Journeys of Despair,
Journeys of Hope

Young Adults Talk About Severe Mental Distress, Mental Health Services and Recovery

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Mihi

E ngā mana,
e ngā reo,
e ngā karangaranga maha o te ao Māori.
Kei te tangi atu ki ngā mate o ngā marae maha o Aotearoa.
He karangatia tēnei ki a koutou katoa ki te whakaohooho
i te Mauri o tēnei kaupapa.
He kaupapa whakahirahira mo tātou te iwi Māori.
Young adults with severe mental health problems have unique challenges and patterns of service use. Not only do many people begin to use mental health services between the ages of 18 and 29, they are one of the largest groups of service users. The decisions, identity formation and life events experienced by young adults can have a powerful impact on the rest of their lives. Conversely, young adults often have a greater ability to grow and change than older adults. Yet mental health services do not always respond to young adults as a group, when they cluster people from 18 to 64 into adult mental health services. That is why the Mental Health Commission has interviewed forty young adults about their experience of mental distress, mental health services and recovery, and thematically analysed them in this report.

Like the people in this report I developed severe mental health problems as a young adult. Becoming an adult and finding our place in the world is a challenge for most people. But too many young adults with mental health problems also have to live through the experience of ‘symptoms’, a marginalised identity, multiple disruptions to their lives, a pessimistic prognosis, and unreliable services. The ordinary job of becoming an adult can suddenly grow into a monumental struggle.

Many of the young adults in this report talk about the accumulated abuse, neglect, insecurity and loss in their early lives that snowballed into severe mental health problems later on. Though many tried to get help from mental health services before they reached crisis point, they were often turned away. Their experiences of mental health services ranged from terror in adult acute inpatient units, to praise and gratitude for some of the other mental health services they used. In the face of such obstacles we can only admire their courage and resilience.

We all know that children at risk should get reliable help at the time, either from their families and communities, or failing that, from education, health and social agencies. If they don’t get help they may be at increased risk of developing mental health problems. It is also self-evident that once people start developing mental health problems, they should be able to access services early, before their lives completely unravel. And the services they receive must be trustworthy and focused on recovery. We all know these things, but we have often failed to translate this knowledge into action.

“Journeys of Despair, Journeys of Hope” should be read by a wide range of people and agencies. It is an important report because it fills a gap in our awareness and in the literature. And its message is very, very clear. Vulnerable children, young people and young adults deserve better than they often get. Responsibility rests not just with mental health services, but with us all.

Mary O’Hagan
Commissioner
Every year around 18,000 young adults between the ages of 18 and 29 are in contact with New Zealand’s mental health services. For over 7,000 young adults it will be their first contact. Sometimes this will involve only one or two appointments, perhaps for an assessment, but for many the contact will come about as the result of a severe mental health crisis and mark the beginning of a significant period of service use.\(^1\)

Adult mental health services in New Zealand are designed to provide treatment and support for recovery for the 3 percent of the adult population who experience severe and often disabling mental health problems in any one six-month period.\(^2\) Our mental health services are delivered through a complex system, which includes crisis, acute, non-acute and specialty services, delivered in hospital, community and residential settings, and run by District Health Boards (DHBs) and non-governmental organisations (NGOs). Services are staffed by people from a variety of mental health professions and backgrounds, often working in multi-disciplinary teams.

Accessing services can be a complex matter, with access criteria involving severity, availability and other factors. The route into mental health service use is frequently through assessment by a crisis service, admission into an inpatient unit, and on discharge, referral to generic community mental health services, which often broker the more specialised services. Many people have continuing relationships with community mental health teams, may use specialised services for periods of time, and have further inpatient admissions at occasions of crisis. Some services are specialised around diagnosis or type of mental health problem (e.g., eating disorders, early psychosis intervention, anxiety disorders); others are developed with a focus on age groups (e.g., youth specialty services), cultural background (e.g., Māori and Pacific services) and gender (e.g., maternal mental health). Other services focus on delivering generalised support (e.g., supported accommodation, employment services, activities programmes). Forensic services have a different route of access, via the criminal justice system.

Overall, the mental health service system has its own unique culture, with rules and expectations that may be quite foreign and difficult for a newcomer to understand. This means that at a time of great turmoil – emotionally, mentally and spiritually – young women and men first coming into the mental health services must learn to negotiate their way through unfamiliar territory, becoming known as “service users”, “tangata whaiaora” or “mental health consumers”. Quite a few of them will have had no choice in their

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1 Data provided by the New Zealand Health Information Service, NZHIS for 2005. This data refers only to contacts with services provided by District Health Boards and excludes contacts with non-governmental organisations (NGOs) providing publicly funded mental health services. However, most NGOs provide non-clinical services and their users usually have ongoing contact with DHB-provided clinical services, so the figure is not a significant underestimate of service use.

2 In this report we use a variety of terms such as severe mental health problems, disabling mental health problems, and at times mental health crisis, to refer to the experience of those who have been judged to have a severe “mental illness” and therefore meet the criteria for access to mental health services. We use this variety of terms to reflect the preferences of the young adult service users we consulted, most of whom disliked the term “mental illness”.

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CHAPTER

Introduction
arrival into this territory, having been delivered via Mental Health (Compulsory Assessment and Treatment) Act procedures. Others will have sought help and safety in their distress.

Some young adult service users will have experienced mental health problems as children or teenagers. However, most first-time users of adult services will never have used child and youth mental health services, which are under-provided in New Zealand (Barnett, 2004; Mental Health Commission, 2005). Those who have used them will, in meeting up with adult services, encounter a quite different system of service provision, although there will be familiar aspects.

So it happens that young adults in crisis must begin to learn to make sense of mental health services, their culture and organisation. Through experience, they need to learn what services can deliver to them that will be useful and, perhaps, what they want to avoid. They may also need to learn how to negotiate being able to leave services to which they have been sent on a compulsory basis.

As well as learning to make sense of services, those who have developed a severe mental health problem need to learn to make sense of the experiences and states of mind that led to and feature in their crisis. They also need to learn more about what will help and hinder them in their recovery.

Further, the disruptions people undergo in crisis, and during the period leading up to a crisis, will have impacted on family and whānau, friends, partners and flatmates, as well as on their everyday activities, work, careers and education. Dealing with these disruptions is part of recovery, too.

To add to these challenges, having severe mental health problems is a socially stigmatising condition. People who experience these problems must learn to deal with prejudice and ignorance, as well as the negative attitudes towards mental illness that they may themselves share, along with others in their circles.

MENTAL HEALTH SERVICES IN THE TWENTY-FIRST CENTURY

Mental health service provision is not what it was. It has changed radically over the last three decades, both in terms of how and where services are delivered and in terms of expectations about recovery from disabling mental health conditions.

Much of the literature dealing with recovery from mental health conditions, including both research literature and personal accounts, has been based on the experiences of people whose first encounters with mental illness and mental health services occurred during the era when large psychiatric hospitals were the basis of service provision. Those environments – strange, separate and closed-off from ordinary life in the community – shaped people’s experiences to the extent of becoming central to their personal identity. The stigmatised identity of “mad people” or “psychiatric patients”, outsiders to the communities they came from, was well theorised by American sociologist Erving Goffman (1963), who investigated the social status and life paths of people who spent much of their adult lives in such institutions.

The recovery literature in mental health has convincingly shown that people with disabling mental health problems can recover and live well when they have a more everyday kind of environment, and that people can recover more rapidly from mental health crises when they are not torn away from their ordinary lives and made to embark on “careers” as psychiatric patients. (Davidson, Harding, & Spaniol, 2005; Goldsack, Reet, Lapsley, & Gingell, 2005; Harding & Zahniser, 1994; Lapsley, Nikora, & Black, 2002; Onken, Dumont, Ridgway, Dornan, & Ralph, 2002).

In the “recovery era” of today, where recovery is embedded as a value and goal into mental health policy, we no longer expect young adults who are first experiencing severe mental health difficulties or a severe mental health crisis to be told that they should greatly lower
their expectations of striving for a satisfying life. They should not be told to give up hopes for a career, or that it would be unwise for them to start a family, as many young adults were told in the past.

Now we expect service users to learn to “live well in the presence or absence of their mental illness,” to quote the Mental Health Commission’s Blueprint for Mental Health Services (Mental Health Commission, 1998, p.1). For New Zealanders in the twenty-first century, it is no longer expected that a severe mental health crisis will lead to a long stay in a hospital setting. The median length of hospital stay in mental health is now only three weeks3, and there are no large psychiatric hospitals remaining. Mostly, hospitalisation will occur in wards of general hospitals. Increasingly, there are alternative settings and techniques developing for dealing with crisis – such as respite and recovery houses and home-based crisis services.

Most mental health service delivery is now based in the community. Community-based mental health teams provide crisis assessment services; if a person is then hospitalised, these teams should follow up afterwards for as long as a person is unwell or at risk of becoming unwell again. Community mental health may refer on to specialised services, if they are available. These include eating disorders, maternal mental health, drug and alcohol, and intensive psychotherapy services. Early intervention services are particularly promising for young adults who experience psychosis. Māori and Pacific providers have services organised around cultural needs and practices, and increasingly, peer support and other service-user run services are available. There are also specialised housing providers, activities and employment services for those who need longer-term or social assistance. Another specialty, forensic services, may be hospital or community based. Overall service provision is designed around a focus on rapid recovery from crisis and, through support and treatment, a lessening of the long-term impacts of disabling mental health experiences.

New Zealand now has recovery-oriented mental health policies in place, and an infrastructure of services that, although falling short of the ideal – far short at times – are set up to offer a range of supports and treatments to facilitate recovery. The Blueprint endorses a recovery approach to service delivery that emphasises empowerment, service user rights, best outcomes, self determination and full participation in society (Mental Health Commission, 1998, p. vii). However, the reality is that in our current mental health services, there are shortfalls in quality, workforce problems, controversies about appropriate treatment, and over-use of compulsion on service users. Access to services when they are needed can also be difficult.

New Zealand has also worked to change discriminatory attitudes and practices towards mental health service users. A number of effective strategies have been in place over the last few years that should have diminished, although they will not have ended, the stigma faced by young adult first-time service users (Mental Health Commission, 2004a).

**YOUNG ADULTS USING MENTAL HEALTH SERVICES**

Young adults aged 18-29 are one of the largest mental health service user groups in terms of age group and are the largest group of first-time users of adult services. In 2005, of the more than 18,000 young adults seen by mental health services, 55% were male and 45% were female. Men and women have different patterns of mental health difficulties, with men in this age group more likely to have psychosis spectrum disorders (Ministry of Health, 2004).

Access to inpatient services via compulsion occurs at a high rate, with around half of those in inpatient settings being there under the Mental Health Act (Mental Health Commission, 2003).

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3 Data provided by the New Zealand Health Information Service, NZHIS, 2006.
In terms of ethnicity, in the age group 18-29, 23% of service users are Māori, 6% Pacific, 3% Asian and 68% of other ethnicities (mainly Pakeha/New Zealand European). This is congruent with the overall picture for all age groups, where access rates for Māori are higher than for the largest population group (Pakeha/other). Access rates are lower for Pacific and especially low for Asian ethnicities (Mental Health Commission, 2005).

Although approximately one-fifth of the adult population may have a mental health condition at any one time, New Zealand’s free mental health service provision is designed around the needs of the 3 percent of the adult population who in any one six-month period are most severely affected by disabling mental health problems. The target access rate for young people aged 15-19 was set at 5.5 percent (Ministry of Health, 1998).

At the present time these access rates have not been achieved. The national access rate for adults 20-64 years is 1.8 percent; it is 2.0 percent for young people aged 15-19 years (Mental Health Commission, 2005). These figures suggest that many people are not accessing the mental health services they need. It seems that, on the whole, only those people who are in crisis, or who have very severe symptoms, or who are already known to the service tend to gain access, unless they have symptoms of psychosis.

YOUNG ADULTS: DISTINCTIVE ISSUES AND NEEDS?

While the Blueprint identifies young people as a target group with particular physical, cultural and developmental needs, and signals the importance of early intervention, there has not been much debate, in terms of policy and practices, around the particular needs of service users in the young adult age group, i.e. 18-29 year olds as opposed to adolescents.

One exception is the development of early psychosis intervention (EPI) services, which has brought a focus on the needs of young adults with first-episode psychosis spectrum disorders. But overall, there is little published research in New Zealand relating to young adults’ lived experiences of a diverse range of disabling mental health problems in the context of first use of adult mental health services.

In New Zealand, and internationally, children and youth are regarded as having distinctive needs and services have been set up to cater for them separately. Child and Adolescent Mental Health Services across the country provide services for young people under 18 years old. Youth specialty services in some regions provide for the age group 15 to 19 years. In several cities there are also specialised inpatient units for children and teenagers, or for youth up to age 19.

Early psychosis intervention services are designed for both youth and the young adult population. They are a specialty service in the spectrum of adult care, and psychotic spectrum disorders do account for a significant proportion of the mental health problems that bring people in this age group into prolonged contact with mental health services. Other than early intervention services, there are no service types designed specifically around the needs of the 18-29 year age group. However, certain service types, e.g. maternal mental health, eating disorders and services for “borderline personality” disorders, may see people predominantly from this age group, although they are not restricted to those under 30.

