*Katharine Greig*

June 2007







## EXECUTIVE SUMMARY

The Confidential Forum for Former In-Patients of Psychiatric Hospitals (the Forum) was announced by the Government in 2004 and established in 2005. Its main purpose was to provide an accessible, confidential environment in which former in-patients, family members of in-patients, or former staff members could describe their experiences of psychiatric institutions in New Zealand in the years before November 1992 (at which date the current mental health legislation came into effect). People coming forward to the Forum would be heard by a panel of (usually) three members who had knowledge of the mental health system and who were receptive, respectful listeners. The terms of reference also said that the panel would assist the former psychiatric in-patients by providing information and access to relevant services and agencies, including provision for access to counselling.

The Forum was a new reconciliation initiative for New Zealand. It offered a constructive approach to dealing with historic matters that had deeply affected people at the time and that still affect present lives.

### *Processes of registration and meetings*

Meetings between the panel and participants commenced in July 2005. At that stage 296 people had registered an interest in attending a meeting with the Forum. When final registrations were accepted in July 2006, 554 people had registered.

The Forum's processes were designed to help people participate and to ensure confidentiality and respect for participants. Hearings were held throughout New Zealand between July 2005 and April 2007. There were 154 days of meetings in 22 different locations. By the completion of the hearing process 493 people had attended a meeting with the Forum. Nearly half of the participants were accompanied by a support person (or two support people, as allowed under the terms of reference).

The length of meetings varied according to each participant's needs. Most lasted about 90 minutes. A facilitator played an essential role in ensuring that each participant was well prepared for meeting the panel. The facilitator, an experienced counsellor, arranged appointments, provided information, telephoned each participant the day before his or her meeting with the panel, and talked to each participant immediately after the meeting and again by telephone the following day.

### *Participant groups*

There were three major groups of participants (with some participants in more than one group): former in-patients (82 percent), family members of former in-patients (17 percent), and former staff members (6 percent). The earliest experiences described at the Forum dated from the 1940s. The majority of participants, however, referred to experiences of the 1970s, 1980s, and 1990s.

### *Themes emerging from narratives at the Forum*

Former patients approached the Forum for various reasons including wanting to make sense of their experiences, wanting Government to know of their experiences and the effects upon them, and hoping that others might benefit from the Forum. For many, it was the first opportunity for them to fully tell their stories.

The individual narratives revealed certain themes in common, mostly negative in nature, concerning institutional culture and treatment regimes. Examples include experiences of fear and distress at admission; unsanitary, overcrowded conditions; unanswered questions arising from a lack of communication between health professionals and patients and family members of patients; occurrences of physical violence and sexual misconduct; inadequate complaints mechanisms; fear and humiliation when held in seclusion; extreme distress caused by the use of electroconvulsive therapy (ECT) and some other treatments no longer in use such as deep sleep therapy; doubts over use of particular medications and treatment regimes, and the possible lasting effects; and lack of support on discharge from institutions.

Among the former patients, certain groups expressed concerns that were specific to their situation. For example, those admitted to psychiatric institutions as children or adolescents often described a loss of youth and innocence. Many women with children, particularly those with babies or young children at the time of their admission, spoke of the loss of connection with or custody of their children and the long-lasting effects on the family.

On the positive side, many participants told the Forum of their recognition and lasting appreciation of instances of caring they received from staff members or other patients.

Family members who attended the Forum did so sometimes to speak of what the experience of having a relative in hospital was like for family members or out of respect for the relative who had been a former patient, or sometimes to make suggestions for change. A theme common to this group was the lack of involvement of families in the care of their relatives, and the lack of information and support for the family, particularly when the patient was discharged from the institution. Again, the positive experiences recounted at the Forum often involved instances of good communication between staff and the patient and family, and where the patient was treated with respect.

Staff members approached the Forum for reasons such as providing context and balance to – or to substantiate – what they believed would be described by former patients and their families. Staff members often described the pressures and difficult conditions of their work in psychiatric institutions. As with former patients, some staff recounted difficulties of making effective complaints about conditions or events within the institutions at the time.

### *Follow-up actions*

The Forum offered assistance to each participant where possible. One of the most appreciated forms of assistance was arranging for referrals to professional counsellors. Participants eligible for counselling could receive up to ten sessions paid for by the Government. These counselling services were arranged for 136 participants.

The Forum provided individually tailored information about local and national support services and networks that might be of assistance to participants. A Freephone telephone service also allowed participants to contact the Forum in the weeks after their meeting.

The Forum also provided linkages and information about other government agencies that could be of assistance, such as the Health and Disability Commissioner, Accident Compensation Corporation, and New Zealand Police.

Other forms of assistance offered to participants involved information on patient rights and pathways in the medical system. Examples include preparation of Advance Directives concerning future treatment; access to clinical records; and personalised assistance at a very specific level, such as how to obtain a second opinion or information about a treatment that had been undergone. The Forum also provided information on how to seek legal advice.

#### *Usefulness of the Forum*

Assessment by panel members of the Forum's usefulness is qualitative and based on information offered by participants or gathered by those involved in the process. The panel concluded that the formalised listening process of the Forum, as well as the personalised follow-up actions taken, provided a useful vehicle for participants in their journey of coming to terms with past experiences. Many of those who attended had never before had an opportunity to recount their experiences.

Many participants also expressed appreciation of the follow-up actions tailored to the needs of individuals and said that the assistance had been helpful to them.

Many said that they wanted the Government to know what had happened to them and to others. They hoped that the cumulative effect of the confidential narratives told at Forum might effect changes in mental health services in New Zealand. Many expressed a hope for a public acknowledgment by the Government that their experiences in psychiatric institutions had been humiliating and demeaning and had often taken a lifelong toll.



## INTRODUCTION

On 7 December 2004, the Attorney-General, Hon Margaret Wilson, announced that the Government was to establish a body called the Confidential Forum for Former In-Patients of Psychiatric Hospitals (the Forum).

The Forum was a new reconciliation initiative of a type not previously undertaken in New Zealand. It was set up to provide people who were patients in psychiatric hospitals prior to 1 November 1992 (see box overleaf), their families, and former staff members of psychiatric hospitals the opportunity to talk about their experiences of psychiatric institutions – positive and negative – in a confidential, supportive environment to a panel appointed by the Government to listen.

The establishment of the Forum was a recognition of the voice of former psychiatric patients. Their own stories, their experiences, and their memories were being given official weight in a way that had not happened before.

The Forum was explicitly designed to be non-adversarial and to concentrate on the real issues affecting those eligible to attend.<sup>2</sup> It was set up to provide participants with an opportunity to reflect on the past and look to the future. It was not designed to determine the truth of participants' experiences or stories, or reach conclusions about what might or might not have happened; or to consider compensation. Rather, it was a process focused on the individual and designed to allow those who had experiences of the historic psychiatric system to talk about their experiences in an affirming environment that accorded participants respect and formal acknowledgment. Further aims of the Forum were to assist participants to make sense of their experience; where relevant to assist participants to make linkages with appropriate current support and complaint resolution services and to access (and pay for) counselling if required.

On 2 March 2005 the Attorney-General, Hon Dr Michael Cullen, released the final terms of reference for the Forum. The terms of reference are set out in full as Appendix 1.

### Catalyst for establishment of the Forum

In 2001 and 2002 some former patients of Lake Alice Hospital<sup>3</sup> received a compensation payment from the Crown, and a personal written apology signed by the Prime Minister, Rt Hon Helen Clark, and the Minister of Health, Hon Annette King, for treatment received while patients in the Child and Adolescent Unit at Lake Alice Hospital between 1972 and 1978. When the settlement was announced in 2001 the two Ministers stated, "Whatever the legal rights and wrongs of the matter, and whatever the state of medical practice at the

<sup>2</sup> Attorney-General, Hon Margaret Wilson, transcript of Radio New Zealand interview on "Nine to Noon", 7 December 2004.

<sup>3</sup> Lake Alice Hospital was a psychiatric institution near Marton, parts of which closed in the mid-1990s and all of which was closed by 2000.

### **Legislative change for users of mental health services**

The 1 November 1992 cut-off date for participation in the Forum was the date the current mental health legislation (the Mental Health (Compulsory Assessment and Treatment) Act 1992) came into force. This Act expressly provides for patients' rights and provides avenues for access to complaints mechanisms such as referral of complaints to district inspectors who have powers of investigation and who can make recommendations to the Director of Area Mental Health Services. If remaining dissatisfied with the outcome, a complainant also has the right to have the complaint referred to the Review Tribunal for further investigation. In 1996 further protections for users of health services (including mental health services) were introduced with the establishment of the Health and Disability Commissioner and the Code of Health and Disability Services Consumers' Rights. The Health and Disability Commissioner is an independent statutory watchdog, and the code of rights sets out 10 rights to which all consumers of health services are entitled when receiving health services. These rights include the right to be treated with respect, to freedom from discrimination, coercion, harassment and exploitation, to dignity and independence, to services of an appropriate standard, to effective communication, to be fully informed, to make an informed choice and give informed consent, to support, and to complain. (Note: in some situations, provisions of the mental health Act authorising compulsory treatment override the rights in the code, which is subject to other enactments.)

time, our government considers that what occurred to these young people was unacceptable by any standard, in particular the inappropriate use of electric shocks and injections.”<sup>4</sup>

By 2004 it had become apparent that many other former patients of psychiatric hospitals had grievances about their treatment and care while in hospital. A number of former patients had commenced litigation against the Crown alleging mistreatment and abuse in psychiatric hospitals throughout New Zealand in the 1960s and 1970s. These claims were under investigation by the Crown Law Office. There were also stories of mistreatment and abuse in psychiatric institutions reported in the media, particularly stories about practices at Porirua Hospital.

Against this backdrop there were calls by former psychiatric patients, mental health consumer leaders, and the lawyers representing the litigants for a process of redress for former patients of psychiatric institutions. Some wished for a public inquiry, some for a process similar to that which had occurred for the former patients of the Child and Adolescent Unit at Lake Alice Hospital.

Those calling for a process of redress noted that for many former patients litigation was not a suitable avenue. They pointed out that there were people who were not able to litigate, or not willing to do so for reasons such as disclosure of identity in open court; there were people for whom the strain of cross-examination would be undesirable; and others who might not be able to establish cases to the standard required in civil litigation.

The response from the Government was to establish the Forum. In announcing the Forum the Attorney-General noted that the Government had considered, but decided against, an inquiry process that awarded patients compensation; anybody who wished to establish liability or claim compensation would be required to follow the court process. The Government's view was that the Courts were the best place to undertake the required

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4 Prime Minister, Rt Hon Helen Clark, “Settlement for former Lake Alice patients”, news release, 7 October 2001, available on [www.beehive.govt.nz](http://www.beehive.govt.nz).

scrutiny of individual claims because there were complex legal issues and also for reasons of natural justice as some alleged abusers denied the allegations.<sup>5</sup>

### **Appointment of panel members**

The terms of reference provided for one or more panels of appropriately qualified individuals to be appointed by the Government to meet (normally in a panel of three) with participants and to hear their stories.

In December 2004 the first chair of the panel, Judge Anand Satyanand, District Court Judge and former Ombudsman, was appointed.

In April 2005 two panel members were appointed: Jan Dowland, former Chair of the Mental Health Commission and previously Chief Executive of IHC New Zealand Inc; and Anne Helm, Consumer Advisor to the Otago District Health Board and Consumer Advisor to the Mental Health Commission and the Ministry of Health.

In March 2006 Katharine Greig was appointed as a further, alternate panel member. Katharine Greig had been Assistant Health and Disability Commissioner and the Commissioner's Chief Legal Advisor and was the Forum's Executive Officer.

On 3 April 2006, it was announced that the Queen had approved the appointment of Judge Satyanand as New Zealand's next Governor-General. As a result of his appointment, Judge Satyanand stepped down from his role as chair of the Forum and Judge Patrick Mahony was appointed as the Forum's new chairperson from 3 April 2006. Judge Mahony was former Principal Family Court Judge (retiring May 2004) and is a member of the New Zealand Parole Board and an Acting District Court Judge.

### **Forum secretariat**

Administrative support for the Forum was provided through the Department of Internal Affairs. The Forum's secretariat comprised the Executive Officer (Katharine Greig), responsible for managing the Forum, Executive Assistant (Sandra Forsyth), responsible for administration of the Forum, and Forum Support Facilitator (Adrienne Mitchell), responsible for liaison with and support of participants.

### **Reporting**

The terms of reference required the Forum to report quarterly to interested Ministers (especially the Attorney-General and Ministers of Health, Justice, Treasury, and Internal Affairs) and to provide a final report detailing matters traversed in the quarterly reports once the role of the Forum was completed. Quarterly reports were delivered on 6 April 2005, 13 July 2005, 7 October 2005, 21 December 2005, 31 March 2006, 7 July 2006, 29 September 2006, 19 December 2006, and 2 April 2007.

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<sup>5</sup> Attorney-General, Hon Margaret Wilson, "New forum for psychiatric patients", 7 December 2004, available on [www.beehive.govt.nz](http://www.beehive.govt.nz).





## PROCESSES OF THE FORUM

**The Confidential Forum for Former In-Patients of Psychiatric Hospitals was a new development for New Zealand. There was no precedent to follow in designing the Forum's processes, other than the general guidance provided in the Terms of Reference. The processes that were developed and utilised are therefore summarised in this section.**

New Zealand is a country that has experienced and encouraged a variety of forms of dispute resolution. Within the court system there is provision for alternatives to the traditional adversarial system for resolving disputes (with its requirements for proof and cross-examination) – for example, reference to mediation in civil matters and provision for criminal matters to be resolved by diversion. Restorative justice is part of the specialist youth jurisdiction and restorative justice provisions are enshrined in the Sentencing Act 2002 for adult offenders.<sup>6</sup> In the Family Courts many matters are resolved at mediation and at family group conferences. In the Waitangi Tribunal explaining, listening, and acknowledging the past is part of the process of settling historical grievances.