We suggest that young adults have a distinctive profile, in terms of developmental needs and life stage transitions. The socially prescribed “tasks” of young adulthood include gaining autonomy from parental authority, establishing independent lives, taking up tertiary education, gaining employment and developing careers, gaining financial independence, travelling overseas, becoming citizens who vote, learning to drive, developing adult relationships and starting families. This age group have also

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4 Data provided by the New Zealand Health Information Service, NZHIS, 2006.
grown up in a particular cultural and socio-cultural context that has shaped their lives in ways that are different from those affecting the group aged 30 and over. In terms of mental health, this is the age at which problems typically intensify and lead to first service contact. International research literature increasingly suggests that this distinctiveness needs to be taken into account in the design and delivery of mental health services (e.g., Castle, McGrath, & Kulkarni, 2000; Harrop & Trower, 2003; Lewinsohn, Petit, Joiner, & Seeley, 2003; Martindale, Bateman, Crowe, & Margison, 2000; Porter, 2002).

Patrick McGorry, a leading figure in the development of early intervention services in Australia, has suggested that young adults are frequently traumatised by the experience of adult inpatient services, because those services are not designed around their needs, but instead cater to a group of older adults with severe and chronic mental health difficulties.5


YOUNG ADULTS, DIAGNOSIS AND MENTAL HEALTH SERVICE PROVISION

In this report, we use the term psychosis spectrum disorders to include a range of disorders characterized by a primary disturbance of thinking which is reflected in certain symptoms, particularly disturbances in perception (such as hearing voices), and unusual or disorganised patterns of thinking. Schizophrenia-type disorders, as well as some bipolar disorders, are commonly associated with psychosis.6

6 Although we refer to diagnoses and diagnostic groupings throughout this report, we acknowledge that diagnoses often have poor reliability and validity and may not relate very strongly to treatment and service needs (e.g., Read, 2004). However, mental health services are typically required to use diagnoses for accountability purposes, and services may be designed around particular diagnostic groupings.

A variety of mental disorders that do not necessarily involve the experience of psychosis also bring young adults into contact with mental health services. These include severe depression and anxiety, eating disorders, post-traumatic stress disorders and “borderline personality” disorders. Although psychotic spectrum disorders are of low prevalence in the population, their severity and distinctiveness, means that those experiencing them gain access to the services more readily. Indeed, some mental health services using strict access criteria tend to see their more intensive services as mainly for people with psychosis spectrum diagnoses.

At times in this report we use the terms “psychosis group” and “non-psychosis group” as convenient phrases to describe people in terms of their diagnoses, even though we have qualms about doing so! However, at times their pathways and experiences were significantly different.

Early Intervention for Psychosis

In New Zealand, there have been significant developments in the provision of early psychosis intervention services. This is also an international trend (Johannessen, 2004; O’Toole et al., 2004; Turner, 2002). National mental health plans and implementation strategies have directed moves toward the provision of more appropriate and better quality services to people in the young adult age group who meet the criteria for psychosis spectrum diagnoses (Mental Health Commission, 1998). At the present time in New Zealand, there are 18 early psychosis intervention (EPI) services or areas where there are mental health professionals working individually to target early intervention. The Mental Health Commission publication Early Intervention in Psychosis: Guidance Notes (1999) spells out the rationale, principles and practices required for a recovery model of early psychosis intervention. The national Early Intervention Steering Group is shortly to publish updated guidelines.

First episode psychosis research, usually carried out from biomedical perspectives, indicates that intervening early – ideally during
the prodromal phase before psychosis has fully developed, but also during and in the aftermath of a first episode—has enormous potential to ameliorate the long-term course of the disorder and its associated disadvantages (Harrop & Trower, 2003; Johannesssen, Larsen, McGlashan, & Vaglum, 2000; McGorry, 2000). Psychosis impacts on people in many ways: its negative impacts include interrupted social, psychological and educational development and functioning, depression, suicidal behaviour, unemployment, economic hardship, impoverished social networks, involvement with the criminal justice system, higher risk of drug and substance use, worsened physical health, loss of self-esteem, alienation, discrimination, and self-stigma. Intervening early also decreases the need for hospitalisation and compulsory treatment. It can enable young adults to remain in the community, in their home environment and ensure faster and more complete recovery. Indeed, there is ample research to indicate that intervening early and appropriately can positively alter the course and duration of psychosis by increasing the chances of optimum recovery and limiting the likelihood of relapse (O’Toole et al., 2004; Turner, 2002).

In New Zealand, there is a small but growing body of local research concerning first episode psychosis and the effectiveness of our Early Psychosis Intervention Services (Geekie, 2004; Turner, 2002; Turner, Nightingale, Smith-Hamel, & Mulder, 2004). There are also wider debates in this country around the conceptualisation of “schizophrenia” (Read, Mosher, & Bentall, 2004) and the effectiveness of traditionally biomedical approaches to psychotic disorders. An influential body of local and international research identifies trauma and childhood abuse, unhappy family backgrounds and poverty as key contributors to psychosis. This work can be used to advocate for including psychological treatments amongst services offered for psychosis. Early intervention best practice guidelines do currently advocate psychological input (Mental Health Commission, 1999).

Non-Psychosis Diagnoses

Patrick McGorry (2000, p 270) has commented that equating the notion of “serious mental illness” with the psychotic disorders has become increasingly popular in Australia and elsewhere where specialist mental health care is constrained by limited budgets. He argues that it is important for mental health services to broaden the diagnostic focus to accurately reflect young adults’ first experiences of severe mental ill health. While the development of early intervention services is a step in the right direction for mental health service provision, there are many young adults, especially young women (see below) whose first experiences of a disabling mental health problem do not meet the criteria for access to EPI services, which are the focus of early intervention approaches.

In fact, most young adults presenting to mental health services for the first time received diagnoses that fall outside the psychosis spectrum such as post-traumatic stress disorder, borderline personality disorder, major depression, and anxiety disorders. This trend is consistent with findings internationally (McGorry, 2000). Many of them are likely to be pointed in the direction of generic adult mental health services where early intervention does not occur, and where services are not specifically designed to meet the needs of the young adult age group. Some do receive specialised services, such as eating disorders, maternal mental health and services for “borderline personality”, where young adults (women in particular) may be the primary age group, although services are not limited by age.

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7 Fraser Health Authority Program http://www.psychosissucks.ca/epi.
8 Data provided by the New Zealand Health Information Service, NZHIS for 2005
Gender Issues

Young women comprised almost half of all young adults seen by mental health services in 2005 and are more likely than men to experience non-psychosis disorders. This needs to be considered in the context of wider mental health discourses, research and practice relating to young adults. In much of this work “serious mental illness” has become a synonym for “psychosis” and primarily centres on the mental health experiences of young men (Castle et al., 2000; Hafner et al., 1998). Database searches using the terms “first episode”, “early onset” and “early intervention” invariably result in hits related to psychoses; these tend to focus on teenagers or youth up to the age of 25.

International research indicates that for men who experience psychosis spectrum disorders, the most common age of onset is between 18 and 25. For women it is between 25 and 30 (Castle, 2000; Castle et al., 2000; Hafner et al., 1998; Hambrecht, Maurer, Hafner, & Sartorius, 1992). This gendered age difference means that women with their first experience of psychosis are less likely to be able to access Early Psychosis Intervention services, where 25 is a common upper age limit. Women were only around a quarter of clients seen in one EPI service in New Zealand, and this may be characteristic of the others because of the cut-off age (Turner, Smith-Hamel, Mulder, 2006).

Young men with non-psychosis diagnoses, more common amongst women, may also find themselves not well catered for by certain services in terms of their developmental and cultural needs.

Overall, it is true to say that most of the energy expended on research and service planning around early intervention and the needs of young adults with severe and/or disabling mental health problems has been focused on people with psychosis, and therefore, inadvertently, on young men.

RECOVERY RESEARCH GROUNDED IN SERVICE USER EXPERIENCE

The Mental Health Commission’s Young Adult Project sits in the context of the “recovery research” paradigm. It aims to throw light on young adults’ experiences of mental ill health and mental health services and on their recovery processes. Systems of health care are usually studied in terms of their organisation, delivery and outcomes, rather than through trying to understand the life-worlds of those who experience them. It is one of the tasks of qualitative health research to investigate the life-worlds of health service users. Through gaining an understanding of what it is like to experience ill-health and health services, it is possible to provide fresh, user-centred perspectives that can be used to lead to improvements in design and delivery of services. That is why investigating the ways in which young adults make sense of mental health services in their early encounters with them, as well as how they struggle to make sense of their own mental health conditions and circumstances, and their recovery, is at the heart of this project.

Recovery research has proliferated in the last decade. An emergent field of mental health research, it has been defined as having two major areas of focus:

- investigating factors and processes significant in the recovery of individuals;
- investigating recovery-promoting mental health (and other health and social) services, as well as other features of social life relevant to recovery (Lapsley, 2005).

Recovery, in this context, is seen as a process resting on a wide range of factors involving personal agency, social connectedness and social participation, as well as on receiving assistance from mental health services. It is essentially defined from the experience of service users, who are regarded as pivotal in defining recovery research priorities and in being involved in recovery research. The New Zealand Mental Health Commission promotes
a recovery model of service provision, and has undertaken or published several pieces of recovery focused research grounded in service user perspectives (Goldsack et al., 2005; Lapsley et al., 2002), as well as publishing service user voices on recovery (Leibrich, 1999; Mental Health Commission, 2004b).

Examination of international mental health research and literature suggests that where research relating to the young adult age group exists, it is often about young adults from the perspective of clinicians and/or researchers, and focuses on clinical outcomes or treatment effectiveness, rather than being grounded in young adults’ own narratives or stories of their mental health experiences (O’Toole et al., 2004). Moreover, the growing body of research that is grounded in service user experience – which we refer to as “recovery research” – is often particular to the “generic” adult and tends to draw largely on the experience of those aged over 30.

There is a scarcity of research relating specifically to the young adult age group who have had their first experience of a disabling mental health problem and used adult mental health services for the first time. A small but unique research project based in Bolton, United Kingdom, focusing on youth (aged up to 25) experiences of mental health services, was carried out by young service users themselves (Laws, Armitt, Metzendorf, Perciveal, & Reisel, 1999). This project identified a range of barriers for youth accessing services, and highlighted various components of mental health service provision that young people said would help their recovery.

A local youth development project undertaken by youth peer support workers from Wellink in Wellington explored the needs of young people experiencing disabling mental health problems. The project identified some key issues, including the importance of peer support, links with family and friends, youth focused meaningful activity, respite, alcohol and drug support, and housing, as critical to recovery (Wellink Trust, 2004).

The Commission itself held one focus group with young adults under 25 using services in Auckland, as part of a wider project in 2003 on user views of services. Key themes from that group were that:

- young adults want a voice in the services they receive;
- young adults want to access services and support groups specifically for their age group;
- young adults prefer interacting with younger service staff;
- young adults want to feel hopeful about recovery;
- young adults emphasise the importance of their whole lives, rather than just their mental health difficulties.

One young adult commented:

“What they [mental health staff] tend to forget is that we had lives before we became unwell. All we’re trying to get back to is our lives and not cause too much of a commotion so people aren’t stressing about us.”
CHAPTER two

Research Aims, Questions and Methods

The Young Adult Project represents a Mental Health Commission initiative to address the identifiable gap in the current knowledge base, research and practice in relation to young adults’ mental health experiences, their experience of services and stories of recovery. It is timely, as mental health services enter into the era of recovery, that we should examine young adults’ journeys with disabling mental health problems and their lived experiences of twenty-first century mental health services. As well, we wanted to look at how they negotiate potential disruptions to careers, relationships and living circumstances, and how they acquit themselves in a world still not free from stigma and discrimination.

This project recognises the importance and power of service user stories or narratives. It involves the systematic collection, analysis and interpretation of peoples’ spoken words and the meanings they give to their experiences. It follows on from an earlier project, “Kia Mauri Taul!” (Lapsley et al., 2002) which explored narratives of recovery from disabling mental health problems amongst adults who were primarily in their 30s and 40s and who regarded themselves as “recovered”. The current project targets a younger age group at a stage far earlier in the recovery journey.

The project aims to contribute to an emerging body of work that gives voice to young adult service users, places young adults’ self-defined needs on the mental health agenda and works towards the development of mental health services that offer recovery based models of practice grounded in young adults’ experiences.

Moreover, it presents piece of research that will contribute to a rich and growing body of international recovery literature.

The Young Adult Project set out to explore the mental health experiences of 40 young adults (aged 18-29 years) who have had significant contact with mental health services. We aimed to investigate the following key issues:

- early experience, during young adulthood, of a severe mental health problem;
- early use of publicly funded adult mental health services; and
- factors that helped or hindered recovery.

More specifically, the Young Adult Project aimed to elicit information in relation to certain key questions. These were:

- what do young adults think contributes to the development of severe mental health problems?
- how do young adults understand and make sense of the experience of disabling mental health problems?
- what pathways do young adults take to access mental health services, and do they access early intervention if needed?
- what are their experiences of mental health services and their pathways through them?
- how do they understand and make sense of service provision?
- how do services and treatments contribute to recovery, from the perspectives of young adults?
• how does gender or ethnicity impact on young adults’ access to and experiences of mental health services?
• do mental health services appear to take into account the developmental and life stage needs of young adults?
• how does the experience of a disabling mental health problem impact on young adults’ social, educational and vocational development?
• what overall factors do young adults regard as helping or hindering recovery?
• what are the aspirations of young adults with a severe mental health problem?
• does it make sense to regard young adults a distinctive group of service users with a particular set of needs specific to their developmental age and life stage?

We planned to include a diverse group of young adults in terms of gender, ethnicity and geographical location, those with diagnoses across a broad spectrum, and those using a range of mental health services in four District Health Board catchments. Using a qualitative research process, we set out to interview 40 young adults with the intention of exploring their narratives of mental health experiences, service experiences and recovery journeys.

The project was designed as qualitative research involving in-depth interviews with young adults aged 18 to 29 who were in touch with mental health services and close to their first experience of severe mental health problems during adulthood. Selection criteria were non-random and purposive, selecting for diversity across age, gender, ethnicity, diagnosis, type of service and geographical location. Narrative and thematic analysis were used to analyse interview text and to develop a picture of young adults’ journeys through making sense of mental ill health and mental health services.

PROJECT DEVELOPMENT

This project grew out of an earlier interest at the Commission in developing longitudinal research on young people’s first experience of psychosis. Although evaluative work was being carried out in the context of early intervention service innovation in New Zealand (Turner, 2002), there was a lack of research on young people’s experiences of mental illness or on their attitudes towards the services they are offered. Moreover, the Commission has always put an emphasis on service user input into our activities and to the activities of the sector. But the voices of young people and young adults have been under-represented in service user contribution to our work, and research carried out in consultation with young service users could improve this imbalance.

It was established that a longitudinal study was beyond the resources of the Commission, because of the need to gather and analyse data over a period of some years. Conceptual and bibliographic work was contracted to inform the development of a more limited qualitative interview project, based on one phase only of data-gathering. This resulted in a report examining international and local studies of the young adult population in relation to age, gender, ethnicity and diagnosis (Barnett, 2004).

The report’s recommendations led to the decision to develop a research project that focused on young adults in the 18-29 year age group, or the “under 30s”. Age 18 signifies legal adulthood, and means that research participants are able to give consent to participate in such a project without parents or legal guardians being consulted. Age 18 is also often the age of transition into adult mental health services, although this does vary between services. Some policies, programmes and research projects on youth or young people have an upper age limit of 25, but we decided that the upper age limit in our project should be 29, and that our focus would be young adults, rather than young people. The mid-twenties are a peak time for presentation to mental health services.
For women, peak presentation for first psychosis is later than for men, and occurs in the later 20s. Therefore, it seemed unwise to make 25 the upper age limit. Also, with many of the tasks of young adulthood occurring at later ages than in earlier decades (including later family formation and later completion of formal education), the 18-29 year age bracket seemed to be developmentally appropriate to the twenty-first century.

The preliminary investigations also led to a decision to include young adults with any diagnoses who came into contact with mental health services for the first time, rather than only those presenting with psychoses. Because many service users have non-psychosis spectrum diagnoses, their experience is significant. The focus of the project was on making sense of the experience of severe mental health difficulties and mental health services, not on diagnosis and measurable outcomes. Moreover, there are more women than men presenting to services who receive non-psychosis diagnoses, so including the whole spectrum of diagnosis would ensure that women’s experiences were not under-represented.

CONSULTATION PROCESSES

During the development phases of the project, we carried out comprehensive consultation processes with Māori communities, mental health service users, mental health service providers, policy makers, consultants, researchers and academics.

Following the initial development of ideas, mental health service users were consulted and an advisory group of young adult service users was established. The advisory group provided input to the conceptualisation and design of the research, and the development and phrasing of the interview questions.

A range of mental health services was also consulted to obtain input on the design of the research, establish criteria for participant inclusion, and enlist their support in identifying potential participants via their services.

The Commission’s Senior Māori Advisor and an independent cultural advisor carried out consultation with Māori communities. This process meant introducing the research to kaumatua, Māori mental health professionals and local communities, obtaining feedback on ethical and culturally appropriate aspects of the proposed research process, and enlisting their support to identify potential participants.

A Pacific cultural advisor consulted with Pacific mental health services and communities.

The Commission’s Service User, Māori and Pacific Reference groups, commissioners and project team were also consulted during the development of the research.

ETHICAL ISSUES AND ETHICAL APPROVAL

The conduct of this project drew on professional research ethics, in particular the New Zealand Psychological Society’s Code of Ethics. We also were informed by service user perspectives on the ethics of mental health research (e.g., Faulkner, 2004; Peterson, 1998) and values-based frameworks from critical psychology (e.g., Prilleltensky & Nelson, 2002).

Ethical approval for the project was obtained from the Health and Disability Ethics Committee. The research was independently approved by management structures in Waitemata, Auckland, Capital and Coast, and Bay of Plenty District Health Boards. The project was also endorsed by Nga Kai Taatagi Māori Research Advisory and Research Centre for Waitemata DHB, the Research Centre at Auckland DHB, Te Kotuku ki te Rangi in Auckland, and Whakatane Māori Mental Health.

Ethical issues requiring particular protocols included cultural safety, confidentiality, anonymity, privacy, the safety of participants and the secure storage of research data including
security protecting computer documents. The research process involved providing comprehensive information to participants, including an initial letter of introduction, a research brochure, an Information Form and a Consent Form (See Appendices 1 and 2 for copies of these forms).

Professional support for participants was arranged via each mental health service involved in the research, in case the interview proved distressing to the young adult. Participants could also obtain independent professional support following the research interviews if this was required. An 0800 free phone was established for participants to call the research team with any queries about the research or to call following their interview.

INTERVIEWERS
Interviews were carried out by the project researcher, the Commission’s Research Director, the Commission’s Māori Advisor, and two contracted Māori and Pacific interviewers. Most interviewers also liaised with services. All interviewers had worked in mental health, most had research experience, all happened to be women and all were older than the interviewees. During the planning phase we did consider recruiting and training young adult interviewers. However, the expense, time and logistics involved in undertaking research in four different geographical areas meant that we decided not to pursue this approach.

Interviewer Training
All of the research team were involved in interviewer training specific to the Young Adult Project. The interviewer training focused on the following:

- project rationale
- thorough explanation of research procedures and protocols
- thorough discussion of ethical issues and protocols for the research, including requirements in relation to the Treaty of Waitangi and culturally safe research practice
- work on our personal attitudes toward young adults and their contemporary cultures, including “memory work” techniques focusing on our own young adulthood.

SELECTING PARTICIPANTS
This qualitative project involved in-depth interviews with young adults aged 18-29 who were close to their first experience of severe mental health problems during young adulthood. The selection criteria were to be non-random and purposive, selecting for diversity across age, gender, ethnicity, diagnosis, type of service experienced and geographical location. The figure of 40 interviewees was chosen for practical reasons, as an upper limit for a qualitative project of this type in terms of manageability, yet still allowing for a wide variety of experiences to be examined.

The more specific criteria for inclusion in the research were developed in consultation with the Young Adult Advisory Group and staff from mental health services (see Research Criteria and Instructions for Inclusion in Appendix 4). We initially aimed to include young adults who had first made contact with mental health services in the last two years because we wanted to include service users who had very recent experience of mental health services. This time limit proved impractical in terms of obtaining a sufficient number of young adults with enough service experience to participate usefully in the study. We therefore extended the time frame to include young adults who first came into contact with mental health services any time since 2000. We wanted to talk to people who had a significant amount of service contact, but we also asked for people with a long and continuous history of contact with mental health services, that is, over five years, to be excluded. This time frame was consistent with the aim of tapping young adults’ experience of services in the 21st century.
Participants were identified by staff working in mental health services within four District Health Board areas and through self-referral. A brochure, outlining basic details about the project, was given to mental health services and various organisations involved with young adult service users (see Appendix 5). We asked for the brochure to be distributed to service users who met the research criteria. Potential participants were then asked for permission to release their name and contact details to the research team. The project was also publicised through Mental Health Commission networks and by word of mouth, and some young adults made direct contact with the research team.

We identified service types that young adults were most likely to come in contact with, and attempted recruiting participants through each of these services. We asked services to identify a diverse group of possible participants, including those who might not be described as the “success stories” or for whom contact with services might not have gone smoothly. We ended up obtaining names of participants through eight different mental health services.

One issue for us was that some young adult service users did not identify themselves as having a “mental illness”. Rather, they saw themselves as having experienced personal and/or social difficulties, or a trauma that resulted in contact with services. These were mainly service users with “non-psychosis” diagnoses, which may in part have contributed to a lower number of participants in this group (14 in all). In hindsight, it would have been useful not to use the term “mental illness” as this meant imposing a conceptual framework over young adults’ mental health experiences that not all were comfortable with and it resulted in the exclusion of some potential participants. Another factor that affected the recruitment of participants was that some young adults did not feel ready to talk about their recent painful mental health experiences, or did not feel safe enough to be involved in research.

The process of selecting and recruiting participants for this project involved many unforeseen obstacles, was lengthy, and involved considerable time and input from staff across a range of mental health services.

THE INTERVIEWS

Interview Development

A comprehensive interview schedule was developed in consultation with the Young Adult Advisory Group and staff from mental health services. The interview questions were divided into three broad areas. These related to the young adults’ background and experience of a disabling mental health problem, their experience of mental health services, and issues relating to recovery. Because of the project’s narrative research approach, interviewers were not required to ask every participant the same questions but rather to cover these three key areas during the course of the interview. The interview themes are included in Appendix 3.

Conducting the Interviews

Once we obtained a list of names of potential participants from services, or from participants who called the research team, we proceeded to make contact with them, send out letters of introduction and arrange interviews. The letter of introduction included the research brochure, the Information Form, and the Consent Form.

We phoned the young adult a few days after the post-out to discuss the project, answer questions and arrange an interview time and suitable venue. An interview confirmation letter was then posted. We suggested that they discuss the Information Form and Consent Form with someone else before the interview.

Interviews took place in a venue where the participant felt comfortable. This typically involved interviewing them at their home, although some were interviewed in an office in a mental health service or another suitable venue. Some interviews with Māori participants
took place in the presence of a relative or Māori mental health professional, and a kaiawhina. Interviews with Māori participants also involved taking food and talking with whānau.

Each interviewer completed a checklist prior to the commencement of the recorded interview to ensure consent had been obtained, to select a pseudonym, to arrange a gift voucher of choice and to ensure all relevant demographic information was recorded. Details were also noted about the duration and location of each interview.

Each interview was digitally recorded and usually took between one to two hours. Within two days of each interview, the interviewer phoned to debrief with the participant and check whether they needed any assistance.

Transcribing the Interviews

Each digitally recorded interview was downloaded and transcribed. Transcribers were required to sign confidentiality agreements and to terminate transcribing if they recognised the interviewee’s voice. Each voice file and transcript was security stored on computer and hard copies were stored in a locked cabinet.

ANALYSING QUALITATIVE DATA

Narrative research relies on people’s stories as a way of understanding and making sense of experience. The stories people tell are constructed in some kind of order that has meaning for them, and events are arranged into a sequence over time. Narrative research is particularly appropriate to recovery research, since recovery is often seen as a journey. In this project, the young adults told us stories of their mental health experiences that, although based around the three key interview areas, wove together a series of significant events in their lives over periods of time.

Managing and analysing a number of lengthy interviews of this kind can be daunting. However, with the use of NVivo qualitative data analysis software, we were able to manage and analyse complex, unstructured interview data. All interviews were entered into an NVivo project. We then identified narrative stages across time from the young adults’ stories, and coded all interviews around these stages. The stages we used for coding were:

- life before the mental health crisis, including childhood history
- going downhill
- seeking help while going downhill
- the mental health crisis
- contact with mental health services
- recovery and reflections.

We were then able to work within each code to identify significant narratives and themes.

All demographic data was entered as attributes into NVivo, which permitted easy access, searching and retrieval of relevant information as it was required.

PARTICIPANT CHARACTERISTICS

We interviewed 40 participants in total, 20 men and 20 women. The participants ranged in age from 18-29 years. Six participants were under 20, eighteen were in the 20-24 age bracket, and sixteen were in the 25-29 age bracket.

In terms of ethnicity, we had aimed to match our participants with overall ethnicity of service users (rather than the New Zealand population) in this age group, and the final selection matched this closely, except for a higher number of Pacific participants. A total of 17 people identified as Pakeha or New Zealanders, 14 identified as Māori, seven identified as Pacific and two identified as Asian. A number of participants referred to having multiple ethnic identities. In categorising ethnicity, we used the “prioritised ethnicity” approach commonly used in health services statistics collection in New Zealand.
Eight of the participants were currently in full-time or part-time paid employment, four were currently in tertiary education and seven were parenting. A total of 17 were in receipt of a sickness, invalids or unemployment benefit and a few in this group also sometimes undertook short courses or casual employment. We did not determine the occupation or source of income for the remaining participants.

Many of the participants had been in paid employment prior to their mental health crisis, and their occupational backgrounds were diverse. These included teacher, mechanic, builder, labourer, office clerk, designer, media person, retail personnel and health professional. Some people had never had the opportunity to gain any educational qualifications or enter paid work, due to their family circumstances and/or the mental health difficulties they had experienced.

Nine participants had undertaken some form of tertiary education, 13 had no high school qualifications, seven had some high school qualifications and the educational background of the remaining participants was unclear.