The Forum required a different process again. Its focus was not on trying to resolve a dispute between parties. Rather, its focus was on the individual participants and providing them with the opportunity to speak about their experiences to a formal panel and, where relevant, to assist them to make linkages with current support services and, to the extent possible, to make peace with the past.

In overseas jurisdictions, the opportunity to relate experiences as part of formal reconciliation processes has been adopted in a number of situations to help resolve long-term grievances. For example, truth commissions have been used to address human rights abuse in civil conflicts in several countries, perhaps most notably in South Africa in the South African Truth and Reconciliation Commission formed in 1995 after the collapse of the apartheid system.

Truth commissions have the following characteristics:<sup>7</sup>

- They are temporary bodies set up to focus on events that have occurred in the past.
- They are officially sanctioned, or empowered by the state.
- They concern a pattern of abuse over a set period of time rather than a specific event.

<sup>6</sup> Restorative justice is concerned with healing victim's wounds, restoring offenders to law-abiding lives, and repairing harm done to interpersonal relationships and the community. It seeks to involve all stakeholders and provide opportunities for those most affected by the crime to be directly involved in the process of responding to the harm caused.

<sup>7</sup> Information source: Brahm, Eric. "Truth Commissions". *Beyond Intractability*. Eds Guy Burgess and Heidi Burgess. June 2004. Conflict Research Consortium, University of Colorado, Boulder, USA. <[http://www.beyondintractability.org/essay/truth\\_commissions/](http://www.beyondintractability.org/essay/truth_commissions/)> (accessed 8 June 2007).

One of the main goals for truth commissions is to offer victims a chance to tell their stories and be heard without interruption or scepticism.

Narrative processes have also been used as part of formal inquiries into institutional child abuse.<sup>8</sup> Although each such inquiry used narrative processes as a means for victims to recount their abuse, there are marked differences in the nature of these inquiries and in remedies for victims. The nearest equivalent to the Confidential Forum appears to be Ireland's Commission to Inquire into Child Abuse, which provides an opportunity for a confidential disclosure process for victims of child abuse in a therapeutic context where individuals have an opportunity to recount their experiences of child abuse.

### **Planning for operation of the Forum**

The characteristics of truth commissions as outlined above, as well as aspects of the Commission to Inquire into Child Abuse, provided helpful background for the Forum. However, the Forum needed to develop its own processes that were appropriate for its mandate.

As part of establishing its processes the Forum consulted with mental health consumer groups. Its processes were developed as a result of forming views about accessibility, individual confidentiality, and respect. Processes were designed to be as user-friendly and as flexible as possible so as to be able to take into account people's emotional, physical, cultural, spiritual, and financial considerations.

### **Details of Forum processes**

Special attention was paid to publicising the existence of the Forum; developing processes for the conduct of meetings and for the support of participants; and establishing protocols with appropriate agencies for follow-up referrals.

#### **Publicity**

The Forum issued public notices in the metropolitan daily newspapers and also in community newspapers throughout New Zealand in the weeks from 23 April 2005 to 14 June 2005 and in several ethnic-specific publications in January 2006. Information and flyers in English and Māori issuing an invitation to the Forum and giving contact details were sent to a wide variety of sources including public libraries, Work and Income offices, Primary Health Organisations, District Health Boards, community organisations, mental health consumer and provider networks, and general practitioner and nursing networks. (The text of the invitation is presented in Appendix 2.) Kōrero about the Forum was conducted on a number of iwi radio stations and at several marae. A Confidential Forum website (hosted by the Department of Internal Affairs) was set up and updated regularly ([www.confidentialforum.govt.nz](http://www.confidentialforum.govt.nz)).

People who wished to know more about the Forum and/or to register to attend a meeting with the Forum were invited to make contact via a Freephone 0800 telephone number or to contact the Forum by email or letter.

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<sup>8</sup> For example, Commission to Inquire into Child Abuse (Ireland, 2000 – ongoing); Law Commission of Canada. *Restoring Dignity: Responding to Child Abuse in Canadian Institutions*, Minister of Public Works and Government Services, Ottawa, 2000; *Report of the Commission of Inquiry into Abuse of Children in Queensland* [Forde Report], Queensland Government, Brisbane, 1999.

## **Response to publicity**

Some 296 people had registered an interest in attending a meeting with the Forum by the time meetings commenced in July 2005. The opportunity to register remained open until 31 July 2006 with the final registration date set on the advice of the Secretary for Internal Affairs. By 31 July 2006, 554 people had registered an interest in speaking to the Forum.

The final close-off date for registrations was widely disseminated through stories in community newspapers as well as the networks and organisations to which information and publicity material had been sent previously. After the announcement of the cut-off date there was a 26 percent rise in new registrations in the three-month period before close off of registrations.<sup>9</sup>

## **Contacts and linkages**

Before the meetings with participants began, linkages were made with appropriate organisations and professionals to allow for follow-through from the Forum meetings if required. In particular, contact was made with New Zealand Police (which appointed a senior member of the police force as a contact person for the Forum), Accident Compensation Corporation, Health and Disability Commissioner, Health and Disability Consumer Advocacy Service, Mental Health Commission, Ministry of Health, Privacy Commissioner, and District Health Boards.

A protocol for the provision of counselling was developed after consultation with the Ministry of Health (see Appendix 3), and a contract was established with Relationship Services to provide counselling services.<sup>10</sup>

## **Support for people contacting the Forum**

Most people who contacted the Forum with a view to participating knew that the process would bring up old wounds and associated feelings of sorrow and disappointment. Some people found that others tried to dissuade them from attending because of concern that talking of a painful past might be traumatic and might not be helpful.

The Forum was very aware of these issues and from the outset recognised there was need for support and a briefing process for participants in the lead-up to Forum meetings, as well as a briefing and debriefing process associated with actual Forum meetings. To achieve this, the Forum engaged the services of an experienced counsellor to work with participants. This person (called the Forum Support Facilitator) answered all the 0800 telephone calls, providing initial information for people interested in the Forum and becoming a continuing point of contact for those who wished to participate. This continuity ensured that consistent information was provided to participants and that people contacting the Forum did not have to repeat themselves or speak to somebody new. An important part of the Forum Support Facilitator's role was to explain how the Forum worked and what to expect, to answer questions, allay concerns, and ensure that participants had sufficient information about the hearing process to feel comfortable about participating.

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<sup>9</sup> Since registrations closed, the Forum has received approximately 50 calls from people who would have liked to participate. Many expressed disappointment, frustration, or anger at having missed out.

<sup>10</sup> Relationship Services Whakawhanaungatanga ([www.relate.org.nz](http://www.relate.org.nz)) is a non-government, not-for-profit agency working in about 70 communities throughout New Zealand. It provides professional counselling services.

## **Appointments**

The Forum Support Facilitator arranged mutually convenient individual meeting times by telephone with each participant. Once an appointment time was arranged, participants were sent a letter confirming the time and venue and providing written information about what to expect at the meeting. The basic text of the letter is presented in Appendix 4.

The day before their meeting, participants were telephoned by the Forum Support Facilitator to confirm the appointment time and venue and to discuss any queries raised by participants.

## **Meetings process**

The Forum developed a set of rules for the conduct of Forum hearings (attached as Appendix 5).

Before meeting with the panel participants were welcomed by the Forum Support Facilitator in a waiting room in which refreshments were available. Last-minute concerns or questions were addressed, and the meeting with the panel members was commenced when the participant was ready to do so.

Forum meetings were held in a reasonably formal setting – with panel members seated across a table from participants (and where relevant, their support people). Where participants wished, the meeting was commenced with a karakia or included prayers in English. After introductions and a welcome were concluded, the chairperson spent time explaining to each participant the purpose of the Forum, and the confidentiality of the meeting. Participants were then encouraged to tell their story in their own words, augmented from time to time by questions from the panel members to distil the experience described and to assist with discussion of what might be of assistance in dealing with the future. Where participants consented, meetings were tape-recorded, with a copy given to participants who wished for this.

The length of meetings with the panel varied – with most lasting up to 90 minutes. Some were much shorter because the participant wished to relate a single issue or experience, others considerably longer. Participants were not hurried, and before the meeting drew to a close, the panel checked with participants that they had said all they wished to say. Support people did not speak unless the participant wished them to do so.

At the conclusion of the meeting the participant (and support people where relevant) met again with the Forum Support Facilitator in a second waiting room.<sup>11</sup> The role of the facilitator at this meeting was to debrief with the participant. This time, at which refreshments were available, provided an opportunity for participants to reflect on their meeting with the panel and to readjust before leaving the meeting venue. Before doing so, participants were given a handout of support services in the local area so that they had information available about a range of people or organisations they could contact if they felt they wished to talk to someone about issues arising from their meeting.

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11 The purpose of having two rooms was to ensure that participants' attendance at meetings was kept confidential, without the possibility of their sitting in a waiting room with other participants; it also meant that participants were not rushed in either waiting room. Having a second room was also symbolic of the participants "moving on" after having spoken to the Forum.

### **Further follow-up**

The Forum Support Facilitator made a follow-up telephone call the day after the meeting to all participants and, with the participant's permission (and on the understanding that the participant was not to be discussed), their support people. The purpose of this telephone call was to thank the participant or support person for attending and to check that he or she was feeling all right after their meeting with the panel. During this telephone call arrangements for any actions discussed with the participant at their meeting were advanced.

### **Quarterly reports**

As noted in the introduction, the Forum's terms of reference required it to provide quarterly reports to the Attorney-General and the Ministers of Health, Justice, Treasury, and Internal Affairs. Such reports were provided every three months during the operation of the Forum and provided the opportunity for the Forum to keep the Ministers apprised of the progress of the Forum. The type of information provided included the numbers of participants registered and met with each quarter; the type of information provided to participants about existing agencies; themes arising from meetings; the panel's impression of how useful the process was to participants; and expenditure against budget.



## HEARINGS OF THE FORUM

**At the heart of the Forum’s operation was the hearing process. Between July 2005 and April 2007 the Forum held hearings at which participants could individually and in confidence recount their experiences of psychiatric institutions in New Zealand before November 1992.**

### *Meeting locations and dates*

Meetings commenced on 11 July 2005 and finished on 12 April 2007. A total of 154 days of meetings were held in 22 locations throughout New Zealand. Meeting location decisions were determined by where registered participants lived, to ensure maximum possible accessibility for all those who wished to participate.

See Appendix 6 for a list of venues and dates.

### *Participant numbers*

By the completion of the hearing process 493 people had attended a meeting with the Forum. Of those participating, 82 percent were former patients, 17 percent family members, and 6 percent staff members. Some participants fell into more than one category – for example as a family member and a staff member, or as a former patient and family member. Overall, 60 percent of those who attended were women and 40 percent men.

### *Support people*

Nearly half (47 percent) of participants were accompanied by a support person or people.<sup>12</sup> Support people included family members, trusted friends, advocates, and key workers. For some it was the first time they had heard the story or parts of the story; others were very familiar with the matters of which the participant spoke. Sometimes, where the support person was a family member, he or she also attended a Forum meeting in their own right to speak of their experiences. Where this occurred, the support person was encouraged to attend the meeting held on their own behalf before supporting their family member.

### *Hospitals referred to at the Forum*

Participants spoke about many of the large psychiatric institutions, now closed – Carrington, Cherry Farm, Claybury House (attached to Kingseat), Kingseat, Lake Alice, Ngawhatu, Oakley, Porirua, Queen Mary, Seacliff, Seaview, Sunnyside, and Tokanui, as well as psychopaedic institutions such as Mangere and Kimberley.<sup>13</sup>

<sup>12</sup> The terms of reference provided for up to two support people (but not legal representation).

<sup>13</sup> The term “psychopaedic” was adopted in the 1920s in New Zealand to distinguish between psychopaedic institutions for the education and training of people with intellectual disabilities and psychiatric institutions.

Psychiatric units in general hospitals and private hospitals that provided psychiatric care were also represented.

A full list of institutions spoken about is attached as Appendix 7.

*Decades mentioned at the Forum*

The earliest experiences spoken of were in the 1940s (fewer than 1 percent of participants). Eight percent of participants spoke about experiences in the 1950s; 28 percent of experiences in the 1960s; 43 percent of experiences in the 1970s; 53 percent of experiences in the 1980s; and 43 percent of experiences in the 1990s.<sup>14</sup> As part of relating their stories a number of participants referred to events occurring after 1992 (the year defining the limit of the Forum's remit). Appendix 8 provides information concerning the different participant groups (former patients, family members, and staff members).

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<sup>14</sup> Many participants spoke of experiences that encompassed more than one decade.



# FORUM PARTICIPANTS: THEIR STORIES

**Participants came forward to the Forum, one by one, to describe their particular experiences. This section of the report summarises certain matters that emerged as commonly noted, though individually experienced, by participants.**

## Former patients

The largest group of people who chose to participate in the Forum were people who had been patients in psychiatric hospitals over the decades from the 1940s to the 1990s.<sup>15</sup> Some former patients had had more than one admission and experience of more than one hospital. Some had spent many months, or years, in hospital and some had had a single, very short, stay.

During much of the period spoken of by participants, placement in psychiatric hospitals was much more frequent than it is today and the reasons for admission much broader. Throughout the country there were large psychiatric institutions such as Kingseat, Tokanui, and Cherry Farm, as well as psychopaedic hospitals and psychiatric units in general hospitals.<sup>16</sup> Over the periods spoken of, treatment methods changed with the introduction of new medications and the large psychiatric institutions began to close as treatment for all but the most acutely ill changed towards being community-based.<sup>17</sup> Some treatment methods described by participants are no longer in use, or not used as widely today, and the standards considered appropriate for some treatment methods have changed over time.

Most former patients gave one or more of the following reasons for coming to the Forum:

- They wished to tell of their own experience in an environment that was receptive and non-critical.
- They wanted people appointed by the Government to hear what had happened to them and the effect it had had on them.
- They wished to add their voice to those of others.
- They wished to honour the stories of people not able to come to the Forum.

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<sup>15</sup> See Appendix 8 for more detail.