Five participants currently had a partner. Seven were engaged in parenting, and another two participants had children who had been adopted out or were living elsewhere. Eleven lived with their parents/family of origin, four lived alone, six lived in board/hostel type situations funded through mental health services, and six flatted with others. Two young adults were residing in mental health services at the time they were interviewed.

**Family/Whānau Contexts**

Almost two thirds (61%) of all participants had grown up in two parent families. Most (85%) of the participants who identified as Pakeha/Other/Asian came from two parent families. Just over half of the participants who identified as Māori (53%) or Pacific (57%) had primarily grown up in one parent families. Two Māori participants had parents who were deceased.

Most of the participants had one or more siblings and several of the Māori and Pacific participants had at times lived with members of their extended family while growing up.

The extent of contact or involvement with families of origin varied, with some young adults and parents having little contact or emotional connection with each other. Participants typically told us that this was due to the parents not wanting contact with their son or daughter, rather than the young adults not wanting contact with their parents.

Other participants were closely involved with their families. Some currently lived with a parent or family by choice. Others had been compelled to return to a parent or family because of a lack of accommodation and financial difficulties associated with their mental health crisis.

**Diagnoses**

Most of the young adults reported being given a diagnosis or diagnoses, or finding out about their diagnosis at some stage through their contact with mental health services. Many participants were given multiple, changing diagnoses over time. Because diagnosis often determined access to and pathways through services, we focused on presence or absence of a “psychosis spectrum” diagnosis. Two-thirds (26) were given a diagnosis that fell into the psychosis spectrum group, including schizophrenia and bipolar illnesses. The remainder were given diagnoses that included one or more of the affective, anxiety, “personality”, eating or post-traumatic stress disorders.

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1 Of this group, two were in full-time paid employment, two were in receipt of the Domestic Purposes Benefit, one was financially supported by a partner, and one was at university. We did not determine the source of income for the seventh parent.
Although some of the young adults rejected the diagnoses that they were given on the grounds that it did not reflect their reality, or because they conceptualised their experience as a social condition resulting from adverse life circumstances, many were to talk about the impact a diagnosis had had on their identity and understanding of their mental health experience.

**Interviewer Impressions**

The young adults who participated in this research were a diverse group of people who brought a wealth of ideas and insights to the project. The interviewers were struck by their honesty and openness, their astuteness and insights, their aspirations and talents, and the humour they conveyed during the interviews. At the time we met the participants, they were going through a difficult time in their lives; however their compassion, thoughtfulness and sensitivity to others was striking.

Some of the participants were high achievers and successful in their chosen careers or educational paths, even though they often had needed to take time out because of the mental health condition they experienced. Although others had not had the opportunity to gain education or training, they nevertheless had clear ideas about how they wanted to live their lives.

Most of the participants, even those in seemingly dire situations, expressed a strong sense of ambition, determination and hopefulness about their futures.
In this chapter, we discuss the research participants’ accounts of a range of childhood and teenage experiences of adversity and trauma that occurred prior to the development of the mental health problems that would impact on their young adulthood.

Not all our participants talked to us about adversity and trauma. For several, the interview narrative did not contain any particular material on early years – either the interviewer or the interviewee just did not go there. A couple of participants specifically stated that their mental health conditions did not in any way stem from childhood situations or experiences. However, most of the young adults we interviewed told us about how their family environments, as well as particular childhood and teen experiences they had undergone, had significantly contributed to or shaped their later experience of mental ill health.

We have organised this chapter around the most common themes to emerge from these narratives of adversity and trauma. However, it is important to recognise that most of those who told us about childhood and teenage situations and events described multiple contributors to later mental unwellness. This should not be lost sight of as we highlight particular themes, because adversity, trauma, abuse, poor communication in families and experiences of loss have often gone hand in hand.

Also, it should be emphasized that these narratives do not tell the whole story of participants’ childhoods. Because the focus of the interview was on disabling mental health problems, naturally the talk about childhood focuses on precursors to mental ill health, rather than on the whole experience of growing up. Some narratives do focus on particular events and experiences, but many describe family atmospheres that provided the bleak and pervasively unsettling landscape within which they grew up.

We analysed the precursors of later mental health difficulties, as described in the narratives, into themes. This chapter is organised around a discussion of each of the main themes, illustrating points by examples. The key themes are as follows:

- The most commonly talked about precursor to later mental health difficulties was growing up in a family atmosphere experienced as lacking safety, security and predictability. Abuse and neglect were often a feature in this kind of atmosphere. They took different forms, including emotional abuse and neglect, physical violence, witnessing domestic abuse (usually of mothers) and sexual abuse. It was common for more than one form of abuse and/or neglect to be experienced.

- Feeling unsafe and insecure at an emotional level was also a strong feature of narratives where family relationships were described as lacking in communication, or the opportunity to express feelings in a safe manner.
• Loss and abandonment issues, also often mentioned, included death of a family member or close friend, separation from someone who mattered, or shifting house in an untimely way and/or frequently because of family stress.
• School and peer related difficulties, such as being bullied or being harassed by teachers, and/or getting in with a “bad crowd” of peers, were also mentioned as a key contributor.
• Several of the participants spoke about the negative impacts of poverty on their day to day lives.
• Some participants talked of their experience of living with parents who had mental health and/or alcohol problems, and said that their parents’ behaviour had impacted on them in negative ways.
• Most participants reported that they began using drugs and alcohol excessively as a way of coping with emotional pain, and that this coping strategy usually began in their early teens.

LACK OF SECURITY, SAFETY AND PREDICTABILITY: SITUATIONS AND EXPERIENCES OF ABUSE AND NEGLECT

About half of the participants who spoke about their childhoods during the interview, talked about growing up in abusive family environments and/or having traumatic abuse experiences. Most children grew up in two parent families, but in the instances where mothers were raising children alone, this was often due to having left a violent male partner, so these children had lived in an environment of family violence. While the participants’ accounts of family environments differed, their stories typically conveyed a sense of all-encompassing tension, anxiety and fear.

Emotional Abuse and Neglect

Emotional abuse was characterised by an array of harmful parental behaviour. Typically, one or more parents engaged in behaviours such as yelling, slamming doors, threatening suicide, giving the “silent treatment”, and generally, creating a chaotic, unpredictable home atmosphere. The participants talked about family environments plagued by high levels of conflict and aggressive parental behaviour, and spoke of not being allowed to express their feelings, ideas or opinions. In many families there was little communication and a lack of intimacy. Several of the narratives of emotional abuse emphasised lack of attachment and love, and an absence of emotional warmth from parents.

Experiencing emotional abuse during childhood was related to reports of feeling stressed and anxious from a young age, and the accounts convey a persistent sense of anxiety, tension and fear. Emotional abuse was most commonly described by participants who grew up in two parent Pakeha families. Cassandra described a “very inconsistent, unpredictable household, not knowing where you were each minute of the day”. She described her mother as “stomping, slamming doors, hiding in the room, crying, driving off, yelling and screaming and shouting”. Cassandra’s father would blame the children for upsetting their mother and she commented that he was “always too busy or too stressed out himself to notice if anything emotional was going on”. At times there was also a lot of fighting between her parents. Cassandra said that she had never felt safe enough around anybody to express her feelings.

“Emotional abuse is very powerful,” she told us, and said that her childhood experiences were “absolutely” the reason she had mental health difficulties as a young adult.

Pippa said that in her family there was “yelling ... a lot of hurtful words ... a lot of tension ... someone was always in conflict with someone else ... we were never allowed to be wrong ... and emotion was a ‘no no’”. If she was having a
bad time she would be told, “Don’t be stupid!” This adversarial environment created intense stress and a build up of emotion. Combined with being bullied at school and having a disrupted school life, it led to her experiencing extreme depression, and she began self-harming.

Gillian described her mother as “an angry person” who frequently “guilt tripped” Gillian and threatened to kill herself. Gillian thought her parents had unrealistic expectations of children, and a highly prescribed idea about her future. She felt she had to leave home when she was still at school to gain some stability in her life. She attributes her mental health difficulties primarily to the aggressive environment and her parents’ lack of emotional warmth.

**Physical Violence**

Stories of physical violence were characterised by a parent or parents being violent to children, and the child or children witnessing the father being violent to their mother and/or siblings. Multiple forms of abuse often co-occurred. As is evident in these stories, physical violence often went hand-in-hand with emotional abuse and neglect.

Taylor said that her parents both had a temper and were both violent towards the children. When Taylor was a young child, her father was so violent to their mother that she and the children fled to a refuge, and the parents subsequently separated. Taylor’s mother also had a drug habit, which meant the children were neglected. Taylor said “Mum had no care for us ... there was no food in the cupboards”. She described never having school lunches, feeling ashamed, and being very fatigued. Because of the constant angst created by both parents, Taylor twice ran away and she lived between parents during her teens. This bleak background created considerable inner conflict and turmoil for her, particularly as her parents espoused a Christian doctrine.

Max described a childhood dominated by a physically and emotionally abusive father. Max’s mother had left the family, due to his father’s ongoing abuse of her and the development of a severe and disabling mental health problem. Max has a learning disability, and although clever, was unable to read or write well. His father used to yell when Max could not read a book, threatened him with a hiding if he did not complete set writing tasks, and beat him, if he misbehaved at school. Max also witnessed severe beatings of his siblings. He saw his father cry only once and his father never expressed emotions. Max felt compelled to leave home while still at school to escape his father’s abusive behaviour.

These stories of childhood physical abuse often occurred in the context of domestic violence. Lolly spoke of regular and extreme violence from her father to her mother, with him using “a bottle or glass or anything he could get his hands on”. A few of the participants also talked about their mothers having to flee to a refuge or go on the run from a gang to escape violent partners. This meant that the children lived in fear, and in transient circumstances. Indeed, many of the participants related stories of pervasive physical abuse as part of their childhood family environment. They saw this, often coupled with emotional and sexual abuse, as leading to the development of mental health difficulties during their teens and early adult lives.

**Sexual Abuse**

Sexual abuse typically occurred in a context connected to the family, and in which the young adult was unable to escape contact with the abuser. The abuser was a stepfather, uncle, cousin or the father’s friend, so their lives were closely intertwined with the family. Since different forms of childhood abuse and adverse childhood experiences often co-existed, it was difficult for the sexually abused child to trust anyone or tell anyone in the family what was happening to them.

Tiare talked about being sexually abused by her stepfather, and physically and emotionally abused by her mother. She described regular
“bashings” from her mother and said she did not feel loved by her. Tiare’s own father had also been violent and had left when she was young. Tiare disclosed the sexual abuse to the authorities and was subsequently removed from her family home. Although the stepfather was charged and imprisoned, he later returned home and continued sexually abusing her. Tiare was unsupported by her mother in the face of this ongoing abuse.

Claire was sexually abused by her father’s friend from a very young age, and the abuse continued throughout her childhood and teens. Her parents sent her to live with this man and his partner. Claire had never had close relationships with her parents, and although she has since disclosed the abuse, does not “feel connected to them at all”.

Toa talked about a childhood where he was sexually abused by his cousin and others from the church his family regularly attended. He was neglected, often moved between parents, was bullied at school and had two significant others in his life commit suicide. The abuse had a significant impact on his concentration and educational achievement, and he subsequently developed a range of emotional and physical health problems that affected his ability to function. Toa described feeling like “a vegetable”, he had difficulty walking and he said the abuse had “plagued his life”.

Susan was sexually abused by an uncle who later named his daughter after Susan and dressed her similarly, so that Susan felt her identity had been stolen. She said that the abuse was a significant component of her “troubled teens” and later mental health difficulties. Both Toa and Susan eventually disclosed the abuse to their parents, who, although initially sympathetic, never spoke about it again.

Participants who had been sexually abused described feeling shame, especially in families where sexual abuse was not understood and “things like that were not talked about”, where they may not have been believed and could even be blamed. As children or young teens, many participants felt that they did not have anyone they could trust to talk to about the trauma they experienced.

Experiencing childhood trauma or adversity, coupled with being unable to talk to anyone about these experiences, meant a build-up of emotion over many years. Young adults often talked about how this process had contributed to their mental health difficulties. Although a few participants had actually disclosed sexual abuse, they had not received effective interventions. Some conveyed a sense that their childhood experiences of sexual abuse and other forms of emotional and physical abuse were so overwhelming, and they felt so low or confused by their feelings, and so unsafe about talking, that they had never been able to talk about these experiences to anyone until recently.

POOR COMMUNICATION IN FAMILIES LEADING TO EMOTIONAL INSECURITY

Lack of communication – families where “no one talks” and where parents did not talk about feelings or personal issues – was another prominent childhood/young teen theme connecting to later mental health difficulties. There were also instances where a parent was so overburdened that participants had not wanted to add to their parent’s problems by talking to them about their own problems. Because so many of the participants had no one to confide in or express their feelings to, their emotions had built up over a long period of time, usually many years. This situation arose in narratives about other contributors, too.

Some of the young adults said that the absence of communication in their family had made it difficult to identify their feelings, to feel safe expressing emotion, and to articulate their experiences in young adulthood. For instance, Shane said his father was “a real staunch man, he keeps to himself ... so it wasn’t never like there was a father there ... you have to be tough, sort of thing”. Shane also said “me and my Mum have never got on”, so there was little opportunity to talk about how he felt.
Participants said that their family literally did not talk much, so feelings were never really talked about. For example, although Susan initially said that her family was “very close”, she later said her family “aren’t very talkative either, we never really sit and talk about how we feel”. Likewise, David related his experience of growing up in a family where there was little talking or communication about feelings. He said it is “a very quiet family” and he did not “communicate with them very often”.