<sup>16</sup> For example, in 1960 there were 13 mental hospitals in New Zealand – Auckland, Kingseat, Ravensthorpe, Tokanui, Lake Alice, Levin, Porirua, Nelson, Seaview, Sunnyside, Templeton (a psychopaedic hospital), Seacliff, and Ashburn Hall (a privately owned hospital). (Source: New Zealand Department of Health, *Report on the mental health statistics of New Zealand for the year 1960*.)

<sup>17</sup> See Appendix 7 for approximate dates a number of the large psychiatric institutions closed as well as the average number of residents in psychiatric and intellectual disability hospitals and rates of hospitalisation per 100,000 of population for the years from 1945 to 1990.

- They hoped that by telling their story they could benefit others and help to ensure that experiences such as their did not happen in the future.
- They wished to try to make sense of their experiences.
- They wished to make peace with the past.
- They wanted some recognition of what had happened to them.
- Many said that they hoped to be believed.

In speaking of their experiences participants described what their daily lives were like in hospital, their treatments, what their experiences felt like for them, and the effect on their lives. For many, the memories and impact of their in-patient experiences and treatment are still a living reality. Many spoke of matters that were deeply distressing for them and that have had a profound lifelong impact. Some spoke of matters that they had never before disclosed, and many said that the Forum was the first opportunity they had had to speak so fully of their experiences.

A few of the former patients who came to the Forum had had overall positive experiences as in-patients; and many former patients spoke of people who had made a difference over the time of their hospitalisation by acts of kindness or care, or by listening. But overall, most people spoke of experiences that were bleak.

Former patients throughout New Zealand spoke again and again of similar experiences. Although each person's experience was uniquely theirs, and the Forum has no wish to homogenise individual recollections or to trivialise the matters of which the participants spoke, some themes common to many participants became evident over the course of the meetings.

Experiences that emerged as common across many of the individual narratives by former patients at the Forum related to

- institutional culture
- treatment regimes.

Experiences common to particular groups of participants also emerged.

### **Experiences of institutional culture**

Participants told the Forum of aspects of the culture of the psychiatric institutions that had had a significant effect on their wellbeing. In addition to the hospital routines, the culture of the institutions was expressed in the staff–patient relationships and, indirectly, in patient–patient relationships. Participants' accounts related to hospital admission, physical conditions and hospital routines, treatment regimes, communication, care and compassion, consent, complaints, discharge practices, physical violence, and sexual misconduct.

#### *Admission experiences*

Most participants spoke about the context within which their admission occurred and of a clear pathway of events leading up to their admission. The context often included distressing or stressful matters such as work pressures; school or study pressures; behavioural issues in adolescence, pregnancy, miscarriage, or childbirth; marital difficulties; dysfunctional family situations; physical illnesses or conditions; specific trauma events; or sexual identity issues. In addition some talked of sexual abuse. Some participants said they knew they were very unwell before admission. Others were not sure why they had been admitted and felt they ought not to have been. Some said that what they had needed at the time was a safe place where they could go to have time out.

Many former patients spoke of their fear and distress at the time of being admitted. They spoke of the confusion of going into an unfamiliar situation, often having been taken to hospital in stressful circumstances where things had happened fast. They spoke of feeling unsure of what was happening or feeling a loss of control as others such as family, their doctor, the police, or the court system made decisions about them – often without their input. Some said they had felt pressured to agree to admission to a psychiatric hospital on the basis that if they did not consent they would be committed.

Many described an admission ritual they found distressing – where they were stripped and their own clothes taken from them, where they were bathed with no privacy and observed by staff, were heavily medicated, and put into seclusion (discussed further below) in a locked room with little or no explanation as to what to expect. Many said that the process of admission heightened their distress; in their accounts they used words such as feeling “terrified”, “alone”, “abandoned”, and “confused”.

### *Physical conditions and hospital routines*

Some participants spoke of the hospital to which they were admitted as having pleasant open spaces in which they could walk. Others, particularly those who were patients in the 1950s and 1960s, spoke of having worked in work gangs supervised by staff or long-term patients doing tasks such as gardening, chopping firewood, or scrub cutting. Some found this physical work enjoyable and beneficial. However, former patients who spoke of pleasant aspects of the physical conditions and environment were few. Most who spoke of the physical conditions described over-crowded, unsanitary conditions and often mentioned forbidding buildings. Participants also described hospitals as closed places where most of the time they saw few people other than staff and other patients and where they received few visitors.

Participants spoke of having to sleep in large dormitories with beds very close together and of a highly regimented life with days spent locked in dirty, noisy, smoke-filled dayrooms with few activities available for them and with access to dormitories locked off during the day. Others talked of poor sanitation and the presence of cockroaches and rats. Many gave an account of a lack of privacy and routines being carried out in ways that they found degrading and humiliating. The latter included the absence of doors on toilets and having to use toilets in front of staff; communal showering with patients being lined up naked and hosed down before showering; or baths with cold water already used by others. Participants also spoke of not being allowed to use their own possessions, often being required to wear communal hospital clothing, and of their property disappearing while they were in hospital. Some spoke of being required to undertake housekeeping duties such as making beds, polishing floors, or washing soiled laundry, sometimes equating such duties with punishment.

Participants talked of learning to smoke and/or smoking heavily in hospital, where they were supplied with Government-issued tobacco. Participants spoke of cigarettes being used as currency, of stand-over tactics used by some patients to obtain cigarettes, and of the practice of picking up cigarette butts to roll further cigarettes. Some said that staff used tobacco as a reward for good behaviour. Many recounted having developed a lifelong smoking habit while in hospital.

### *Communication*

A matter commonly spoken of was scant and often poor-quality communication between patients and staff, including doctors. A lack of interaction between patients and staff, as well as a lack of interest by staff, featured in many of the experiences related. Participants described

not being listened to and being given little, if any, information about their diagnosis and reasons for treatments or medications. Many described rarely seeing a doctor or of seeing a series of different doctors. Most had never seen a psychologist. Many described receiving several changes of diagnosis, but not knowing why the labels had changed or what they meant.

Participants often said, “No one ever asked me what was going on for me.” They recounted how, during their hospital stay, no one had made time to listen to them, to talk to them, or to find out about their feelings or the context of their lives. Some participants related how the staff did not know (or acknowledge, if they did know) anything to do with their lives outside hospital (for example participants’ occupations or whether they had children).

Many participants described not being taken seriously or believed, and of having things they said about how they felt or what was happening for them disregarded or reinterpreted by staff. Participants said that having matters disregarded or reinterpreted was often linked to trying unsuccessfully to raise with staff concerns about aspects of their treatment such as use of a particular medication or electroconvulsive therapy (ECT).<sup>18</sup> Some participants said that issues to do with Māori spirituality and values were misunderstood by staff – often being turned into symptoms.

Many former patients who spoke to the Forum said they still have unanswered questions arising from the reasons for their admission to and their experiences in psychiatric institutions, the basis for diagnoses given, and the reasons for treatments given.

### *Care and compassion*

Many participants spoke of feeling that care and compassion by staff was absent or minimal. They described experiences of care ranging from indifference and lack of respect to callous, threatening, abusive, and/or violent treatment, together with poor communication and lack of information.

Another situation frequently voiced by participants was of receiving messages of hopelessness about being admitted to a psychiatric hospital and about their future. Former patients reported being told by staff members, and also sometimes by family, things such as they would never get out of hospital, they would never recover, they should not have children, they would never get a job. Participants gave an account of how these messages had had an impact on their self-image and influenced them over the years.

Former patients were, however, careful to distinguish times when they had an experience of staff members who cared and who took the time and effort to connect with them and to communicate effectively. Some participants spoke of individual acts of kindness and caring by staff members when they were in very bleak situations; and they had carried appreciation of these acts with them over the years. They spoke of staff members who made a real effort to provide compassionate care, sometimes in the face of institutional resistance. Former patients gave examples of how staff had made a positive difference: where staff had treated him or her as a person; where staff were prepared to spend time and build a rapport with them; where staff were prepared to listen, talk, and explain – and, in the words of one participant, “humanise my care”.

Many participants spoke of the support, camaraderie, and caring received from fellow patients and the importance of this while they were in hospital. Some participants spoke of

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18 ECT involves the brief passage of an electrical current through the brain via electrodes applied to the scalp to induce a generalised seizure (a fit or convulsion). Further description is given later in this report.

being taken under the wing of older patients and attributed their survival in hospital to the care and protection they received.

### *Consent*

People who were admitted as voluntary patients often said that in reality it did not feel as if there was a distinction between being a voluntary patient or a committed patient and said that even though they were voluntary patients, they felt they had little choice as to their treatment or whether they stayed in or left hospital. A number of participants who had been voluntary patients talked about being cajoled or bullied into consenting to treatment (particularly ECT) by comments such as, “If you don’t consent we will section you,” or, “If you don’t consent you won’t get out of hospital.” Others spoke of their consent for ECT being sought when they were heavily medicated.

### *Physical violence*

Many participants spoke of feeling fearful much of the time they were in hospital – both of certain other patients and of the attitudes and actions of particular staff. They spoke of an atmosphere that was violent, and of witnessing or experiencing physical violence from other patients or staff. Many former patients spoke of being placed in dayrooms or dormitories with patients of whom they were afraid because they were aggressive, distressed, or predatory. A number felt that some staff condoned physical abuse. Participants described a culture of threats, verbal abuse, taunting, goading, and bullying. Some spoke of observing or experiencing staff goading patients until they lost control and then the patient being punished by staff – usually by being heavily restrained, medicated, and put into seclusion. On several occasions participants spoke of practices in the restraint of patients going well beyond acceptable limits. They described beatings and patients being dragged by their hair to seclusion rooms.

Former patients spoke graphically of witnessing and hearing frightening situations such as crying and wailing from the seclusion units, episodes of physical or sexual violence, patients who had self-harmed or suicided, and people screaming while having ECT. Participants also spoke of being fearful of some treatment methods and whether they would be subject to such treatments.

Many participants spoke of memories of distressing events they had witnessed happening to other patients. Some spoke of their abiding regret or shame at not intervening or not having been able to do more to assist in some situations.

### *Sexual misconduct and abuse*

Some participants, both male and female, spoke of experiencing or witnessing sexual misconduct. Those who spoke of this described experiences ranging from sexual taunting, to inappropriate touching, to sexual violation. A few spoke of rape. Some who spoke of sexual misconduct described experiences involving another patient; sometimes they also talked of staff members having been aware of – but ignoring – sexual misconduct by patients. A few spoke of experiencing or witnessing such sexual misconduct by staff members, and a few spoke of having been seduced by staff members and of sexual relationships continuing for some time, often leaving the patient with feelings of betrayal, guilt, and anger when the staff member ended the relationship. Participants almost universally used the words “sexual abuse” when speaking of what they had experienced.

A common theme was that although psychiatric hospitals were supposed to be safe for patients, the experience of many participants was that they were not.

### *Complaints*

Former patients spoke of the futility of complaining about aspects of their care or about matters such as physical assault or sexual misconduct, saying that complaints by patients usually went nowhere. A few spoke of making a complaint to an official visitor or a district inspector that did not have a satisfactory outcome. Some said that staff members had taunted them by saying, “Who will believe you? You are a patient.” They also spoke of fear of repercussions if they did complain.

### *Discharge practices*

Many spoke of having been discharged from hospital with no follow-up or support and often on heavy medication regimes. Some participants described having nowhere to go or of going to unsatisfactory half-way houses. Some described being released suddenly for no clear reason, and with little notice. Others spoke of being expected to pick up previous responsibilities without help or support and of difficulties doing so. Some mentioned the problems of trying to adjust to life outside hospital, having become used to the institutional way of life. Many spoke of the difficulties of obtaining or sustaining employment.

### **Treatment regimes**

Former patients told the Forum of the long-lasting effects (physical and mental) of the treatments they received during their stay in hospital.

### *Seclusion*

Many people spoke of having experienced being put into solitary confinement in a small locked room – often describing fearful and degrading experiences whilst there. People spoke of being “locked up in a cell” – sometimes as a matter of routine on admission and sometimes for extended periods at other times. Participants spoke of seclusion rooms as often being dark, often without a visible clock, and often very dirty. They described graphically the room having only a mattress, blanket, and a chamber pot. Some recounted having no drinking water and/or having no provision for toileting and having to use the floor as a toilet. Many described calling for assistance and no one answering. Others spoke of being sexually or physically assaulted while in seclusion. Participants spoke of losing a sense of time, of fear, humiliation, and a sense of powerlessness and degradation when in seclusion. Some participants spoke of being put into seclusion as a punishment for reasons such as annoying a staff member or as part of a reward and punishment regime. Many spoke of feeling that unnecessary force was used by staff when they were restrained and put into seclusion or when staff administered medication while they were in seclusion.

The ongoing effects described by participants who experienced seclusion included fear of small and locked rooms, claustrophobia, and intense feelings of loss of dignity.

### *Electroconvulsive therapy*

Many participants related experiences of receiving ECT, often without explanation or consent. Most spoke with distress of having received ECT. A few spoke of ECT having been helpful for them. Some who had been given ECT particularly before the 1960s

described receiving unmodified ECT.<sup>19</sup> Some spoke of receiving ECT as a child and others of receiving ECT when pregnant. A number of participants described receiving extensive treatment with ECT.

Participants had detailed recollections of the administration of ECT and the rituals that occurred before its administration. They spoke of waiting with others for ECT and building levels of fear as their turn approached; of hearing the screams of the others as they received ECT; of their own terror as they were about to receive ECT; unpleasant and undignified effects of ECT; and of supporting or observing other patients after they had received ECT. Some spoke of being threatened with ECT if they did not comply with what was desired of them. Others spoke of believing that on occasion they had received ECT as punishment.

Most participants spoke of the effects they felt ECT had had on them. Many spoke of forgetting skills they once had – for example cooking and needlework skills, or the ability to play a musical instrument or to do mathematics – and often of the efforts they had made to regain these skills. Others spoke of having forgotten segments of their lives and increasingly poor memory as they get older, conditions that they attributed to ECT. Others spoke of still being fearful of anaesthetics or needles.

### *Medication*

Most participants spoke about the role medication had played in their hospital experience and the effect of medication on their lives. Many said medication was the major, or only, treatment they received while in hospital. Participants spoke of experiencing frequent changes of medication, often coinciding with changes of diagnosis, and of feeling as if they were being experimented upon because of the frequent changes. They also spoke of being given multiple medications and heavy dosages.

Participants often said they were given little in the way of explanations about the medications they were given, including why they were being given them and their effects and side effects. Participants spoke of the effect on their lives and self-esteem of the side effects of medication such as weight gain, tremors, burning easily in the sun, tongue rolling and facial movements, shuffling gait, drowsiness, difficulties with concentration, slower thinking, sexual dysfunction and agitation – often saying that the side effects were worse than their illness. Some spoke with concern about possible long-term effects of medications they received or of organ damage already identified.

Many participants spoke of heavy use of specific medications – in particular, paraldehyde and chlorpromazine (Largactil)<sup>20</sup> to control behaviour and for disciplinary rather than therapeutic reasons. Some remembered vividly the pain associated with the administration of paraldehyde and its smell.

### *Other treatments*

Various former patients spoke with distress about receiving deep sleep (narcosis) therapy in the 1960s or 1970s.<sup>21</sup> They spoke of an ongoing quest to try to piece together what had happened during the treatment, and of disconnected fragmented memories associated with the treatment and still having questions as to why it was given.

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19 ECT administered without anaesthetic or muscle relaxant.

20 Paraldehyde is a quick-acting hypnosedative. Largactil is an antipsychotic agent.

21 An experimental therapy where patients were kept asleep with medications for a week or more in the belief they would be less unwell when they woke up.

Some spoke, again with distress, of being given experimental drugs or behaviour modification therapies in the 1960s and 1970s such as aversion therapy and abreaction therapy.<sup>22</sup>

Some participants who were patients in the 1970s and 1980s spoke about group therapy delivered within the context of a therapeutic community. Some felt it had been helpful for them, but others described it as counter-productive and unsafe. They spoke of experiences where patients were pitted against other patients; where patients were belittled; and where therapies were focused on sexual matters and there was sexually inappropriate touching. Participants also spoke of sessions run by unqualified staff and of feeling that group therapy sessions were experimental. Some said that the group therapy experiences had been deeply traumatic and they continued to live with the effects.

### **Experiences of particular groups**

The themes outlined above were common to many former patients. In addition, particular themes arose from the matters discussed by some categories of former patients as described below.

#### *Children and adolescents*

Participants who had been admitted to hospital as children or adolescents described desolate experiences.<sup>23</sup> Most spoke of having no understanding of why they had been admitted to a psychiatric hospital. Some had been given a diagnosis of epilepsy (either before or after admission); some said they were considered wayward or naughty; some had been transferred from other institutions; and many were state wards, who spoke of a pathway from foster care and residential homes to psychiatric hospitals. Many spoke of their grief at having been separated from family members, and Māori and Pasifika participants spoke of their sense of dislocation at being away from their families and community in a world where their cultural and spiritual beliefs were not acknowledged.

Participants who were admitted as children or adolescents spoke of confusion and extreme fear dominating their lives while in hospital. They described vivid memories of living in a regimented, punitive environment with dangerous and/or “crazy” people and (to them) big, often frightening, staff members, and of being starved of affection. They spoke of seeing and experiencing terrifying things. Many said they had been given ECT and heavy medication regimes, often saying they had been given ECT and paraldehyde as punishment. Some spoke of being put into seclusion, also as punishment. They described their schooling ceasing or largely ceasing when admitted to hospital.

A number of participants in this group talked of sexual and physical abuse and of becoming the target of sexual abuse from staff or other patients. Some spoke of becoming sexually active themselves and modelling their behaviour on how they had been treated. Many described lack of caring and sometimes cruelty by staff members. Some described developing survival strategies, trying repeatedly to escape, and experiencing feelings of hopelessness. A number said they became smokers while in hospital.

A strong common thread amongst such participants was the loss of their youth and innocence. Many said they had been discharged without the skills needed to deal with adulthood, often

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22 Aversion therapy was a punitive behaviour modification therapy. Abreaction therapy was a therapy designed to enable patients to release repressed or unconscious emotions relating to earlier painful events.

23 Several participants who spoke to the Forum said they were admitted to hospital between the ages of four and ten years; and 15.5 percent described being younger than 16 years old when admitted.



saying that their lives had been a tremendous struggle and that their experiences had cast a shadow over their whole lives.

### *Mothers*

Women who had children at the time they were admitted to hospital described very difficult experiences; this was particularly so for those with babies and young children. Some spoke about the loss of their children, who were often given to others for care – sometimes being fostered out, or given up for adoption, or lost in a custody battle. Others spoke of a failure to bond with a child born shortly before admission or loss of a bond with older children. Many spoke of being given ECT and the impact on their homemaking skills when discharged. They also spoke of memory loss that they felt came from ECT, and some spoke with sadness of not remembering periods of their children's growing up years. Many noted that there was no support for their partners or children while they were in hospital, or for them and their families when they were discharged home. Many talked of the difficulties of trying to pick up responsibility for caring for their family again and of medications adversely affecting their ability to function in the family environment. Some spoke of the breakdown of their marriages and some of losing custody of their children at the time of the divorce because of having been a psychiatric patient. Some spoke of having their fitness to be a mother questioned by staff and being told not to have further children or to consent to sterilisation.

Some said that one of the impacts of their hospitalisation was how badly their children were affected, both at the time and later.

### *People with undiagnosed or untreated physical conditions*

A number of participants spoke of being admitted to a psychiatric hospital because their doctors did not believe they had a physical illness. Those with this experience had often, before admission, had an ongoing battle to be believed about symptoms, particularly chronic pain. Others spoke about medical conditions or injuries being ignored and not treated while an in-patient – for example infections, broken limbs, and injured backs. Some spoke of not being taken seriously by staff when raising physical conditions or injuries.

Participants who spoke about these matters often described feeling vindicated when at a later stage the physical issue was identified.

### *People with an intellectual disability*

Very few participants with an intellectual disability spoke to the Forum.<sup>24</sup> Those who did told of grim personal experiences of sexual and physical abuse by staff and other patients, of no education, and of witnessing abuse (physical and sexual) to others.

A number of former psychiatric patients spoke of the intellectual disability wards in psychiatric hospitals. Some spoke of staff threatening them that they would be sent to these wards if they did not behave. Others spoke of being taken by staff to see the patients in

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24 Some people with an intellectual disability were patients in psychiatric hospitals prior to 1992; many others were patients in psychopaedic hospitals (hospitals specifically for people with an intellectual disability). The Forum's mandate from the Government was to hear from former patients of psychiatric hospitals, and although it did hear some stories from people who had been patients in psychopaedic hospitals, the Forum's processes were not designed to meet the needs of this particular grouping of former in-patients. Because of their intellectual disability they would need different levels and types of support to tell their stories.

these wards as a punishment. Others spoke of being sent to work in these wards, also as a punishment. Some recounted coming across these wards by accident when walking in the hospital grounds. These participants spoke of overpowering visual and auditory memories of adults and children crowded together, living in distressing conditions.

### *Transgender people*<sup>25</sup>

People who had been admitted to hospital with sexual identity issues spoke of being mistreated and misunderstood. Some described being treated with ridicule by staff and other patients, of having their stated sexual preference ignored and of sexual abuse while in hospital. Some said that they were admitted to hospital deeply unhappy and looking for help and were put on behaviour modification programmes and/or treated psychiatrically for gender issues. Lack of access to medical treatment was also mentioned.

A common concern expressed by this group of participants related to breaches of confidentiality.

### *Women with anorexia*

Those who spoke of being treated for anorexia in hospital generally said that they felt that they had been treated cruelly, often saying they felt that staff had not understood how to treat them. They spoke of a focus on gaining a target weight and of underlying problems not being addressed. Their treatment programmes were often spoken of as punitive or missing the point. Most said they were discharged while they were still very unwell.

## **Impact of experiences**

Most participants told the panel how their experiences of hospitalisation had deeply affected their lives. The impacts described included enduring psychological and physical distress; significant disruption to education, employment, and social and family lives; and the ongoing experience of stigma and discrimination from having been in a psychiatric hospital. Participants often spoke of having to work hard to try to rebuild their lives once out of hospital. Many still lived with the scars. For many, the experiences had influenced their life choices and options, and for many the emotion and distress of their experiences remains close to the surface. Several expressed the view that as a result of their experiences they have not been able to reach their potential and be the person they might otherwise have become.

A particular cause for concern voiced at the Forum involved clinical records and their potential for causing persistent problems. Many former patients felt troubled about their historic psychiatric clinical records. A number who had seen their records spoke of hurtful and judgmental evaluative comments made about them, of experiences trivialised or not recorded, and of the patronising way in which they were described. Many spoke of their concern that their old records were still available for others to see. Some said that they believed that their current care, including physical care, was detrimentally affected by health care providers having access to old records and making judgments about them based on their history of in-patient care in psychiatric hospitals. Others said that knowing that the records still existed affected their willingness to engage with health services because of the

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25 The term “transgender” is used for people who do not identify with the biological sex designated at birth, and who adopt the social role of the different gender with which they identify. A transgender person wishes to change their bodily characteristics (whether or not surgery is an option). (Refer *Human Rights in New Zealand Today*, Human Rights Commission, Wellington, 2004.)

stigma attached to the records. Others said that they feared the effect of disclosure to family or employers. A number said that they wished the records could be destroyed.

Some impacts of treatment or experiences spoken of by the participants have been noted already in the report. Other impacts frequently reported included

- feelings of shame and loss of dignity arising from what participants had experienced and seen
- vivid unbidden memories of things they had seen or experienced in hospital (flashbacks) and nightmares
- grief, anger, or sadness at what they had experienced and at the loss of personal aspirations concerning, for example, career or family
- fear of people in positions of power or authority, of ever having to use the mental health system again, and of raised voices and fighting
- experiencing stigmatisation and abandonment by family and friends, as well as stigmatisation by social agencies, in legal processes, and in employment
- not being believed as a result of their mental health history
- low self-esteem and confidence, and feelings of loss of respectability and credibility
- financial struggles and poverty from loss of income and earning ability
- having current physical conditions attributed to mental illness
- a constant quest to make sense of who they are
- moving frequently seeking a place to feel settled
- difficulty in trusting people and in developing and sustaining personal relationships
- feeling the need to prove their worth and sanity.

## **Family members**

Seventeen percent of Forum participants were family members. This group included parents of former patients, or sons, daughters, siblings, or extended family members. Family members came to speak of their own experiences while their family member was in hospital and how their experiences affected them. They also reflected on the quality of the experience for their family member in hospital.

Family members spoke of experiences in every decade from the 1950s to the 1990s.<sup>26</sup>

The main reasons given by family members for speaking to the Forum included

- to have an opportunity to tell someone what the experience was like for them and their family
- to express their grief
- to honour the story of a family member
- to say the system failed their family and to make suggestions as to how things could be improved for families.

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26 See Appendix 8 for further details.

As with former patients various themes arose from the stories of family members. Concerns common to many of the individual narratives by family members at the Forum involved

- communication
- support
- institutional conditions
- experiences as children of in-patients.

### **Communication**

Many spoke of the difficulties for family members trying to deal with and navigate their way through the mental health system. A key theme was lack of involvement of family members and lack of information given to them.

Most family members spoke about how little information they were given about their relative's diagnosis and how best to manage their illness, even when they were their spouse, parent, or principal caregiver. They spoke of little discussion or consultation about proposed treatments or reasons for treatments given. A number described trying unsuccessfully to find out more about their relative's diagnosis or treatment. Some said that their relative's doctor changed frequently, and with changes of doctor there were often changes of diagnosis and medication with no reasons given as to why, or information about the new diagnosis or medication.

Many said that doctors and nurses were not interested in input or information from family members; they recounted how, in seeking to be involved or of trying to give or get information, responses ranged from their being totally ignored to being actively shut out or a reluctant response being made. Many spoke of being treated disrespectfully by some staff.

Family members also spoke of trying without success to discuss with staff treatments they felt were harmful or were causing their relative distress and of trying to intervene and stop some such treatments. Some described feeling as if their family member were caught up in a system they could not escape; they described being given messages of hopelessness by staff about their family member's future and also sometimes of being blamed as being "responsible" for their relative's illness. Some spoke of their efforts to try to secure the release of their family member from hospital.

Family members gave accounts of feeling disempowered, isolated, and excluded. Some spoke of feeling as if they had to battle all the way and some described the pain and loneliness of being deprived of information and left out of decisions. Māori participants described their distress at whānau not being included as part of their relative's care and healing. They spoke of care that was not consistent with Māori culture and values and of observing the detrimental effect this had on their relative.

Where family members had positive experiences they described what a difference it made when they were listened to, included in discussions, had things explained and questions answered, and when they and the patient who was their family member were treated with respect and both were recognised as having valid input.

### **Support**

Another theme was the practical and financial difficulties faced by many families. There were accounts of spouses carrying heavy burdens on their own for caring and protecting their children, earning money, and coping with a husband or wife in hospital – without

any assistance or support from external agencies such as housing and welfare. Some spoke of families having to be split up, with children being sent to grandparents or others for care, sometimes permanently. Some spoke of difficulties of visiting their relative in hospital, which often involved travelling considerable distances, sometimes by public transport.

Participants described hospitalised relatives being discharged or sent home on leave with little notice, and the home-based family being expected to assume responsibility, with no practical assistance and scant information. Some spoke of children, siblings, or other family members assuming responsibility for relatives when they were discharged. Many commented that there was no assistance for caregivers and no acknowledgement of the caregivers' needs. They also spoke of there being no counselling or marriage guidance support available as families tried to re-establish relationships. Some participants said they felt they had "lost" the person that their relative had been before admission.

### **Institutional conditions**

Several family member participants spoke of feeling that the institution did not care well enough for their relative. Participants spoke of observing their relative's health deteriorating in hospital. Participants spoke of a variable quality of staff, with some very caring and some rude and disinterested. Some said they felt the staff had not been vigilant enough and some said they felt betrayed by a system that had been entrusted to look after their relative but had failed to do so.