Jo described one adverse consequence of poor communication. She said she was “really loved as a child”, but had never been able to talk to her parents about the violence and rape that occurred when she got in with a “bad group” as a teenager. It seemed that the lack of approval of her friends, coupled with one of her parents having a prominent position in the health system, meant that she did not feel safe talking to her parents about this traumatic incident. Jo said that she knew not to talk to a local health professional because things could get back (and had done so in the past) to her parent. The combination of a lack of communication within the family and censoring what she could say to others resulted in her keeping her feelings to herself.

**LOSS AND ABANDONMENT**

Many of the young adults experienced some form of loss or abandonment during their childhood or early teen lives, and this came in various guises. Some talked about childhoods where a parent, usually their father, had left or abandoned the family, often after domestic violence. For example, Bob’s father had abandoned the family when Bob was a young child. He talked about feeling sad that he did not have an older male to talk to as he grappled with his feelings during adolescence. He did not want to burden his mother, who was studying while also raising several children alone and struggling financially.

Max experienced loss through his mother leaving the family when he was a child because of domestic violence from his father and the severity of his mother’s mental health problem. Although Max spoke little about his mother’s absence during the interview, it was apparent that being left with an abusive father and no mother figure had been particularly stressful for him. Further, Max conveyed sadness when he spoke about his mother in the present, because he barely recognised her as the woman he had known as a child, due to her current mental health problem, which features psychotic symptoms.

Other participants spoke of parents, siblings or significant others who had died, and of having little opportunity to talk to anyone about their grief. Sometimes little was actually said about significant life events of this kind, but the impact of these events was apparent in how they talked about and described feeling about their lives. When Gillian experienced the death of a close friend and grandparent in close succession during her early teens, she received no support. When the death of a significant other occurred in tragic and traumatising circumstances, in the context of other adverse family circumstances, this resulted in significant and unresolved feelings of depression or despair throughout the teen years and into early adulthood.

Several of the young adults talked of having little connection with their cultural “roots” and being estranged from whānau. Victor, who is close to his mother, was rejected by his father and is isolated from his whānau. He said “our family doesn’t even exist to us”. His mother’s whānau had tried, at different times, to have both Victor and his mother placed under mental health care.

Other participants spoke of some support from whānau, but said little about their whānau during the interview. Although Lolly had supportive whānau who were involved in her life, her grandfather was physically abusive, and her family told her that she had the same negative traits as her estranged abusive father. Further, she had become isolated from her whānau while in a violent relationship. Joe’s mother had passed away when he was a child;
he had support from his father, but said it was
difficult not having a mother around when he
was growing up. Outlaw’s parents had both
passed away when he was young, and his only
support included two aunties who were there
for him when he came out of hospital.

For others, loss came in the form of shifting
towns or countries, often in the context of
family dislocation and abusive backgrounds.
Shifting resulted in leaving behind friends and
social networks, and the historical familiarity
of the local landscape and the community
they had grown up in. For some participants,
shifting meant the loss of cultural connections.
Some of the Māori participants talked about
moving between New Zealand and Australia,
or between rural areas with traditional tikanga
and an urban city where they sometimes felt
culturally dislocated. For others, shifting meant
movement into a substantially different cultural
environment. This was especially so for Pacific
participants who had moved between New
Zealand and the Pacific, sometimes several
times during their young lives.

SCHOOL AND PEER GROUP
DIFFICULTIES

Some young adults reported multiple childhood
and early teen stressors relating to school
life and peer groups. In the context of wider
family issues, these contributed to their mental
health difficulties. These stressors included
being bullied at school, being harassed by
teachers, getting in with a “bad crowd”, being
truant from school, getting into trouble with
authorities and getting into drugs and alcohol.
As noted earlier, some had also shifted at
various stages during their teen lives, causing
disruption to their education and relationships
with others. Several talked of the difficulties
associated with re-establishing friendships and
social networks during the early teen years.

Johnnie commented, “I was in an all boys
school and got bullied ... I was in the low
stream classes and people would take my
lunch off me and there would be fights”.

Chris said he got in with “a bad crowd in
third form.” He started smoking, “wagging”,
and was given drugs and alcohol by an older
man.

Some of difficulties during school lives and
with peers were due to learning difficulties.
Others experienced illness or were involved in
accidents that had disrupted their school life,
educational progress and peer relationships.

POVERTY

Several young adults, the Pacific young men
in particular, despite having academic or
vocational aspirations, left school prematurely
because their parents could not afford
their continued education. Some spoke of
families that had shifted to New Zealand
from the Pacific, and having parents who
had low paying jobs and hard lives in New
Zealand. Others, due to financial difficulties
at home and the pressures that arise from
not having enough money for daily survival,
started wagging school, got into trouble with
authorities and/or failed exams. For some,
the lack of financial resources was combined
with having strictly religious parents. These
combined factors made it difficult to negotiate
the tension between their parents’ values and
contemporary, consumer oriented urban teen
lives. Some of the Pacific young men had
been required to leave school to support their
families financially.

PARENTS WITH MENTAL HEALTH
PROBLEMS AND/OR ALCOHOL
PROBLEMS

Some of the young adults reported that one
or more of their parents had experienced
a mental health problem, and that this had
impacted on the way the parent/s behaved or
interacted with their children. For instance,
Mary talked about her mother having post-
natal depression and living separately from
her when Mary was a baby. She described a
mother-daughter relationship characterised by
lack of attachment, disconnection, high levels of criticism and various forms of emotional abuse.

Some participants, such as Max, said that because of their parent’s mental health and/or alcohol problems, the parent no longer lived with the family. Jennifer’s father had a severe mental health problem and used alcohol excessively. He had left the family when Jennifer was a child. He continued living a transient lifestyle, which meant she did not see him and barely knows him.

**DRUG AND ALCOHOL USE**

A prominent feature of the vast majority of participants’ early teen narratives was excessive use of drugs and alcohol. Many of the participants talked about getting into drugs and alcohol from their early teens as a way of coping with exceedingly difficult lives and with intensifying feelings of distress and depression. For some, getting into drugs and alcohol was more related to the peer group they started hanging out with. This was often associated with having shifted to a new school and having to make new friends.

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In summary, the young adults in this project made clear links between their experiences of childhood and/or early teen adversity or trauma, and the later development of mental health difficulties. Much of the adversity and trauma spoken about by the young adults occurred in the context of families where there was significant dysfunction and/or discord, and where there was a lack of safety, security and predictability. Many also spoke of a lack of communication within families, and a lack of permission to express feelings or discuss personal issues. Being unable to talk about how they felt was dire enough, but for those who experienced childhood adversity and trauma, the lack of communication compounded their already stressful childhood and early teen lives. Many also experienced significant loss and/or abandonment by significant others, which contributed to later feelings of depression and despair. Again, having no one to talk to exacerbated the cumulative distress some of the participants experienced during their childhoods and early teen lives.

Many of the young adults also spoke about a raft of other daily stressors, relating to difficulties at school and problematic involvement with peers, and the negative impact of poverty. The interactive effect of these stressors created considerable stress for the participants, some of whom also had to deal with broader issues of abuse and neglect. In addition, some participants had to negotiate their way through the unpredictability of parents who used alcohol to excess. Others had experienced disrupted or damaging relationships, due to the fall-out from having parents with mental health problems. The range of experiences which the participants spoke about in relation to childhood adversity and trauma was related to the fact that, from a very young age, many used drugs and alcohol as a means of emotional escape and survival. Not surprisingly, a central feature of the young adults’ narratives was the cumulative effect of a build-up of emotions, their unmet need to talk about these experiences, and the negative effects of drugs and alcohol over many years.

Irrespective of whether participants experienced childhood/early teen adversity and trauma or not, many went on to experience traumatic events, or a succession of significant life events, in their late teens or young adult lives. The young adults’ accounts of these experiences are addressed in the next chapter, “Going Downhill”, which explores the period leading up to and including the young adults’ mental health crisis.
"Going Downhill": Declining Mental Health, Help-Seeking and Mental Health Crises

In this chapter, we focus on those experiences during teen and early adult years that the participants described as the route to worsening mental health. We describe the psychological and behavioural changes experienced during this time, help-seeking and some of the difficulties that were encountered in gaining access to appropriate services. “Going downhill” narratives climaxed in the experience of a mental health crisis and encounters with crisis services.

Stories of “going downhill” usually told of a lengthy process of declining mental health – typically over a year or more – before the mental health crisis. We identified three significant themes in these narratives about “going downhill”:

• a sustained build-up of emotion, resulting from the adverse childhood/early teen experiences discussed in the previous chapter

• traumatic or stressful life events during late teens/early adulthood, compounding these adverse early experiences.

• a series of significant life events in close succession.

Many narratives described a complex web of distressing events building up from childhood onwards, into their teens and early 20s, which led downhill into an eventual crisis.

"ALL OF THAT CAUGHT UP WITH ME" – THE LEGACIES OF CHILDHOOD ADVERSITY AND FAMILY DIFFICULTIES

When adversity from childhood continued as a feature of teen and young adult lives, the impact was described by one participant as “All of that caught up with me.” Family, for many, continued to be ongoing source of distress, and declining mental health was attributed to continuing to live in an insecure, unsafe and unpredictable family environment, and having no one to talk to. Some still lived with their families during the downhill period; others had returned because they lost jobs or accommodation as their mental health deteriorated. Some were shuffled between parents or family members and some were “kicked out” of home. The legacy of childhood/teen sexual abuse was also a significant contributor in “going downhill” narratives.

Toby, who described his childhood in a hostile and volatile family environment, had left home at 18 to escape the torment. However, he had to return as he was unable to support himself. He talked about his father’s continuing abuse, constant put-downs and criticism, his parents’ ongoing fighting, and the family’s inability to communicate or talk about how they felt, as contributing to his deteriorating mental health.

Other participants related emotionally painful stories of poor parent-child relationships, and parents who wanted little to do with them. Both Gillian and Mary talked about being unable to live with their parents from their mid teens. Both felt unloved and neglected by their
mothers. They had fathers and/or siblings who were emotionally dependent on them, and one father had attempted suicide. Their parents’ behaviour was abusive and unpredictable, and remained so during their teens and young adult lives. Neither Gillian nor Mary were able to talk to their parents and they had few people they could confide in. Both left home and had little contact with their parents during the downhill period, and the parents provided little, if any, emotional or practical support.

Fiona, who had “a traumatic upbringing” involving domestic violence, being hunted by a gang, and frequent shifting, said “All of that caught up with me when I was sixteen and we had to move again.” She subsequently got into drugs and was also raped. Fiona was quite clear that this culmination of events had led to her going downhill and into crisis.

Several young men had moved between family members, often in different towns or countries, during adverse childhoods. Their increasingly “difficult” behaviour – stealing, being “antagonistic”, drinking and drug taking – meant that no one was willing to give them a home. As a result, some spent time living on the streets.

RECENT TRAUMATIC OR ADVERSE EXPERIENCES

Many who experienced recent traumatic incidents or multiple adverse events said that these were in addition to childhood/early teen adversity. The types of incidents and events included:

- being raped or sexually assaulted
- suicides or deaths of significant others
- being pregnant while also experiencing sexual/violence/emotional abuse from a partner and having no other emotional, financial or practical support.

Most had no one to talk to about these adverse experiences, and this compounded the distress they felt.

Anna related pervasive sexual violence and sadistic, emotional abuse from her partner, who was also her colleague and the good friend of her employer. She became pregnant and had a termination. Anna described being alone in a foreign country, and a work/home life plagued by excessive drug taking, alcohol abuse and money difficulties.

Susan, who had a new baby, talked about a long history of never feeling good enough in her family, childhood sexual abuse, a partner who see-sawed between abandoning her, being emotionally abusive, and threatening to kill himself, and having no family support or a place to live when she had her baby.

David talked about three close friends who had committed suicide prior to his going downhill. He said, “Thinking about it really hurt, so I just kept away from the topic really.” He subsequently took drugs and alcohol to cope with his feelings.

Outlaw said that both of his parents had died while he was in his early teens and he subsequently started taking drugs to cope with his feelings. Joe was at primary school when his mother passed away. He commented that his dad had to work all the time and was never around. “We just had no one there to, you know, be a mother.” Neither Outlaw or Joe had anyone to talk to about the grief they experienced.

Jennifer related a powerful story of being pregnant, being regularly raped and beaten by the baby’s father, having her home burgled by a flatmate’s gang friends, being home invaded by a group of gang girls, and having a cousin die in tragic circumstances. She became so afraid that she could not sleep, barely ate, lost weight and took marijuana and alcohol every day during the downhill period.
SIGNIFICANT LIFE EVENTS OR STRESSORS IN CLOSE SUCCESSION

Although significant life events or stressful circumstances in close succession, in and of themselves, might not contribute to mental health difficulties, participants said that their timing and close succession had been destabilising. Most emphasised the speed of such change as particularly stressful. Sometimes these events involved a change to their identity, involving occupational status, relationship status, and/or becoming a parent. Several had financial difficulties or got into complicated financial circumstances. These circumstances interacted, for many, with ongoing tensions and interpersonal difficulties in relation to their family of origin and the fall-out from childhood adversity and lack of communication. Some experienced significant loss or the threat of loss during this time.