Family members also spoke of their concerns about treatment methods. Many spoke about how much reliance there was on medication and the negative effects of medication on patients. Some described seeing dramatic changes in their relative after he or she had been given medication; they related instances of hospitalised family members being over-medicated to the point where they were unable to stand or suffered distressing side effects. Participants also spoke of frequent changes of medication and of an apparent inability to get the right medication.

Many spoke of their relative being given ECT – often against the wishes of the patient and the family member. Participants described seeing how fearful their relative was about receiving ECT and of the effect ECT had. Some described ECT as having a detrimental effect on their relative's personality.

Participants expressed concern about the use of seclusion and the conditions of the seclusion rooms, describing the experiences of their family member as abhorrent and sometimes having long-lasting effects such as a fear of being locked in a room or of small spaces.

Family members' reflections on the physical environment echoed those of former patients. They spoke of forbidding buildings; dirty, noisy, smelly environments; smoke-filled rooms; and lack of privacy. They also spoke of patients not wearing their own clothes and of their personal items going missing. Some said that their relatives had spoken to them of being sexually assaulted while in hospital and no action being taken on complaints.

Some spoke about how emotionally difficult they found it to visit their relative in hospital, of feeling scared of other patients and the environment, of lack of privacy for them and their relative while visiting, of feeling distressed at how they found their family member and humiliated by staff being rude or ignoring them. Some remembered being able to take their relative out into the grounds of hospital when visiting and spoke positively of visits where they had space, privacy, and pleasant surroundings.

## Experiences as children of in-patients

Participants who were children when their mother or father was admitted to a psychiatric hospital spoke of experiences that were particular to them. Such participants described examples of abiding memories such as the confusion and disruption to family life caused by their parent's illness and their parent being taken away to hospital sometimes by the police. They talked of having no real information about what was wrong with their parent and no support from the mental health system or anywhere else to deal with their parent's illness and absence; of children taking on an extra responsibility in the family and/or of families being split up. Some spoke of having to move house, of disrupted schooling, and of being stigmatised by classmates and communities. Some spoke of their parents coming home "different" from the way they were before admission – sometimes heavily medicated, sometimes having forgotten their children or skills they had before going into hospital. Some spoke of feeling "robbed" of their parent. A number spoke of becoming a carer for their parent when they were discharged and assuming major and long-standing caregiving responsibilities from a young age – often without support or information.

Overall, many family members spoke of the loneliness and sadness of the experience for them and their family – of feeling stigmatised by association and of becoming increasingly isolated and insular – with no practical help or counselling offered.

## Staff members

Staff members formed the smallest group of participants – comprising 6 percent of the total number of participants. Those who came included health professionals and allied staff. They spoke of experiences from the 1940s to the early 1990s.<sup>27</sup> Most of the large psychiatric institutions and one psychopaedic institution in New Zealand were spoken about.<sup>28</sup>

The main reasons for attending the Forum given by staff members included

- to provide some context and to describe the complexity of the psychiatric institution environment
- to give balance to what they believed the Forum would be hearing from former patients and families
- to substantiate what they believed the panel would be hearing from former patients and families
- to bear witness for particular patients who were no longer living or unable to speak for themselves
- to unburden and alleviate their own sense of sadness and guilt.

Matters raised by staff members at the Forum involved

- historical context
- environment and culture
- complaints
- treatment regimes.

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<sup>27</sup> See Appendix 8 for further details.

<sup>28</sup> Carrington, Cherry Farm, Hillmorton, Kingseat, Lake Alice, Mangere, Ngawhatu, Oakley, Porirua, Seaciff, Seaview, Sunnyside, Tokanui, and Wakari. See also Appendix 7.

## Context

Staff members spoke often about the working conditions, physical environment, and daily routines of hospital life. Most who came specifically to give context were careful to say they did not wish to minimise the experiences that former patients and family members may have spoken of, but that it was important to bear in mind the historical period and context, including the difficult conditions in which staff and patients were placed.

Many staff members spoke of a testing practice environment. They spoke of high patient numbers and a mixture of types of patient, including those who were very ill or difficult to handle, patients hospitalised under criminal justice provisions, and some who did not have a mental illness but for whom there was no other provision for residential care. They spoke of an environment where staff encountered physical and verbal abuse from some patients, with few options for dealing with such incidents. Staff member participants described hospitals being short-staffed and having relatively low numbers of registered nurses in proportion to untrained staff, low numbers of psychiatrists, and recruitment and retention difficulties. Some spoke of lack of training for staff and of rosters being filled by casual workers such as seasonal workers in their off season.

Staff member participants spoke of a strong hierarchy and a strong authority structure in psychiatric institutions, which some described as “a chain of command structure”. Psychiatrists were in charge of treatment regimes, with most day-to-day care provided by registered nurses, nursing students, and nurse aides.<sup>29</sup>

Participants spoke of the multiple roles nurses played in keeping hospitals running including duties such as cleaning and supervising work gangs, particularly in the earlier periods. They spoke of long hours worked and of nurses being called back for extra shifts because of staff shortages. They also spoke of heavy workloads and nurses and doctors having responsibility for high numbers of patients. Some spoke of psychiatric institutions being places that had containment and safety of patients as their primary objectives – with nursing staff more like warders than nurses.

Some spoke of staff attitudes to patients being different from those held today. They gave an account of a period in which patients were viewed as people who were not expected to get well or to stay in touch with their families and where there was a societal attitude of “out of sight, out of mind” for patients in psychiatric hospitals, which were closed environments with relatively few visitors. Some described a prevailing public attitude of fear of mental illness and of psychiatric patients and the stigma attached to psychiatric disability; they said that staff experienced stigmatisation because of where they worked.

Some spoke of hospitals being self-contained, close-knit environments in which husbands, wives, and sometimes whole families were employed. They spoke of camaraderie and a strong social life among staff outside work. Some said that staff culture was easily transmitted in the closed environment and described an informal culture among staff that ran parallel to the formal hierarchy and that could be very powerful. They spoke of staff members being stigmatised or punished through this informal structure if they stepped out of line with the established “rules”.

## Environment and culture

Like many former patient and family member participants, a number of staff members spoke of over-crowding and primitive sanitary conditions in psychiatric hospitals. The

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<sup>29</sup> Nursing training was undertaken in hospitals until the 1980s.

descriptions given by patients of unpleasant physical conditions were echoed by a number of staff members. Some spoke of what they described as appalling physical environments with buildings that were old, cold, and badly ventilated. Some spoke of dire conditions, particularly in what were known as refractory wards.<sup>30</sup> Some described shortages of supplies such as linen, blankets, and clothing.

Some staff described the work done by patients in the laundry, kitchens, and gardens; social activities such as dances organised for patients; and tobacco and sweets being issued to patients. Some who spoke of these matters felt that psychiatric hospitals were a world within a world and relatively good places for patients to live in.

Most staff members spoke of highly structured days for patients and staff – organised by staff as a way of managing the environment. Some spoke of tight rules and of patients being punished for infractions of these rules. A number described patients' physical care being done in groups or "bulk lots" – for example taking groups of patients to the toilet on a regular schedule or bathing patients in groups on set days. Some spoke of lack of physical privacy afforded to patients during these routines. Some said these routines were a matter of necessity; others spoke of patients being stripped of their dignity by the way their care was organised and delivered.

Many said that the difficult conditions affected the way staff worked. Some spoke of a lack of time for kindness, and a number described an attitude of benign paternalism moving in some instances to acts of cruelty. Some staff were described as being callous to patients and a number of staff member participants said that unkind and sometimes violent behaviour towards patients by staff was not uncommon. Participants also spoke of having witnessed staff goading patients until they assaulted another patient and then not intervening. Several said that physically violent and abusive acts by staff were often known about by other staff and not reported, or if reported not acted upon. Various participants spoke of the effect on people of working in such an environment – saying that the behaviour of some staff deteriorated over time from kind to unkind or violent.

Several participants described witnessing acts of cruel and inhumane treatment by staff to particularly vulnerable patients such as the elderly, the dying, children, and those who were physically or intellectually disabled. Some who came especially to speak of these matters described trying to make a difference for such patients by acts of caring and compassion or intervening to stop practices they thought wrong and being reprimanded or intimidated by other staff for doing so.

A few staff spoke of patients telling them of having been sexually abused by a staff member or patient, and some staff said they were aware this sometimes occurred. Some had tried to complain at the time but their complaints had been ignored – sometimes on the basis that no one would believe a patient. Others said they had witnessed no incidents that could be described as abusive.

Many staff member participants said that there were some excellent staff; some said that although they had been horrified by some things they saw, they had also worked with some wonderful staff who had made a difference in the lives of patients – often despite the system.

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30 Wards where long-term patients, including intellectually disabled patients, lived.



## **Complaints**

Another theme raised by some staff related to the difficulties of trying to effect change by complaining. Some more junior staff spoke of not knowing where to go to make complaints about treatment of patients or behaviour of staff members or of being too scared to challenge such behaviour. Others spoke of making complaints to more senior staff that were not progressed – or sometimes experiencing negative repercussions because of complaining. Senior and junior staff spoke about a sense of powerlessness about being able to stop things that were happening or to effect change despite trying to do so. Some also spoke of personal and career repercussions arising after they complained.

## **Treatment regimes**

Staff members spoke of the evolution of treatment methods, with ECT being the main treatment for patients before the introduction of new medications. Participants spoke of heavy use of ECT particularly in the earlier decades, of ECT being given to children, used as aversion therapy, and being given without anaesthetic on occasions. They also spoke of patients' fear of ECT. Some noted that obtaining consent was not routine because many patients were committed and so consent was not necessary.

Seclusion was spoken of by some as being necessary to manage and contain abusive, aggressive, or disturbed patients; and some said that the physical handling and manhandling required to place people in seclusion should be understood in that context and not taken as assault. Others spoke of the primitive conditions in seclusion and of seclusion being used to punish misbehaviour. Some spoke of the use of paraldehyde to manage and control angry behaviour because it was “effective in dropping people very quickly”. Others spoke of patients receiving increased medication when there were particular staff shortages.

Many staff spoke of the changes that occurred with the introduction of new medications, which opened up further treatment options. Some described over-use of such medications, and experimentation with drug combinations and dosages and types of treatment as new drugs became available.

Some staff spoke of sterilisation of patients without consent, particularly those with an intellectual disability.

## **Impact of experiences**

Some staff members spoke of living with memories of the conditions and the things they experienced that have haunted them, and some spoke of years of not speaking about painful matters or matters that made them feel guilty or ashamed. Several spoke of their distress at not having intervened in particular situations or not being able to do more for patients. Some spoke of the feelings of powerlessness at being ignored when they complained or of their careers being affected by speaking out. Some spoke of an ongoing emotional toll.

## **Then and now**

The period covered by the Forum's mandate ended at November 1992 when the current mental health legislation came into force. Nevertheless, many participants rounded off their stories speaking of experiences since that date. Although there were stories from former patients and family members of negative matters (such as misunderstandings and breakdowns of communication with staff, frequent changes of psychiatrists and key workers, medication and treatment concerns, complaints not always taken seriously, and sometimes

difficulties in obtaining hospital or respite care), overall former patients and family members gave stories that were more positive about care they or their relative had received over recent times. They talked often of people having greater involvement in decisions about their own care and treatment, and of staff who care, listen, work alongside them, and treat them with respect, and of greater emphasis on the rights of patients.

Staff members speaking about the present talked of commitment to improving the quality of care, greater emphasis on the rights of patients, and changes and improvements to treatment methods.

## FOLLOW-UP ACTIONS

**The Forum's terms of reference included assisting participants to make linkages with current support services and complaint resolution services, accessing (and paying for) counselling for participants if appropriate, and – to the extent possible – assisting participants to come to terms with their experience. As part of the meeting process the panel worked to identify practical steps the Forum could take to assist individual participants.**

Among the forms of assistance arranged for participants were

- counselling and other support services
- access to relevant government agencies
- information on medical and legal systems.

### **Counselling and other support services**

One of the most significant contributions of the Forum was the facilitation of professional counselling services for participants.<sup>31</sup> Other support services with which participants were put in touch included non-governmental support networks and the use of the Freephone 0800 telephone number.

#### **Counselling**

The panel advised participants of the availability of counselling, where relevant. The Forum Support Facilitator often discussed this matter further with the participants, and for those who decided they wished to undertake counselling, the Forum Support Facilitator arranged referrals to an appropriate counsellor.

Access to professional counselling was arranged for 136 participants (equivalent to more than 25 percent of participants). (See Appendix 3 for detail of how counselling referrals were made.)

Participants who chose to take up counselling decided to do so for a variety of reasons, including

- so that they could address issues arising from the telling of their story
- because they had started a journey by telling their story and wanted to continue
- because the sharing of their experiences of psychiatric hospitals had exposed other historic concerns that they needed to address

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31 The terms of reference provided for participants to have up to ten sessions of counselling paid for by the Forum. Counselling was available to any participant if the counsellor's initial assessment was that counselling would be helpful.

- because they had felt for a long time that they would benefit from counselling but had not been able to access it or afford it
- because counselling would be a safe place to read their old clinical records and deal with issues that arose from doing so.

### **Peer support services**

Information about local consumer peer support services and networks was made available to participants at Forum meetings. Panel members often discussed with participants specific local or national organisations (such as the Balance NZ Bipolar & Depression Network and Supporting Families) that might be of assistance in the participant's particular situation. On certain occasions further information about organisations was obtained and sent to participants – to some because they wished to have information about particular organisations that may be able to assist, to others because they were interested in becoming involved as a peer support worker.

Several participants were supported to prepare for and attend hearings by advocates from peer support services. Where this occurred, the peer support worker was an important link for the participant. Many people spoke with appreciation of the support, understanding, and encouragement they had received from peer support workers.

### **Calls to the Freephone 0800 number**

An important aspect of the Forum's follow-up service was the ability of participants to make contact with the Forum Support Facilitator via the 0800 number in the weeks and sometimes months after their meeting with the Forum. Among the reasons for participants to continue contact were

- to seek information or advice on options to deal with a particular situation
- to speak about unresolved issues
- to celebrate a milestone or achievement
- to touch base about issues arising from counselling
- to let the Forum know that things were or were not going well for them
- to check how the Forum was going
- to seek support or reassurance when things were not going well.

Sometimes calls from participants were about matters outside the remit of the Forum, but participants made the calls because they wished to speak to someone they trusted.

## **Access to relevant government agencies**

Among the government agencies that had the ability to help certain participants with their concerns were the Accident Compensation Corporation (ACC), Health and Disability Commissioner, and New Zealand Police.

### **Accident Compensation Corporation**

Information on the ACC Sensitive Claims process was available and, where appropriate, provided to participants. On occasion participants who spoke of sexual abuse were assisted to re-establish links with an ACC-approved counsellor, or counselling referrals were made to an ACC-approved counsellor. Information was also provided on how to seek

ACC assistance for injuries received while in hospital, sometimes arising from treatment, sometimes from accidents or assaults.

### **Health and Disability Commissioner**

Information on the Health and Disability Commissioner and the Health and Disability Consumer Advocacy Service was made available to participants who had concerns or complaints about aspects of their current health care.

Some participants used health and disability consumer advocates to assist them to prepare for their meeting with the Forum and brought the advocate to the meeting as their support person. In such situations, the advocate often agreed with the participant to provide ongoing assistance to help resolve current issues.

### **New Zealand Police**

Some participants spoke of historic matters that warranted a link with the police being made for them by the Forum, so that they could discuss the issues with the police. Several referrals were made to the Forum's Police Liaison Officer on the basis that such referrals would enable the participant to discuss their options and police processes with a senior member of New Zealand Police.

## **Information on medical and legal systems**

Some participants were assisted by the provision of information that they could use in making personal choices on what actions they might take at a later date. Information on their rights and pathways in medical systems was important, as was information of legal options.

### **Access to clinical records**

A number of participants told the Forum that they wished to see the records made about them when they were in hospital. For some this was to try to fill missing pieces of the jigsaw and to help them make sense of the past; for others it was to see what had or had not been written about them or because they had been told in the past they were not allowed to see the records.

The Forum developed an information sheet on how to seek medical records, and made this available to participants. It included information on how to contact the Privacy Commissioner for further advice if difficulties were encountered. When participants indicated an interest in obtaining their records they were advised that it was important to have someone available for support and to talk to if they obtained their records.

Where participants wished, the Forum assisted them to trace and obtain their records. In most cases where records were obtained, the participants planned to go through them with a counsellor or their doctor.

The Forum assisted several participants to deal with issues arising from their records. Assistance included advice on how participants could seek corrections of records or put a statement on their files setting out what they saw as the correct picture. Some participants were advised to seek further information and assistance from the Privacy Commissioner.

## **Advance Directives**

Many participants voiced concerns about their current situation or what would happen to them if they became ill again. Some spoke of specific treatments they never wished to have again (for example, ECT); some spoke of knowing what was helpful if they did become ill again and what was not (for example, medications they had found to work and those that proved unhelpful); some spoke of their fear of being put into hospital again or put into seclusion; some said that they did not feel their relationship with their general practitioner or psychiatrist was well enough established to feel confident that their care needs were understood; and some said that they felt that their health care provider might make judgments based on their old clinical records.

Where participants raised concerns about future treatment the panel talked to them about Advance Directives,<sup>32</sup> and information prepared by the Mental Health Commission and Health and Disability Commissioner was provided to them.

Although some participants were sceptical about the limits of Advance Directives, many were pleased to know about a process for them to record their treatment preferences.

## **Access to legal advice**

A few participants who came to the Forum had also made a legal claim against the Government in relation to matters to do with their psychiatric experiences and were involved in litigation. Others said that they wished to seek advice about whether they had a legal claim.

With the assistance of the New Zealand Law Society, the Forum developed an information sheet to help participants who indicated that they wished for information about how to seek legal advice.

## **Other personalised assistance**

A range of other individualised actions were taken to assist particular participants, often when they had been able to make no headway for themselves. Such matters included seeking information on whether action had been taken on certain recommendations by a coroner; referring participants for assistance and advice on dealing with agencies such as Work and Income New Zealand; and assisting participants with information on how to obtain a general practitioner or seek a second opinion or how to obtain information about a specific treatment received.

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<sup>32</sup> An Advance Directive is a statement setting out a person's treatment preferences to be used if they are neither competent nor able to communicate their treatment choices.

## USEFULNESS OF THE FORUM

**Many participants told the Forum that they found the process of attending hearings and being offered follow-up support to be useful. They valued the opportunity to tell their story, the opportunity for their story to be heard by those in authority, and reported positive outcomes on a personal level.**

The Forum was a legal first for New Zealand. It provided for a new sort of process in which people could come without lawyers and speak directly to a Government-appointed panel in a way that guaranteed confidentiality. The process was focused on the individual and designed to

- allow those who had had experience of the psychiatric system to talk about their experiences to a specially designated panel
- assist participants to make linkages with current support and complaint resolution services
- assist participants (as far as practicable and within the terms of reference) to come to terms with their experience and to achieve closure.<sup>33</sup>

The panel was required by the terms of reference to report its impressions of how useful the process was to participants.

### Panel's assessment of usefulness

People who came to the Forum did not expect to forget the past. The hope for many was that the Forum would assist them to make peace with the past so that they could move positively towards a better future.

Forum members cannot judge the extent to which individual participants were assisted by the Forum process to make peace with the past. For many, coming to terms with their experiences is an ongoing journey. However, we can say that we consider that the Forum process is an important development in the spectrum of reconciliation processes. The formalised listening process of the Forum in which people were able to speak about intimate, personal matters (of which they had often not spoken before), as well as the availability of counselling and the individualised follow-up actions taken, has provided a useful vehicle for

<sup>33</sup> The panel noted with interest the description of the meaning of “closure” given by Brandon Hamber and Richard Wilson in an article titled “Symbolic closure through memory, reparation and revenge in post-conflict societies”, published in *Journal of Human Rights* Vol. 1, No. 1, March 2002: “By ‘closure’ we mean a situation where the trauma is no longer seen as unfinished business, requiring, for instance a compulsion to take revenge. Grief and loss no longer plague the individual consciously or unconsciously, and the victim lives not in a state somewhere between denial and obsession, where the loss is to a large degree accepted and incorporated into the functioning of everyday life.”

many people who participated.<sup>34</sup> There was value for participants in telling their stories; and, through the quarterly and final reports, there has been registration of opinion and views to the Government in a way not possible under other processes.

### **Participants' reports of usefulness**

The panel's overall assessment of the usefulness of the Forum was, for the most part, based on the reports received from participants. Presented below are some more detailed responses of those participating in the process, often expressed in their own terms.

#### **Opportunity to tell the story**

Most who came to the Forum did so because they wanted to tell their story and to be taken seriously. The Forum provided former patients, family members, and staff members with an opportunity that they had not had before. Most participants were very appreciative. They spoke of having the chance to speak to an independent official panel appointed by the Government as being positive, constructive, and helpful. They particularly appreciated the opportunity to tell their story in a non-judgmental environment. Many participants said that when they saw the publicity about the Forum they felt relieved to have been given the opportunity to speak about their experiences.

Participants reported that they felt listened to at their meetings and generally that they found the whole Forum process supportive and "easy to navigate". Participants often said that being able to tell their stories to the panel made them feel important. Many commented on how the way in which they were treated throughout their dealings with the Forum helped to make them feel respected and valued.

Approximately half of the participants wished to have a tape-recorded copy of their meeting. Reasons for doing so varied, but for many it was because they wanted a record of what was for them a very important meeting that they could keep and listen to, or give to family members and others to hear. Some said it would relieve them of their need to repeat the story to others whom they would like to know about their experiences. Many were appreciative of the opportunity of having a record of the meeting.

The panel's view is that these outcomes are in themselves useful ones for participants, many of whom have had less than positive experiences with State sector organisations.

#### **Opportunity to be heard**

Participants often expressed the view that they wanted the Government to know what had happened to them and how their experience affected them. Many linked their desire for the Government to know to their hope that the stories told by them and others would together make a difference to the mental health system and help others. Many reported that they derived comfort from knowing that the Government would hear of the experiences of participants – albeit in a non-particularised way with identities protected.

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34 The panel's view was that a formal "satisfaction survey" taken sometime after participants attended the Forum would be inappropriate. Feedback is accordingly based on what participants said at the time of their meeting with the panel or later, in written correspondence with the Forum or discussions with the Forum Support Facilitator.



## **Hopes for positive personal outcomes**

As noted earlier, the hope for many participants was that the Forum would assist them to make peace with the past so they could move positively towards a better future. Some expressed the hope the Forum would assist them in making sense of their experiences. Some said that they felt coming to the Forum was the beginning of being able to move forward; some said that they felt coming to the Forum was the end of a journey; and some said specifically they hoped for closure.

Many reported that they found taking part in the Forum had been positive and useful for them and spoke of the process helping them move on. They expressed this in various ways:

- They felt relief at having told people in authority what their experience was like for them.
- They had spoken of matters they had never before shared.
- They felt they had been listened to in a way they hadn't experienced before and felt more confident.
- They now wanted others (sometimes family or current mental health staff) to know their stories.
- They wanted assistance with particular issues.

Some participants came to the Forum despite having low expectations of the process and doubting whether it would have any positive outcomes. Sometimes such participants were cynical about the Forum and the motivations for its establishment. After meeting with the panel, most of these participants expressed appreciation of the opportunity to speak to the panel, and of the opportunity for counselling and other actions that could assist them, although they remained cynical about the bigger picture.

A few participants came despite feeling that nothing could ever make things right for them, sometimes having told their story repeatedly with no resolution. Such participants often saw the Forum as another opportunity to tell what had happened to them. Although these participants had low expectations of any sort of resolution, they, too, said they felt listened to and accepted.

A very small number of participants found the experience extremely difficult and traumatic – sometimes attending the Forum against their better judgment. Most such participants said that they found the experience as difficult as they expected and that they ought not to have come.

In summary, many who came to the Forum with the hope or expectation that the process would be beneficial said that they found it to be so and they were pleased to have had the opportunity to take part.

## **Benefits of individual actions**

Another factor to be taken into account in considering the usefulness of the process to participants is the practical individual steps taken by the Forum to assist people. The range of such steps is discussed earlier in this report. Most of the steps taken related to matters that participants felt would assist them to make sense of the past and work towards a better future.

Many participants said that the information given and assistance provided was helpful. Those who were referred for counselling appreciated that access to counselling was available, and several reported back how beneficial it had been.

## Hopes for the future

As already noted, many participants hoped that the Forum process would bring further improvement to the mental health services in New Zealand.

Another hope of many former patients who came to the Forum was that the Government would give a public acknowledgment or apology showing that the Government understood that many former in-patients of psychiatric hospitals had had experiences that were deeply humiliating and demeaning, often taking a lifelong toll. Many who spoke of this said that a public acknowledgment/apology would make them feel valued and accepted in a way that was very important for them, often saying that such recognition of the experiences of former patients would help bring closure.

**The panel members of the Forum acknowledge the courage and tenacity of those people who were willing to come forward to speak to the Forum in the hope that it would help to make New Zealand a better place in which the kinds of experiences they described would never happen again.**

# APPENDICES

## List of Appendices

Appendix 1: Terms of Reference

Appendix 2: Invitation to Participate in the Forum

Appendix 3: Protocol for Counselling Referrals

Appendix 4: Letter to Participants Before Attending the Forum

Appendix 5: Conduct of Forum Hearings

Appendix 6: Venues and Dates of Forum Hearings

Appendix 7: Psychiatric Institutions

Appendix 8: Participant Groups

# APPENDIX 1: TERMS OF REFERENCE

The final terms of reference for the Forum were approved by the Attorney-General, Hon Dr Michael Cullen, on 2 March 2005.

## Confidential Forum for Former In-patients of Psychiatric Hospitals

### Purpose

1. The purpose of the Confidential Forum for Former In-patients of Psychiatric Hospitals is to:
  - a. provide an accessible, confidential environment where a former psychiatric hospital inpatient may voluntarily describe his or her experiences in a psychiatric hospital (negative or positive), in complete confidence, to an informed, caring, receptive and non-critical Panel, concerning their treatment and experiences while an inpatient of a psychiatric hospital.
  - b. assist the former psychiatric inpatient at the discretion of the Panel by providing information on available services and referring them (and facilitating access via the Department of Internal Affairs, DIA) to appropriate services and agencies which may be able to provide counselling or other assistance and assist, where appropriate, with costs associated with counselling.
  - c. Allow family members of former in-patients who were in psychiatric institutions before 1 November 1992, and former staff members to describe their experiences to the panel.
2. The Confidential Forum for Former In-patients of Psychiatric Hospitals is not designed or intended to:
  - a. require or compel anyone to attend a Forum
  - b. determine liability nor the truth of the Participants' experiences or stories
  - c. make diagnoses of mental illnesses
  - d. recommend a particular course of treatment
  - e. pay, or recommend the payment of, compensation
  - f. judge Participants or anyone mentioned by a Participant, or to reach a conclusion about what might or might not have happened
  - g. in any way attempt to resolve differences of views

- h. share or make public any information relating to the stories it hears or make any public comment about anything presented to it
- i. allow Participants to have legal representation at Forums.

### **Panels and Meetings**

- 3. One or more Panels of appropriately qualified individuals are appointed by the Government to meet in Forums with Participants and to hear their stories. One panel will be appointed initially. Further panels may be appointed if needed.
- 4. Panels will normally comprise three members
- 5. Membership of Panels will include:
  - a. a person who is familiar with New Zealand's mental health service from a consumer's perspective (such as a member of a recognised mental health group),
  - b. a person who thoroughly understands the mental health system,
  - c. a person with a significant and respected community profile, and
  - d. a gender mix.
- 6. Each Panel will have a chairperson.
- 7. A Forum may be held with two Panel members if necessary, and in circumstances where a Participant prefers to tell their story to only one individual, that may be permitted if the Panel agree.
- 8. A member of the first Panel will also be appointed as Chair of the Forum and be the person responsible for overall leadership of the Forum.