Susan talked about going downhill following a series of significant life events and stressful circumstances, during which her life was “hectic”. She had started a business venture involving considerable financial assistance from her family, got engaged, got ripped off by her business partner, went bankrupt, and the relationship broke up. She later got into a “messy relationship”, became pregnant, and was subsequently unsupported by the father of the child or her family. Susan said, “I guess the emotional feeling...was guilt...and that I wasn’t good enough for my family and was constantly letting everyone down.” Susan also had a history of sexual abuse, came from a family where no one talked about how they felt, and had no one to talk to.

Cassandra said that in a short space of time she had gone from a student life to working full-time in an emotionally demanding job, left home, bought a house, got married and changed jobs, was supporting her parents through a difficult time, including a suicide attempt. Cassandra had never been allowed to talk to her parents about how they felt, and had no one to talk to.

Michelle talked about her father dying, hating being pregnant, being in a difficult relationship, experiencing hormonal changes, shifting several times, having no money and no support, living a life of secrets and interpersonal dishonesty, and feeling too afraid to tell her strictly religious mother about the pregnancy until after the baby was born. Michelle had a long family history of not being allowed to express how she felt, and had no one to talk to.

Almost all of the young adults in our study related stories about going downhill that included identifiable contributors. Very few were unable to identify factors that contributed to their mental health difficulties during this period. In the next section, we move on from a discussion of contributors to describe psychological and behavioural changes experienced during the downhill period.

GOING DOWNHILL: PSYCHOLOGICAL AND BEHAVIOURAL CHANGES

Going downhill was marked by a significant change in overall well-being and functioning, and undesirable changes in thoughts, feelings and behaviour. Many of the participants spoke in uncensored detail of the depressing, confusing and often frightening experiences they had through this time.

They used a diversity of language and phrases to describe these overall changes, including: “I just tumbled into despair”; “[it was] an all-consuming problem”; “it just got worse and worse and worse”; “things proceeded to go downhill”; “I couldn’t really function”; “I was getting out of control”; and “I tried to commit suicide”. Many spoke of depression, hearing voices, self-harming, anxiety and other mental ill health experiences.

Most participants discussed how negative changes in overall well-being and functioning had occurred over a long period of time. They spoke of the way these changes affected their ability to operate in the day-to-day environment. Specific changes in feelings, thoughts, and/or
behaviour were also talked about. Interestingly, very few talked about experiencing sudden change. For most, it was an accumulation of change over a period of time. For those who said they “flipped out” or “lost the plot”, this had occurred after going downhill for some time.

Depression

The most frequently talked about change during the downhill period was feeling depressed, irrespective of the development of subsequent symptoms or any given diagnosis. Many of the young adults said they had felt depressed for some years. Depression was associated with feeling flat, empty, despondent, withdrawn and lonely, and accompanied by behavioural changes such as frequent crying, erratic eating, difficulty sleeping, and becoming socially isolated.

The young adults talked about the all-encompassing nature of the experience of depression during the downhill period. Anna talked about having “huge negative thoughts and dark moments”. Lolly said she felt “depressed all the time”, and Julia said her feelings were “all consuming”. Cassandra said, “I was going downhill...[but]...trying to keep myself coping in this depressed, cloudy kind of world.” Sarah said it was difficult to determine “how much of it was being a teenager and how much of it was actual mental health issues”.

The young adults talked about how depression impacted on their day to day lives. This included not attending school, university, training or work; failing exams or courses; resigning or being fired from jobs; having difficult relationships with family members and losing friends; and generally not functioning well. Over time, changes in feelings, thoughts and behaviour escalated to a point where the young adult felt overwhelmed and despairing: descriptions included feeling “desperate”, “out of control” and/or suicidal.

Self-Harming

Many of the participants, especially the women, who experienced depression during the going downhill period also self-harmed. Self-harming ranged in severity and frequency, with some reporting repetitive and/or severe forms of self-harm, while others reported less frequent incidents involving superficial cutting of themselves.

Julia talked about slashing her stomach or any part of her body on a daily basis; this got progressively worse over time. Sarah, who was coping with a new baby, described regular cutting, hitting and scratching; one day, in desperation, she started wrecking the house. Gillian talked about cutting herself from about age 14, and remembered “feeling better, it felt cathartic”. She continued cutting her arms, legs and stomach throughout high school. She was told by school authorities to cover herself and not to talk about self-harming.

For most who self-harmed, it provided a way of coping with feeling desperate. A potentially fatal self-harming incident or suicide attempt was commonly reported amongst this group, and typically constituted “the crisis” in the young adults’ mental health narratives. Such crises became the catalyst for coming into contact with mental health services, as discussed later in this chapter.

Thought Disturbance

Changes in thought or perception, such as hearing voices, experiencing delusions, feeling “speedy”, and/or hallucinating, were also common during the downhill phase. For about half of the young adults who had these experiences, such changes followed a lengthy period of feeling depressed and unable to cope with their lives. For the other half, the going downhill period started with hearing voices, “speeding up”, experiencing delusions and/or seeing things. For both groups, the disturbances...
of thought or perception became more intense with time. ²

Tommie commented that he had been depressed for four years following a relationship break-up. “I was about 18, I seemed to be really depressed all the time and wondering what was the meaning of life and always sad and nothing ever really made sense.” After some time, he started hearing voices. He became confused and resigned from his job.

Jenny said, “By 16 I was pretty depressed and smoking dope each day. Then things just one after the other went wrong…I was really depressed and couldn’t hold it together, I was really upset all the time.” She said that others would have seen someone who was “quite happy and quite stable, slip quite dramatically…it was over a period of time”. Jenny recounted a drugging and sexual assault incident, and commented that she then “started to lose the plot and hear stuff”.

Samuela talked about being depressed, suicidal, isolated and unemployed for a long time and smoking a lot of marijuana. He later started hearing voices.

Bob talked about “blocking out the world, staying home, being withdrawn …smoking a lot of dak”. He described ongoing depressive feelings that were “unconquerable”, and said he then started hearing voices which “got worse and worse”. At this point Bob described getting heavily into drugs and alcohol as a way to help him sleep.

Johnie, who did not experience depression prior to the onset of voices, commented, “It took a good six months to a year to build up enough paranoia to become psychotic and with my heavy drinking…and the worry and paranoia…I suffered more and more stress…it basically drove me psychotic.”

The cumulative intensification of disturbed thought, and feelings of depression or despair, often resulted in becoming suicidal and/or making a suicide attempt, as did the frightening nature of thought and perceptual disturbances. Participants described feeling terrified of other people, spirits or intangible entities. For some, this led to feeling driven to harm themselves, harm others in order to defend themselves, or damage property.

Bob talked about voices telling him to fight, to go out in the middle of the night with no clothes on to meet someone, and to hurt himself. Fiona thought that her flatmates and family were plotting to kill her. She became so afraid of them that she eventually held her flatmate up at knife point.

Jennifer talked about hearing voices and having intrusive anti-Pakeha thoughts to such an extent that she thought anything in her home from a Pakeha was poisonous. Chris talked about hiding in his house for three months because he was so afraid. Over time, the paranoid thoughts he experienced became worse and worse. Chris thought he had been drugged and raped by someone living in his house, and was afraid of people coming to beat him up.

Lizzie said, “I was 14…I started hearing all these people…voices…ever since then I was just getting sicker and sicker…hearing the voices just scared me so much.” She talked about drinking alcohol as a way to cope with the voices; however, she said this made “everything worse”. Jo said, “I had the idea my body was contaminated…my skin was crawling…the air was contaminated and I couldn’t breathe”.

**Anxiety**

A smaller group of young adults talked about being overwhelmed by anxiety during the downhill period. Claire described constant anxiety, feeling unreal, physical discomfort in her chest and not wanting to talk to anyone. She said that following her close friend’s suicide, she couldn’t make sense of her feelings and she eventually felt suicidal herself. Some of this group experienced anxiety as well as obsessive

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² These participants were nearly all in the group we refer to as the psychosis group.
thoughts, feeling out of control, agitation, pacing, panic attacks and feeling suicidal. James-Jim said things had been building up for about a year and he was smoking a lot of marijuana to cope with how he felt. His father noticed changes such as agitation, pacing, obsessing and withdrawing. As things got worse, James-Jim began to think people were poisoning him.

**Drug and Alcohol Use**

For the vast majority (over 85%) of the young adults, going downhill was associated with excessive use of drugs and/or alcohol, especially marijuana. A minority used only alcohol, and only a few said that they did not use alcohol or drugs prior to their mental health crisis.

Fiona started using marijuana and consuming excessive amounts of alcohol around age 15, as her life became increasingly difficult to cope with. She regularly smoked marijuana, took magic mushrooms and hung out with a lot of "druggy mates".

Anna said she had been drinking heavily from age 14, and later got into drugs in an industry where, instead of shouting a drink, “they’d shout a line of cocaine”. She described going clubbing, getting drunk, taking a range of drugs and generally getting “wasted every day”, in a spiral of despair and self-destruction.

James was smoking dope regularly and thought it was getting addictive. He said “I just had all these friends that were having parties, getting drunk and smoking dope...the drugs were the main thing...[I] went a little bit crazy.” He also had started stealing and breaking into cars with his mates, and getting into trouble with the police.

David said that he started taking drugs to relieve depression, following the suicides of his close friends. As was mentioned in Chapter Three, the use of drugs and/or alcohol often started in the participants’ early teens and continued throughout early adulthood, as feelings of depression, anxiety or despair, and/or voices or delusions intensified. This cyclical process of feeling bad, using drugs and alcohol, experiencing temporary escape, taking more drugs and alcohol, and eventually feeling worse became entrenched over time. Many of the young adults said that they had known the use of drugs and/or alcohol was making their mental health much worse, but that the temporary escape was a means of survival or had become a way of life.

**Becoming Suicidal**

Many young adults in both the psychosis and non-psychosis groups talked about becoming suicidal as they moved towards their mental health crisis. Many had already attempted suicide or seriously self-harmed at the time they first had contact with mental health services.

**SEEKING HELP WHILE GOING DOWNHILL**

Many of the participants tried to get help from an agency or professional during the downhill period. The young adults in the non-psychosis group were keenly aware of changes in how they were feeling. They spoke of being depressed and/or distressed, and many felt suicidal. Most of them (11 out of 14) sought help. Jo said, “I wasn’t feeling good… I knew I was starting to get worse, I was trying to get help for a long time…I had an overdose…it wasn’t a suicidal thing…I was seeing my doctor quite regularly after that.” Gillian and Mary told us they had felt depressed for some time and had been self harming progressively more during the downhill period. Because they were at high school, they initially sought help from school guidance counsellors. Julia said she felt progressively more distressed over time, self harmed more and had greater difficulties with an eating disorder during the downhill period. Max told us that he was ‘becoming obsessive’ and said, “[I] realised I was getting out of control.” Both Julia and Max initially sought help from tertiary counselling services.

Some people in the psychosis group were aware of feeling depressed and not coping with their lives during the downhill period. Others talked
about being unaware of the extent of changes in their behaviour or mental health during the downhill phase, although they often said they and felt “confused” or “strange”. Many talked about resorting to drugs or alcohol to cope with the distress they felt.

However, no one in the psychosis group, (who were mostly male, Māori and Pacific participants) sought help of their own accord. Sometimes family or friends, noticing changes in their behaviour and/or mood, suggested that they seek help, but participants were usually resistant to such suggestions. Overall, for five of the 26 people in the psychosis group, help was sought in the going downhill period.

Jerry said, “I had stress and stuff and felt ... on another planet.” His employment course coordinator noticed changes in his behaviour and called in a mental health professional. David told us that “things started getting rather strange ... I persevered for quite a while [at work] ... then just went nah, it’s too strange mentally ... and left”. David said this had been stressful but he was more concerned with “trying to figure out what was going on”. He did not think he needed help from a mental health service and was not impressed when his parents eventually called the local crisis team.

Tommie was unaware of changes in his behaviour, and said “there’s nothing wrong with me” when his friend talked to him about the changes he saw happening. Tommie was well down the road to a crisis before his friend took him to a Drug and Alcohol Service, where he was referred to Early Intervention.

**SOURCES FOR HELP SEEKING**

The most common assistance sought was from a general practitioner. Other sources of help included sexual abuse services, university student counselling services, school guidance counselling services, and Community Adult Mental Health Services. Sources mentioned only once included Women’s Refuge, the Phobic Trust, and a Pacific mental health service. Sometimes the young adults sought help from more than one source, although few had contacted more than two places for help. In this next section, we discuss issues surrounding the young adults’ experience of help seeking from different sources.

**General Practitioners (GPs)**

Participants who went to GPs came mostly from the non-psychosis group. They were prescribed medications as the first option for treatment. Jo said she repeatedly went to her GP during the downhill period. She commented, “I was explaining it really clearly and I wasn’t sitting there looking completely nuts”, so she did not think her level of distress was taken seriously by the GP. Anna told us that she had been feeling depressed and felt suicidal. She consulted a GP, who prescribed her antidepressants which exacerbated the depression, produced unwanted side effects and intensified her suicidal thoughts. Mary said she had been “getting worse, things had just been going downhill” for a long time and she was experiencing increasing levels of anxiety and feeling out of control. Eventually she took an overdose using medications prescribed by her GP.