### **Processes and Consultation**

- 9. The Chair of the Forum will
  - a. consult with mental health consumer representatives over proposed Confidential Forum processes, administration and accessibility, including sitting locations and assistance with travel costs for Participants.
  - b. ensure that the Confidential Forum determine its own processes and operations, within the parameters of these terms of reference.
  - c. Be the spokesperson for the Forum in the media to the extent that any media liaison is necessary or desirable to give effect to the terms of reference and is not inconsistent with the terms of reference.

### **Access by Participants**

- 10. The Chair of the Forum will:
  - a. publicly call for participation by eligible people once systems are in place
  - b. arrange for Forums to be held in locations and at times determined by the Chair of the Forum that are reasonable and accessible for Participants
  - c. arrange for Participants to be assisted, if necessary, with actual and reasonable transport costs in attending Forums (and other necessary costs

- in special circumstances), all assistance to be determined at the discretion of the Panel within specified parameters.
- d. arrange to hear stories of the families of former psychiatric in-patients and former staff in the same manner as the Panel hears the stories of Participants.
  - e. permit Participants to be accompanied by up to two support people to the Forum (but not legal representation), noting that support people will not have speaking rights except with the permission of the Panel.
  - f. permit Participants to bring to the Forum any documentary material that assists them.

### **Forum Environment, Confidentiality and Process**

11. The Panel will:
  - a. arrange to hear a Participant's experiences and stories in a comfortable, confidential and private setting, where the Participants can be confident of being heard in an appropriate manner.
  - b. ensure adequate processes and systems are established to maintain complete confidentiality.
  - c. advise each participant that they participate on the basis that what is said at a forum will be treated as strictly confidential and that all information will be retained confidentially and none of it will be used in any other Forum.
  - d. listen in an appropriately non-critical, non-judgmental, receptive and constructive manner.

### **Counselling and Support**

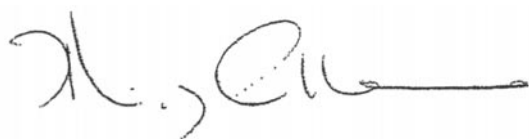
12. The Panel will:
  - a. advise the Participant of any current services, such as counselling services, the ACC, the Health and Disability Commissioner or other services as may be appropriate to provide additional treatment, support, assistance or management of any claims; including, if appropriate, referral of the Participant to the Police.
  - b. pay for an initial assessment for Participants who wish to attend counselling and if that assessment indicates that counselling is required, pay for up to ten counselling sessions with an approved counsellor (recognised by the Ministry of Health).
  - c. To the extent permissible within the bounds of the terms of reference, assist the Participant to come to terms with their experience and to achieve closure, as far as is reasonable within the context of the Forum.

## Reporting

13. The Panel will:
  - a. report quarterly through the Department of Internal Affairs to interested Ministers (especially the Attorney-General and Ministers of Health, Justice, Treasury and Internal Affairs) on the numbers of Participants heard, the type and amount of information about existing agencies provided to Participants, and the Panel's impressions of how useful the process was to Participants and expenditure against budget.
  - b. provide a final report to the Government through the Department of Internal Affairs once the role of the Confidential Forum has been completed, detailing the matters in 13(a) above.

## Administration and Support

14. The Department of Internal Affairs will provide administration and support of the Forum services.
15. The Panel(s) will work with the Department of Internal Affairs to establish initial and on-going administrative and financial services and support that will facilitate the operation of the Panel(s) and ready access by Participants, including when necessary the assistance of kaumatua, kuia and mental health experts.



Hon Dr Michael Cullen  
Attorney-General

2 March 2005

# APPENDIX 2: INVITATION TO PARTICIPATE IN THE FORUM

In the initial stages of its work the Confidential Forum for Former In-Patients of Psychiatric Hospitals prepared an invitation (in English and Māori) to attract the attention of those people who might wish to participate in the process. The invitation was printed as colourful posters and flyers. Its distribution (see page 10) was aimed at reaching its intended audience. The basic text of the two versions is provided below.

## English language text

### AN INVITATION

#### **Confidential Forum for Former In-Patients of Psychiatric Hospitals**

People who have been in-patients of psychiatric hospitals in New Zealand before the end of 1992 are invited to relate their experiences in confidence to Forum members appointed by the Government to listen. You can come forward by yourself or with support people.

- The Forum is a response to calls for a process to enable people to be heard.
- The Forum is available to former in-patients, family members and staff, in individual sessions.
- The Forum is an opportunity to reflect on the past and to look to the future.
- The Forum is not intended to reach a conclusion about what might or might not have happened, nor to recommend payment of compensation.

The Forum members are:

Judge Anand Satyanand

Mrs Jan Dowland

Ms Anne Helm

To attend a meeting of the Confidential Forum in an area near you, please contact us by letter, email or telephone at:

PO Box 10 076, The Terrace, Wellington

Email: [confidentialforum@dia.govt.nz](mailto:confidentialforum@dia.govt.nz)

Telephone: **0800 22 55 90**



A full copy of the Terms of Reference for the Forum is available on the website [www.confidentialforum.govt.nz](http://www.confidentialforum.govt.nz) or by telephoning 0800 22 55 90.

**For practical reasons this opportunity is time limited.**

## Māori language text

### HE KARANGA

#### Wānanga (Te Āiotanga) Noho Tapu mō ngā Tūroro i noho ki ngā Hōhipera Mate Hinengaro

He karanga tēnei ki ngā tāngata i noho hei tūroro ki roto i ngā hōhipera mate hinengaro o Aotearoa i mua i te tau 1992, ki te hoatu i ā rātou kōrero, wheako hoki mō te wā i reira rātou, ki ngā mema o te Wānanga kua whakaritea e te Kāwanatanga hei whakarongo ki a rātou. Ka noho tapu katoa āu kōrero. Kei i a koe te tikanga mehemea ka haere mai ko koe anake, ka hari hoa tautoko rānei koe.

- He urupare te Wānanga nei ki ngā tono kia whakatūria he huarahi e taea ai te whakarongo ki ngā tāngata hāngai.
- E wātea ana te Wānanga mō ngā tūroro, ngā whānau me ngā kaimahi o mua. Ka taea te haere takitahi.
- He huarahi te Wānanga hei hokinga mahara, hei titiro whakamua hoki.
- Ehara i te mea ka tutuki i te Wānanga nei he whakataunga ki ngā kōrero ka puta, ki ngā whakaaro hoki mō te utu, paremata rānei.

Ko ngā mema o te Wānanga ko ēnei:

Kaiwhakawā Anand Satyanand

Jan Dowland

Anne Helm

Ki te hiahia haere koe ki tētahi hui a te Wānanga Noho Tapu nei ka tū ki tō rohe, me whakapā mai ā-tuhi, ā-īmēra, ā-waea rānei ki:

Pouaka Poutāpeta 10 076, The Terrace,

Te Whanganui-a-Tara

Ī-mēra: [confidentialforum@dia.govt.nz](mailto:confidentialforum@dia.govt.nz)

Nama Waea: **0800 22 55 90**

Ka taea he kape o ngā tikanga whakahaere mō te Wānanga nei i runga i te paetukutuku [www.confidentialforum.govt.nz](http://www.confidentialforum.govt.nz), mā te waea rānei ki te nama 0800 22 55 90.

**He here kei runga i te roa o te haerenga o ngā mahi o tēnei hui.**



# APPENDIX 3: PROTOCOL FOR COUNSELLING REFERRALS

The protocol for counselling referrals was developed in August 2005 to formalise the counselling support that was made available to participants of the Confidential Forum.

## Confidential Forum for Former In-Patients of Psychiatric Hospitals

### Protocol for Counselling Referrals

Term of Reference 12(b) provides that the Forum will:

Pay for an initial assessment for Participants who wish to attend counselling and if that assessment indicates that counselling is required, pay for up to ten counselling sessions with an approved counsellor (recognised by the Ministry of Health).

In accordance with TOR 12(b) Forum participants will be referred to a counsellor for an initial assessment, if they indicate an interest in counselling. The process for referral depends on whether or not participants have an established counselling relationship they wish to use.

Set out below is the protocol to be followed.

#### *Participants without an established counselling relationship*

1. The Forum has contracted with Relationship Services to provide initial assessments and where relevant, counselling for participants who wish to have counselling support, but do not have an established counselling relationship.
2. Relationship Services has undertaken to ensure that all counsellors it provides will:
  - a. hold a relevant professional qualification
  - b. hold relevant professional membership
  - c. have experience working with clients who are, or have been, mental health consumers
  - d. follow Relationship Services policies, processes and both Relationship Services and professional codes of ethics.
3. If after initial assessment Relationship Services considers that further counselling is required, the Forum will pay for up to 10 sessions by a counsellor from Relationship Services, unless Relationships Services advises referral to another provider.
4. The number of counselling sessions provided will be based on ongoing assessment of the participant's requirements by the Relationship Services counsellor.

5. In circumstances where Relationship Services personnel advise that referral to another provider with different skills from those available through Relationship Services is required, the Forum will accept its advice and facilitate referral to the type of provider recommended.

*Participants with established counselling relationship*

6. Where a participant has an established counselling relationship but does not wish to have counselling from that provider in relation to issues that arise from their participation in the Forum, the same arrangements will be made as for participants who seek counselling but do not have a provider they wish to use.
7. Where a Forum participant has an established counselling relationship, and wishes to have counselling from that provider in relation to issues that arise from their participation in the Forum, the general principle is that they will be referred to that provider for an initial assessment. However, the Forum reserves the right to seek the assessment from a Relationship Services counsellor if the provider concerned is not able to provide satisfactory evidence of professional qualification, professional membership and experience of working with clients who are, or have been, mental health consumers.
8. Where a referral to a provider with whom the client has an established counselling relationship is made, and after initial assessment the provider considers that further counselling is required, the Forum will pay for up to 10 counselling sessions.
9. The number of counselling sessions provided will be based on ongoing assessment of the participant's requirements by the counsellor.

# APPENDIX 4: LETTER TO PARTICIPANTS

The document below formed the basis for the letter sent to individual participants in the Confidential Forum for Former In-Patients of Psychiatric Hospitals. People who had registered their interest in participating in the Forum received such a letter once a meeting date and time had been scheduled.

## Confidential Forum for Former In-Patients of Psychiatric Hospitals

Dear

### Meeting with Confidential Forum

Your meeting time with the panel members of the Confidential Forum is as follows:

**Date:**

**Time:**

**Place:**

**Panel members:**

### *What to expect*

When you arrive our Forum Support Facilitator [ ] will meet you. Your meeting with the panel is expected to last for up to 90 minutes. You may have to wait for a short time before your meeting starts if the person before you has taken a little longer than planned. There will be a private waiting room and hot or cold drinks and biscuits available.

### *Meeting with the panel*

You are welcome to bring two people with you to support you while you speak with the panel. If you wish, the Chairperson will offer the opportunity for karakia. He will welcome you and introduce the panel and then ask you to introduce yourself and to introduce any support people you bring.

A panel member will then ask you some introductory questions. These will be general questions, for example the institution(s) you will be talking about; when (approximately); and what the main issues are that you would like to tell the panel about. Then it will be your opportunity to relate your experience to the panel. The panel may ask questions to check they understand or to clarify something. Sometimes the panel may suggest a short break during the meeting and you also can ask for a break if you wish.

If you would like your support person to say some things for you, you need to tell the panel.

What you tell the panel will be confidential and the information you give will not be made public. The panel is required to report to the Government quarterly, but no-one will be identified in those reports.

#### *Preparing for the meeting*

If you would like some help to work out how you would best like to present your experience to the Panel, you can speak to our Forum Support Facilitator on 0800 22 55 90 or contact a health and disability consumer advocate. The number for the advocacy services for [ ] is [ ]. The advocates can help you identify and clarify issues and help you prepare for the meeting.

#### *Recording the meeting*

In order for the panel to do its work the meeting will be recorded. If you do not wish the meeting to be recorded please let the panel know. The recording will be treated as confidential to the Forum. A copy of the recording will be available for you, if you would like a copy.

#### *Documents/Records*

You are welcome to bring any documents or records with you that will help you give your account. If you wish to give these to the panel they will be kept stored safely in a locked cabinet and kept confidential.

#### *Tikanga Māori*

If you have any cultural or spiritual protocols or practices you would like observed, please let our Forum Support Facilitator know by telephoning our 0800 number (0800 22 55 90). If you wish to speak to the panel in Māori, please also let us know and we will arrange an interpreter. Likewise, if you wish to speak in another language, please let us know.

#### *After the meeting*

After the meeting you are welcome to go back to the waiting room for some refreshments and to spend some time. The person who greeted you will be available during this time.

If you need any special assistance for the meeting or have any questions, please do not hesitate to telephone 0800 22 55 90.

Yours sincerely

Katharine Greig

**Executive Officer**

# APPENDIX 5: CONDUCT OF FORUM HEARINGS

In July 2005 the Confidential Forum for Former In-Patients of Psychiatric Hospitals established rules for the conduct of its meetings. All members of the panel were involved in establishment of the rules and were familiar with them. Some of the information in this document was also provided to participants at the time of their attendance at the Forum.

## Conduct of Confidential Forum Hearings

The Terms of Reference (TOR) require the Chair to ensure the Confidential Forum determines its own processes and operations, within the parameters of the Terms of Reference (TOR 9(b)).

Set out below are the rules for the conduct of Forum meetings.

### 1. Hearing times

Hearings will be held between 9am and 5pm with early evening sittings possible on a 'case by case' basis, but not as a general rule.

### 2. Number of hearings per day

There will be four hearings per day and five if time permits. Hearings are by appointment with appointment times generally 0900; 1100; 1330; and 1530 – with up to 90 minutes allocated per hearing.

### 3. Quorum

- a. As a general rule, all three panel members should be present for hearings.
- b. In the event of a request from a participant, fewer than three can be present; such requests to be decided on a case by case basis by the panel (TOR 7).
- c. At the request of any member of the panel the quorum can be two – for example in the event of a conflict of interest or illness.