Therapy or counselling was rarely suggested by the GP, even in situations where the young adult had talked about a distressing life event. Two participants said that the GP they saw had not referred them on to mental health services because, they thought, their GP wanted to protect them from potentially harmful, or at least unhelpful services, and possibly also from the stigma associated with getting into “the mental health system” at a young age.

Sarah talked about being well supported by her GP, who strongly advocated on her behalf to gain access to a Community Adult Mental Health Service. However, these attempts were met with resistance from the services on the grounds that her distress, relating to sexual abuse issues, was not regarded as a “mental health” problem and that she should instead be referred to ACC for sexual abuse counselling. Sarah had already been to sexual abuse
counselling and this had not been effective in dealing with the range and severity of mental health difficulties she now experienced.

Fiona was one of the few from the psychosis group who reported going to a GP; and this was prompted by concerns expressed by her grandmother. Fiona was aware that she “couldn’t make sense” and said “I was really paranoid” during the GP’s interview. The GP, who had been the family doctor for many years, prescribed antipsychotic medication, took Fiona back to her grandmother, and called the intensive mobile mental health team. It is unclear what happened next, but some time later Fiona spiralled down to a mental health crisis involving police, crisis team, and a compulsory acute admission.

In a couple of instances, people from the psychosis group who saw a GP were referred on to a mental health service, but were told after an assessment that they did not have a significant enough level of distress or sufficient “symptomatology” to warrant intervention.

**Counsellors and Counselling Services**

During the downhill period a number of participants approached counsellors and counselling services, including school and tertiary education counselling, sexual abuse services, workplace assistance, and specialised services such as the Phobic Trust.

Of those who had seen school counsellors, some indicated that their counsellors were not equipped to deal with their level of distress, complexity of circumstances and multiple needs. However, they had not been referred on to an appropriate mental health service. Furthermore, school authorities could be punitive in the way they reacted to distress. One young woman who self-harmed through her high school years said that she was told by the school authorities to cover her body (i.e. her scars), not to read books by authors such as Janet Frame, and not to talk about self-harming to other students.

Claire went to a sexual abuse service when she was initially going downhill. Around this time she experienced a distressing life event, and was also using drugs and alcohol as a way of coping. What she saw as a lack of professionalism from a drugs and alcohol service negatively affected her. It was not until she experienced a major mental health crisis, some time later, that she gained a referral to an intensive therapeutic service which helped her deal with both issues.

The most common outcome of involvements with counselling services was that, at some point, it seemed apparent that the complexity of difficulties the person concerned was experiencing required a more comprehensive approach, and broader resourcing, than could be offered through these services. However, in most instances, referrals to mental health services were not made, or if made, they were not successful, and a crisis had to occur before access was gained to mental health services.

**Community Mental Health Services During the Downhill Period**

Significant barriers were put in the way of access to community mental health services, and their crisis teams, during the downhill period, particular if participants did not display obvious signs of psychosis.

Some who did manage to get referred said they were assessed by a mental health professional, but were not regarded as seriously distressed enough to warrant access to the service. One said she thought she was denied access to community teams because she was articulate, coherent, and able to express how she felt. She felt that this meant her distress was not taken seriously. “Oh, God! Here’s another person who’s wasting our time,” was the attitude described by another. Participants spoke of not being seen as “serious” by crisis teams because they had not described themselves as “actively suicidal”, even though they were experiencing extreme despair and often seriously self-harming. Sarah, who had contact with a GP and a sexual abuse service, but was denied access to the
community adult mental health team, ended up seriously self-harming on multiple occasions. After the first two times, the crisis team refused her contact because she was not regarded as “serious enough” to warrant their assistance. She continued waiting for a community adult team appointment for seven months, and even once she had an assessment, was denied access to this service.

Other participants told us that crisis teams had not responded to requests for help during the downhill period in a way that they thought was appropriate or useful. Some tried to get direct access. Jenny’s parent had called the crisis team on numerous occasions to get help for her as she became more depressed and suicidal over time. She said “no one was interested”, and her parent “couldn’t get hold of anyone at crisis teams”. He eventually called the Minister of Health to get some action. Overall, she did not receive the assistance she needed from mental health services; she continued going downhill and after a traumatic incident, she started hearing voices and proceeded through a distressing series of acute inpatient admissions.

James-Jim’s family sought help for him from multiple sources. He told us that his grandmother and cousin talked to him about their concerns for him. Although he was taken to the Phobic Trust and an appointment with a psychiatrist was suggested, he never went back. Later on, his parents persuaded him to see a GP and from there he was referred to a crisis team. At this stage James-Jim was unable to continue with university, but the crisis team “didn’t identify any major problem ... I wasn’t hearing voices ... but I’d stopped going to university so they thought there wasn’t a problem”. He was subsequently left without a referral to a mental health service at that time. Further down the track, James-Jim had a major crisis. He was admitted to hospital under a Compulsory Treatment Order on that occasion, and on other occasions later on. It was only after one of his inpatient admissions that he received a referral to an Early Intervention Service.

Anna, who had sought help from her GP previously, was referred through her workplace assistance programme. She saw a psychologist from a community mental health team on a weekly basis for about 18 months. As far as we know, she was the only participant who gained direct access to and substantial therapeutic assistance from a community mental health service as the result of a referral from a GP or a community source. This intervention was highly successful, as shown by Anna’s ability to address the issues that caused her distress, maintain a managerial role in her chosen career and go on to experience a successful process of recovery.

The young adults’ stories of help seeking during the downhill period (and around half described seeking help or having help sought for them) convey a clear picture: when they did seek help, the help they received was largely ineffective. They were not referred on, or if they were, they did not gain access to secondary mental health services. Those who did not seek help (or did not mention help-seeking during this period) described significant changes in their emotions, thoughts and behaviours which most likely would have been observable to those around them over a period of time, yet effective actions were not taken.

Participants then went on to experience a major mental health crisis, which compounded the level of distress they were already experiencing, especially if it led to a distressing inpatient stay under compulsion. In the next section, we describe some of the young adults’ stories of crisis in order to convey some idea of the intensity of distress they were experiencing at the time they “jumped the barrier” and gained access to mental health services.
MENTAL HEALTH CRISIS

Our participants spoke powerfully of the intense feelings and/or disturbed thoughts they experienced at the time of crisis, and told moving stories of what they had been going through during the period of going downhill and “hitting rock bottom”. Although the young adults’ stories of crisis were diverse, a dominant theme was the pervasive and extreme level of distress they experienced, and the serious extent to which their lives had been disrupted by the time they first accessed mental health services.

Many spoke of feeling or being actively suicidal at the time of their mental health crisis; they felt they had no way out of their despair other than to overdose or attempt suicide even though many did not really want to die. Others believed they were being driven by voices to kill themselves. It was alarming that more than one-third of the young people who participated in this project told us about suicide attempts and/or serious self-harm before they came into contact with mental health services, and some others may have had this experience but not discussed it with us.

Claire, who had experienced considerable abuse and neglect through her life, a recent trauma, and withdrawal from drugs, spoke of feeling “the lowest I’ve ever been” at the time of crisis. She said “I didn’t necessarily want to kill myself, I just didn’t want to be here, didn’t want to be alive, everything was too painful.” Shane spoke in an understated way of having a “real hard time ... and getting real depressed”, and said he had tried to kill himself after a quarrel with his girlfriend.

Max described how he was feeling just before he overdosed for the second time:

I was just...what’s the point of living when it’s all.... And that’s pretty much what was going through my head – what’s the point of living when it’s just pain? And it was pretty much just like that – there was no joy in my day. I had to do things like...I

work in the mornings...my anxiety was so bad that I couldn’t eat, so I’d do things like put a movie on to distract myself while I ate, and my life was just a series of little tricks, and I was losing friends by the gallon, I wasn’t handling school, and I’d do things like I’d work a full day on my project and achieve nothing – it was eerie, it was just bizarre, and I’d try to work harder, I’d...work myself more and the anxiety would pick up and I’d get less work done and I just finally went, “Fuck it.”

Sarah, who said she took an overdose, commented, “It wasn’t that I wanted to die but if I did, if that happened ... then that’s fine ... I just didn’t want to think about anything [any more].” She described how “things had got progressively worse over the years and they weren’t showing any sign of getting better and it was frightening”.

Pippa described her crisis by saying “things seemed to fall to pieces”. She talked of there being a long time of “lots of little things ... there were things in the family going on, there were other experiences that I’d had and they all just came together”. She talked about being depressed and keeping her feelings to herself, because it was not safe to tell or show her family how she felt. After a family fight one day, Pippa started “crying hysterically and couldn’t stop ... and ... didn’t want to live”. At this point the crisis team became involved and she was admitted to an inpatient unit.

Some of the young adults who had taken overdoses spoke of the anguish they felt at the thought of being found dead. This had prompted them to call for help after an overdose. Further, they talked about their distress being compounded by doctors or family who did not believe how many tablets they had taken. Hine said “one day I’d just had enough ... I didn’t really want to die ... I took my aunty’s pills ... like a 100 ... and some antihistamines ... and wine ... I think all I wanted was to be loved ... and I just wanted freedom”. When her father did not believe how many tablets she had taken she said “that just stopped my heart” and when
the doctors did not believe her she said she “felt like a fucking idiot and that just made me more sad”. Hine who was in her late teens at the time of the crisis said “I don’t think anyone really realised what I was actually going through”.

Many of the young adults, especially those in the psychosis group, spoke of the anguish created by disturbed and confused thoughts, and how distressing the content of voices had been. Bob had been depressed for some time. He said, “I felt all these negative thoughts and feelings and I couldn’t get rid of them no matter what I did ... I stopped eating ... went heavily into drugs and alcohol ... I felt dirty, nothing could take it away.” Over several years Bob feelings intensified. He told us that he “just felt ... like concrete, [I] couldn’t get out of bed, it was the worst feeling in the world”. Bob said eventually, “I just had enough ... the voices in my head ... all these feelings ... it was real real difficult ... the voices said the only way you can get rid of the voices is by taking out your eyes ... that was my first episode ... I tried to commit suicide.”

Taylor, who was one of the youngest participants, spoke in detail of the feelings, thoughts, fears and all-consuming nature of her experience of a crisis following a long period going downhill. She talked about her strong religious convictions, and spoke of the tension she experienced trying to adhere to her Christian faith while being a teenager living in difficult family circumstances, and having grown up in an abusive family environment. Taylor spoke about the inner turmoil she felt around the time of crisis:

I had a whole lot of things going on in my mind, it was hard to distinguish reality from what was in my head ... I was really emotional and was constantly changing my attitude ... I would isolate myself in my room because I was quite depressed and didn’t have a job and wasn’t doing the things most people my age do ... I really started to have low self esteem ... unrealistic things started coming into my mind ... they were really out of it.

She also spoke of being “really afraid” as her thoughts had become frightening and disturbing:

I [thought] I was a pig and people wanted to boil me and chuck me in a freezer and put me on a slab and cut me up and eat me ... what was really bad is that they wanted to feel each phase so they had some sort of power over me to keep me alive ... I felt like I didn’t belong anywhere ... that my family weren’t my family and I stole somebody’s place. There are so many things. Much more things than this ... I didn’t feel safe, I felt like everyone wanted to do really hurtful things.

MENTAL HEALTH CRISIS: CONTACT WITH SERVICES

Accident and Emergency

The experiences of a mental health crisis described above led to the contact with mental health services. Although not all of the participants had the same pathways into mental health care, most came into contact with accident and emergency services or a crisis mental health team.

Several of the young adults took an overdose or seriously self-harmed during the downhill period. Some said they had been seen by Accident and Emergency, spent a night in a general or psychiatric ward, and were then discharged without follow-up or referral to a mental health service. This process escalated their despair. These young adults said they then seriously overdosed and self-harmed a second or third time, and at this level of crisis, were admitted to an acute inpatient unit. For example, Max, who originally sought help from student counselling, proceeded downhill until he felt so distressed that he took an overdose and self-harmed. He said “I had the worst night in A & E, they didn’t have any beds in psych, so I got thrown into a general ward.” Max told us that in the morning “all the students, they just hauled around my
bed”, and he was discussed by the doctor and students. Following a brief meeting with a crisis team nurse, he was discharged onto the street without anyone being called and only in his “singlet and shorts and some trainers”.

**Mental Health Crisis Teams**

Most participants came into contact with a mental health crisis team. Although this contact was not usually the focus of young adults’ stories, it was often the pivotal moment in terms of entering the mental health system and accessing a range of services.

Participants who reported psychosis spectrum diagnoses generally had a quick response from crisis teams and an immediate referral to a mental health service, typically an acute inpatient setting. They often talked unfavourably of their experiences with crisis teams, especially when police were involved. In contrast, those who reported non-psychosis mental health experiences continued to have a poor response from crisis teams and difficulties gaining access to appropriate mental health services.

**Psychosis spectrum diagnoses**

A few in the psychosis group said the crisis team “was quite good”, although this was not a common view. Many talked about a sense of shock and bewilderment at the sudden and unexpected arrival of a crisis team. James-Jim, who was already feeling bewildered by his mental health experience, described being “stunned by the whole process” of entering the mental health system for the first time.