### 4. Conflicts of interest

If at any stage before or during a hearing a panel member feels they may have a conflict of interest, such as a personal or professional relationship with any Forum participant, this should be brought to the attention of the Chair of the Forum, who will decide on the appropriate course or action.

## **5. Hearing Process**

- a. The Chair will welcome participants, where appropriate offer the opportunity for karakia; introduce the panel to participants and support people; commence the hearing with a statement about confidentiality based on the Forum's legal advice, followed by opening, introductory questions to assist the participant to commence.
- b. All panel members can ask questions.
- c. Hearings will be recorded unless the participant requests that their hearing is not.
- d. The Chair will consider all requests by participants for a copy of the hearing recording, on a case by case basis.
- e. The Executive Officer of the Forum may attend hearings, unless a participant expressly asks that the Executive Officer not be present, but has no speaking rights.
- f. In accordance with TOR 10(e) participants may have up to two support people at a time with them in the hearing.
- g. The Chair will consider all requests for speaking rights by support people on a case by case basis (TOR 10(e)).
- h. Participants and panel members can request a break during the hearing. The Chair will decide the length of the break.
- i. At the conclusion of the hearing the Chair will prepare a dictated 'anonymised' minute to which all panel members may contribute.

## **6. Administrative Processes**

- a. The guiding principle for meeting venues is that to the extent possible they should be accessible, comfortable and private.
- b. Before and after hearings there will be hot and cold drinks available and to the extent possible, participants and their support people waiting to attend hearings will have a separate waiting room from participants and supporters who already have had their hearing.
- c. A support person for participants will be present at hearing venues, to greet participants, answer any queries about the process, and to be available for participants to talk to after the Forum hearing. Because of the desire of participants for confidentiality, the support person will not be a local of the area in which hearings are held.
- d. Written information for participants on organisations and groups that can assist with providing support post-hearings will be available at hearing venues.

## **7. Concerns about well-being of Participant following meeting**

- a. The Forum acknowledges a responsibility to take action in situations where, following a hearing or settling period with the Forum support person, concern is registered about the immediate well-being of the participant.

- b. In such a situation, the basis on which assistance will be sought is as follows:
- the Forum support person will discuss with the participant appropriate avenues of assistance and will seek the participant's consent to access this;
  - if consent is not given by the participant, the Forum support person will endeavour to negotiate with the participant a course of action to obtain appropriate assistance;
  - if negotiation is not possible or successful, and the Forum remains concerned, the Chair will decide the appropriate course of action.

What is appropriate assistance will be determined on a case by case basis.



## APPENDIX 6: VENUES AND DATES OF FORUM HEARINGS

*A total of 154 days of Forum hearings were held in 22 locations throughout New Zealand between July 2005 and April 2007.*

Table 1 summarises the locations of Forum hearings in 21 towns and cities around the country (together with one hearing held within the Mason Clinic, an institution in Auckland). Table 2 lists the dates for individual hearings.

**Table 1: Forum hearings by locations, number of visits, and days involved**

Hearing location	Visits	No. of hearing days
Auckland	13	34
Blenheim	1	1
Christchurch	8	21
Dunedin	3	11
Gisborne	1	2
Greymouth	1	2
Hamilton	5	12
Invercargill	1	1
Kaitiāia	1	2
Mason Clinic	1	1
Napier	2	3
Nelson	3	6
New Plymouth	2	4
Palmerston North	3	9
Rotorua	2	6
Taupō	1	2
Tauranga	3	6
Thames	1	2
Wanganui	1	2
Wellington	9	18
Whakatāne	2	3
Whangarei	2	6
<b>Total</b>	<b>66</b>	<b>154</b>

**Table 2: Location and dates of Forum hearings**

Venue	Month	Dates	Days Total
<b>2005</b>			
Wellington	July	11, 12	2
Wellington	July	18, 19, 20	3
Wellington	July	29	1
Wanganui	August	17, 18	2
Dunedin	August/September	31 Aug, 1, 2 Sep	3
Auckland	September	8, 9,	2
Auckland	September	12, 13	2
Auckland	September	27, 28, 29	3
Christchurch	October	11, 12, 13	3
Auckland	November	2, 3, 4	3
Auckland	November	10 & 11	2
Hamilton	November	14, 15, 16	3
Wellington	December	1	1
Blenheim	December	6	1
Nelson	December	7, 8, 9	3
<b>2006</b>			
Christchurch	January	11, 12, 13	3
Palmerston North	January	18, 19, 20	3
Tauranga	February	8, 9, 10	3
Whakatāne	February	15, 16	2
Auckland	February	21, 22, 23	3
Whangarei	March	6, 7, 8	3
Thames	March	15, 16	2
Tauranga	March	17	1
New Plymouth	March	21, 22	2
Wellington	March	30, 31	2
Hamilton	April	5, 6, 7	3
Wellington	April	19, 20	2
Hamilton	April	27, 28	2
Rotorua	May	3, 4, 5	3
Auckland	May	9, 10	2
Christchurch	June	7, 8, 9	3
Dunedin	June	13, 14, 15, 16	4
Palmerston North	June	21, 22	2

Table 2 continued

Venue	Month	Dates	Days Total
Napier	July	12, 13	2
Wellington	July	14	1
Christchurch	July	19, 20, 21	3
Christchurch	July	25, 26, 27	3
Nelson	August	9, 10	2
Auckland	August	14, 15	2
Mason Clinic	August	16	1
New Plymouth	August	30, 31	2
Wellington	September	5, 6, 7, 8	4
Auckland	September	12, 13, 14	3
Hamilton	October	24, 25	2
Taupō	October	26, 27	2
Auckland	October/November	31, 1, 2, 3	4
Tauranga	November	7, 8	2
Whakatāne	November	9	1
Auckland	November	14, 15, 16	3
Rotorua	November	28, 29, 30	3
Christchurch	December	4, 5, 6	3
Greymouth	December	7, 8	2
Gisborne	December	13, 14	2
<b>2007</b>			
Auckland	January	23, 24, 25	3
Dunedin	January/February	29, 30, 31, 1	4
Christchurch	February	12, 13	2
Invercargill	February	14	1
Palmerston North	February	20, 21, 22, 23	4
Whangarei	March	5, 6, 7	3
Kaitiāia	March	8, 9	2
Wellington	March	19, 20	2
Hamilton	March	21, 22	2
Auckland	March	26, 27	2
Napier	March	28	1
Nelson	April	11	1
Christchurch	April	12	1

# APPENDIX 7: PSYCHIATRIC INSTITUTIONS

**This appendix deals with New Zealand institutions for those with psychiatric and intellectual disabilities.**

The appendix is in three parts:

- the institutions spoken about by participants at the Forum (Many of these institutions are now closed.)
- the institutions according to location, the type of resident, and the closure date, with some explanatory notes
- the trend over time in the numbers hospitalised in psychiatric and intellectual disability institutions.

Note that whereas the first part is specific to the Forum, the other two parts provide national data.

## **Institutions mentioned by Forum participants**

Table 3 lists the institutions referred to by participants as ones with which they had association by virtue of being patients there, staff members there, or family members of in-patients. No attempt has been made to identify official names. Sometimes participants referred to mental health units within public hospitals by the name of the unit (for example, Manawaroa, which is part of Palmerston North Hospital). Sometimes they referred only to the name of the hospital. Where the name of the unit within the hospital was referred to often by patients as “the institution” it has been included.

**Table 3: Psychiatric and intellectual disability institutions referred to by Forum participants**

<b>Institution</b>	<b>Institution</b>
Ashburn Hall/Clinic, near Dunedin	Aspell House, near Wellington
Auckland Hospital (including the Connelly Unit and Te Whetu Tawera)	Avondale Mental Hospital, Auckland
Barrett St Hospital, New Plymouth	Bexley Clinic, Auckland
Braemar Hospital, Nelson	Buchanan Clinic, Auckland
Calvary Hospital, Christchurch	Carrington Hospital, Auckland
Cherry Farm Hospital, near Dunedin	Dunedin Public Hospital, Dunedin
Gisborne Hospital	Hastings Hospital, Hawke's Bay
Hillmorton Hospital, Christchurch	Hutt Hospital (Te Whare Ahuru), Lower Hutt

*continued opposite*

Table 3 continued

Kenepuru Hospital, Wellington	Kew Hospital, Invercargill
Kimberley Hospital, Levin	Kingseat Hospital (including Claybury House), Auckland
Lake Alice Hospital, near Marton	Mangere Psychopaedic Hospital, Auckland
Mason Clinic, Auckland	Middlemore Hospital (Tiaho Mai), Auckland
Nelson Hospital	Ngawhatu Hospital, Nelson
North Shore Hospital (Taharoto), Auckland	Oakley Hospital, Auckland
Orokunui Hospital, near Dunedin	Palmerston North Hospital (Manawaroa)
Porirua Hospital	Princess Margaret Hospital, Christchurch
Queen Mary Hospital, Hanmer	Rotorua Hospital
Seacliff Hospital, Dunedin	Seaview Hospital, Hokitika
Selwyn Hospital, Auckland	Sunnyside Hospital, Christchurch
Taranaki Base Hospital, New Plymouth	Tauranga Hospital
Templeton Hospital, Christchurch	Te Whare Mahana, Golden Bay
Thames Hospital	The Cottage, Auckland
Timaru Hospital	Tokanui Hospital, Waikato
Waikato Hospital and Henry Rongomau Bennett Centre	Waitakere Mental Health Unit (Te Atarau)
Wakari Hospital, near Dunedin	Wanganui Hospital (Te Awhina)
Wellington Hospital	Whakatane Hospital
Whangarei Base Hospital	

## Historic and current psychiatric and intellectual disability institutions

Table 4 records information about the closure dates (or, in some instances, reconfiguration) of psychiatric and intellectual disability institutions referred to in this report. Information in the table below on the date of closure should be read in conjunction with the table footnotes.

**Table 4: Psychiatric and intellectual disability institutions in New Zealand, including former institutions and their date of closure**

Name	Location	Type of residents	Approximate date of closure
Kingseat (includes Ravensthorpe)	South Auckland	PD and ID	1993–94
Carrington	Auckland	PD	1992–93
Oakley	Auckland	PD	1987
Mangere	Auckland	ID	1993–94
Tokanui	Waikato	PD and ID	1998–99

*continued overleaf*

Table 4 continued

Kimberley	Levin	ID	2007
Lake Alice	near Marton	mainly PD	National Secure Unit closed 1999–2000 Open side of the hospital closed mid-1990s
Braemar	Nelson	ID	Closed after 2002
Ngawhātu	Nelson	PD and ID	1999–2000
Porirua	Wellington	PD and ID	Reconfigured since 1996
Seaview	Hokitika	PD and ID	1999–2000
Templeton	Christchurch	mainly people with ID	2000
Sunnyside	Christchurch	mainly people with PD (one ward for ID)	Reconfigured 2001 Now known as Hillmorton Hospital
Cherry Farm	north of Dunedin	PD and ID	1991–1992
Seacliff	Dunedin	PD and ID	1966 as a result of fire. Replaced by Cherry Farm

Source: Adapted from data and notes provided by the Ministry of Health.

Abbreviations: PD: psychiatric disabilities; ID: intellectual disabilities.

Notes: The information has been compiled from a Ministry of Health media response dated 5 September 2001, with some updates. It should be used as a guide only because there are reasons, including those set out below, why it is difficult to collate such information.

When using the information it is important to remember that institutions were reducing their bed numbers over time, since peak number of beds in the late 1940s.

After an announcement is made that an institution will close it can take a number of years before the final resident moves out.

Closure may be recalled as the time when most residents had moved out, when the final resident moved out, or at some other time such as when the site was recommissioned or disposed of, hence the difficulty of ensuring consistency of interpretation across different times and locations.

Before 1993 deinstitutionalisation was not subject to central government planning provisions. It was not until 1994 that guidelines were issued that health authorities were required to follow in managing and planning deinstitutionalisation.

All institutions have now either closed or significantly downsized and reconfigured their services, for example, Porirua Hospital campus.

The information provided does not include the only privately organised psychiatric hospital – namely Ashburn Clinic in Dunedin (formerly known as Ashburn Hall), which is still operating. Neither does the information include Alcohol and Drug Treatment residential facilities.

## Population of psychiatric institutions over time

Table 5 records the trend over time in the numbers hospitalised in psychiatric and intellectual disability institutions in New Zealand.

**Table 5: Hospital populations of psychiatric and intellectual disability institutions, 1945 to 1990. Average number of residents and rates per 100 000 of population**

Year	Numbers hospitalised	Per 100 000 population
1945	8 308	490.3
1950	8 852	463.7
1955	9 723	454.6
1960	9 957	418.9
1965	10 492	398.1
1970	10 169	360.6
1975	8 475	274.6
1980	7 321	233.8
1985	6 464	197.8
1990	4 910 residents on 31 December 1990	

Source: Mental Health Data 1985, National Statistics Centre, Department of Health; Mental Health Data 1990, Department of Health.

## APPENDIX 8: PARTICIPANT GROUPS

This appendix categorises participants according to gender and age of first admission. It also tabulates the time periods under discussion at the Forum according to the three primary groups of participants (former patients, family members, staff members).

**Table 6: Gender and age of first admission of participants who were former in-patients**

Former patients participating	% of Former patients
<b>Gender</b>	
Female	60
Male	40
<b>Age of first admission</b>	
12 or under	5.5
13–15	10
16–19	23
20–25	28
26–29	14
30s	11
40s	3
50s	1
60s	0.5

Note: Some participants did not indicate their age at first admission.

**Table 7: Decades discussed at the Forum by participants according to their designation as former patient, family member, or staff member**

Decades spoken about	Participant groups		
	% of former patients	% of family members	% of staff members
1940s	<1	0	1
1950s	8	11	14
1960s	29	26	21
1970s	44	42	39
1980s	53	53	50
1990s	44	55	29

Note: Some participants spoke about more than one decade.