The team often arrived accompanied by police, and the combination heightened the sense of shock reported by some. David was eating his dinner after work one day while watching a DVD when the crisis team and police appeared. He said, “all of a sudden they took me away... they just came and grabbed me and said ‘you’re coming with us’.”

Jennifer was hearing voices and sought help from a relative, who arranged for the crisis team to assess her at her home; they later “turned up with two or three policemen and my mum and [child]”. The police took her to hospital. Victor said he had been having an argument with his mother and she called the police. He was held in police cells for a few hours before the crisis team arrived. The crisis team said “You’re going to hospital”, and told him he would be put in seclusion.

A couple of participants talked about the physical force used by the crisis team and/or police. Fiona said she was holding a knife and had barricaded her flatmates in a room because she was so afraid of them. Once the crisis team and police arrived, it took five of them to hold her down, she told us.

Although most participants saw a crisis team, a small number in the psychosis group who were in crisis or post-crisis mode seem to have gained direct access to Early Psychosis Intervention services (EPI) through a family member or friend calling, or being referred by an adolescent service, Corrections or Child, Youth and Family. EPI either sent an assessment team to the young adult’s home, or arranged for them to come in. Shane, who was discharged from a general hospital following a suicide attempt, reported a positive first contact experience. He said that they came out within an hour or two of his family’s call, and he found them “really good”. In contrast, some of the Pacific young adults were uncomfortable with the initial approach taken by Pakeha staff from EPI. Victor said the EPI team came to his home and that he did not “get along with them”. They were all “white” and Victor wasn’t comfortable with the man in charge because of how he greeted Victor. Victor said the man “bombarded him with questions and did not take time to get to know him. Afterwards, Victor said, “Two white people came over” and then he was “chucked in jail” for being “hyper” and “angry”. The young adults’ experiences with EPI services are further discussed in the next chapter.

Few of the young adults talked about how they felt about having family members or others call a crisis team or take them to a mental health service. However, some, like David, were not
happy about the call to mental health services, and commented, “My parents have never really spoken to me about it since.” Others were pleased someone had arranged help for them. Rocky said his mother had been worried about his unusual behaviour. She called a Pacific mental health service, was referred on to an Early Intervention Service, and they came to the home to assess Rocky. He said, “I reckon it was good what she [mother] did, she was helping me out.”

**Non-psychosis diagnoses**

Young adults with non-psychosis diagnoses spoke of largely negative experiences with crisis teams, particularly in terms of staff attitudes and response to their distress. A few made comments such as, “there were a couple of good people in the crisis team”, whereas others talked at length about difficulties getting any help, not being taken seriously, delays in being referred to an appropriate mental health service and the time it took to get an appointment once a referral was made. Some participants had several contacts with the teams over the course of several crises, and were therefore talking about their experiences as clients known to the service, rather than as people undergoing their first crisis assessment.

Sarah who had made several suicide attempts and self-injured was taken by ambulance to accident and emergency following a suicide attempt. She was subsequently seen by the crisis team. She described the first staff member she saw as “genuine”, as someone who listened well, gave good support and did an immediate referral. The staff member acknowledged how stressful Sarah’s life had been and said that she should have been able to access mental health services before this crisis occurred. However, a week later Sarah consumed alcohol and medications, and damaged her house. This time the crisis team said there was nothing they could do, “because it wasn’t serious”. They simply advised her to wait for the appointment at Community Adult Mental Health to come through. This response was “incredibly stressful” for Sarah and her family, and she described feeling as if “all the doors had been shut”. Sarah said it would have helped her enormously if the crisis team could have just seen her for half an hour and perhaps talked over some safety issues.

Max said that one of the police officers who accompanied the team had read out his suicide letter in a derogatory manner:

They get my note – I’d written a few pages. The dick was just having a look at it – it was clear that he didn’t understand it. [He’s thinking] “Ah, stupid turd wants to kill himself, wants to waste my time. I should be in homicide.” And he’s looking at me and he’s got my note to my loved ones, just reading it: “Well! Had lots to say, didn’t we?!”

The other officer was sympathetic, but seemed very uncomfortable with the situation. He said to Max:

“I don’t understand – why’d you do it?”

[Max replied:] “I just couldn’t see any options. You never just get to the point where you don’t know what to do?” And he goes, “Nah, man, I fly-fish. As long as I can fly-fish... So I think, everything goes wrong – fly-fish.”

Michelle, who was pregnant, depressed and suicidal, called the crisis team while waiting for an appointment at Maternal Mental Health. She spoke to them one night when she was feeling “really, really desperate”. Michelle said she spent most of her time “trying to get through” and “getting shunted from department to department on the phone”. When she eventually made contact with them, they said “Oh...you’ll have to ring in the morning”. At another time, while in the process of transfer from one DHB to another, she called the crisis team in both DHB areas and was told they would not talk to her because she “wasn’t properly transferred”.

Susan was also pregnant, had recently separated from an emotionally abusive relationship, had no support and was suicidal. One night she
called the crisis team in desperation. The staff member who answered the phone said, “So what do you want us to do?” When Susan said she just needed someone to help her out of this problem, the staff member said, “There is nothing we can do tonight, you are just going to have to get through this by yourself.” She had hoped someone could have come to visit her. Pippa said the crisis team was “absolutely useless”. Once when she was suicidal and had called them she was told to “calm down” and “have a cup of tea”. She commented, “They’re not exactly someone I would recommend to people…there’s no way I would ring them on my own, it’s just not worth it.”

Jo had a similarly poor response from a crisis team. She had recently experienced a series of adverse events, and had been trying to get help from mental health services for many months. Jo was at home with her young child, hallucinating and very distressed. She said, “I had been trying to call them all day…it took hours and I kept ringing…I was still trying to call them around 7pm at night.” With each attempt, she got the answer phone and left a message. Eventually the crisis team called back and she was later taken to hospital. Jo felt sure that the crisis team and staff she saw at the inpatient unit “can’t stand manic-depressives because they are [seen as] a pain”. She commented, “I think they just get like ‘Oh, here we go again’…I was never once asked how my child was…and I was desperate.” Jo also talked about being articulate and able to explain herself well, which meant the staff “assumed that I was okay”. Jo concluded, “I am quite resentful about the way I was treated.”

In summary, participants identified a range of precursors that interacted to produce declining mental health. For many, a legacy of childhood and/or early teen adversity and trauma had a negative flow-on effect into young adulthood. Early adversity “caught up” with participants as they entered young adulthood. During this time, for many of them, family life continued to be discordant, dysfunctional and distressing.

Participants often contended with more adversity and/or trauma during their late teen/early adult years. For a few of these, adversity and/or trauma had not been characteristic of their childhood or early teen life but recent experiences of this nature were extreme enough to jeopardise their mental health.

Many of the participants lived with the impact of distressing experiences for many years without the opportunity to talk to anyone. They felt they had no one who would listen, understand and validate the experiences they had been through.

Some also spoke about experiencing a series of significant events (not necessarily adverse in themselves) in close succession during the downhill period. Experiencing too much change, too quickly and in too short a space of time, particularly in relation to identity issues, was a significant precursor to declining mental health.

The pervasive and excessive use of drugs and alcohol figured prominently in the going downhill period as the young adults struggled to cope with their lives, or hung out in groups or workplaces where excessive drug and alcohol consumption was part and parcel of the lifestyle.

Most participants identified significant emotional and behavioural changes during the going downhill period, and said that these changes occurred over a long period of time, with depression usually being the initial key change. Sometimes they were unsure if their feelings of depression were symptomatic of being a teenager, or due to more significant mental health issues. Self-harming was a severe and significant issue for some of the young women; none of them, despite seeking help, received appropriate interventions prior to a mental health crisis. Other participants spoke of significant negative changes in their thoughts, in addition to feeling depressed, and of how frightening and distressing this had been. These experiences often led to an increase in the frequency and intensity of drug and alcohol consumption, as the participants tried to cope.
Many of the participants, mainly in the non-psychosis group, had sought help at various times during the downhill period. For most, help-seeking was unsuccessful: the problems they presented seemed too complex for primary care and counselling services; yet if referrals to mental health services were made, they were often turned down as not being severe enough to meet criteria. In the psychosis group, most participants had not looked for help, although in some cases families and others had been concerned and had sought help. For some, this led to a prompt response, but others failed to meet access criteria.

The going downhill period ended in crisis, as feelings spiralled into a desperate state. Crisis was often marked by suicide attempts or family difficulties extreme enough to lead to calls to police or crisis teams. Crisis assessment, usually by crisis teams and occasionally by early intervention, marked the gatekeeping function, beyond which lay the provision of mental health services. It was a barrier for participants to cross (although some had already tried to cross it before). For some of the participants who were deep in crisis, assessment led to compulsory and unwanted mental health treatment.

For around two-thirds of the participants, service provision as the result of crisis took the form of hospitalisation and a stay in an acute inpatient psychiatric unit. A few others were given different forms of acute provision. The others transitioned directly into a variety of what we decided to call post-acute mental health services. We describe our participants’ experiences of acute mental health services in the next chapter, and of post-acute services in the subsequent chapter.

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3 “Post-acute” is not a term used in the usual description of mental health services, but it seems to most accurately describe the range of services participants engaged with after a severe mental health crisis.
In the previous chapter, we showed participants “going downhill” to the point of crisis. At the end of the chapter, we told of encounters with crisis assessment services, the most common route into mental health services, and which in two-thirds of cases led to an acute inpatient stay. In this chapter, we focus on young adults’ accounts of their experiences with acute mental health services. As well as the 26 in all who spent time in an adult acute psychiatric ward, there were several who described different forms of acute provision. A couple narrated earlier experiences of a child and/or young person’s psychiatric unit; and a few others had experienced home-based treatment, crisis respite and a crisis house.

ADULT INPATIENT PSYCHIATRIC UNITS

Many young adults were hospitalised for surprisingly long periods of time. It was not uncommon for participants to have stayed in hospital for between two and six months, and some stayed for longer, including up to a year. Only a minority stayed for less than three weeks, which is the average length of stay in a New Zealand adult inpatient unit.

Those who had an inpatient stay spoke at length about their experiences. Their narratives were powerful, constituted a focal point of their early contact with mental health services, and were overwhelmingly negative. We have organised our analysis of what they said as follows:

- arriving
- the inpatient environment
- experiences of compulsion in acute units
- describing nursing staff in acute unit
- associating with other service users in the unit
- safety for women, sexual harassment and sexual abuse in acute units
- treatments: focus on medication and absence of talking therapies
- the need to be somewhere
- leaving hospital and returning.

Arriving

As noted earlier, crisis assessment procedures usually preceded admittance to hospital. Sometimes this occurred via emergency services following a suicide attempt, or via the involvement of police and a crisis team coming to the young adults’ residence.

The young adults’ contacts with an adult inpatient unit frequently began in the context of Mental Health Act provisions. Two-thirds or more of those who had been hospitalised said they were subject to a compulsion; virtually all of these were people who received psychosis diagnoses.¹ Several more participants said that the crisis assessment team and/or inpatient staff had threatened them with compulsion if they did not voluntarily go to hospital (or remain in hospital). A smaller number said that they had wanted to be admitted to an inpatient unit because they felt out of control, were extremely distressed and suicidal, and had been unable to

¹ Some other participants may have experienced of compulsion, but not discussed it.
obtain the help they needed from mental health services elsewhere.

People arriving at the hospital under compulsion often found themselves immediately placed in a locked Intensive Care Unit (ICU) or in seclusion\(^2\). David, who had described the crisis team as “all of a sudden” coming to his housing, “grabbing” him and taking him to the acute unit, was “put in a room ... and I just sat doing nothing for a week”. Similarly, the crisis team told Victor he would be put in seclusion and that was what happened: “They locked me up ... it’s like prison.”

**Inpatient Environment**

Many of the young adults told us that they had felt frightened staying in an adult inpatient unit. Indeed, most of the participants described inpatient units as “terrifying”, “scary”, “frightening”, “incredibly awful” or a “really horrible experience”. “Scary” staff and other service users created an atmosphere that did not feel safe or conducive to sleep, rest or well-being.

Jenny provided a vivid account of her experience of a ward:

[I]t was really busy [and] overcrowded, I was sleeping on the floor ... there were no beds ... It was just constant noise and movement ... they stuck me ... next to ICU and there were people banging and howling and screaming ... which wasn’t really conducive to me getting sleep or feeling safe ... I was pretty scared ... you’d hear [the staff] bring people up and they’d be throwing up in the toilets and then ... it sounded like they were being beaten up ... and they’d be screaming ... I guess they were just being restrained ... it was just noise like that constantly ... when I’d left hospital I was still hearing the people.

Jennifer also said, “All night I heard screaming and banging.” Lizzie spoke about being “surrounded by people that have got mental illness and they constantly scream and cry ... it was always like that”. After describing an inpatient stay as her “worst experience” of mental health services, Lizzie commented:

You’re not supposed to put sick people with sick people ... [it] doesn’t make a good equation, it’s supposed to be a well person with a sick person because then the well person can look after the sick person. If you’re among all sick people then how are you all going to look after each other?

Some participants spoke of the humiliation associated with certain inpatient practices. Max was prevented from wearing shoes or shoe laces, or the belt to his trousers, during his extended stay in ICU. Further, he was required to ask to use the phone and had to repeatedly check in with staff. He said, “I felt nothing but embarrassment and shame,” and suggested that “leaving out the shame factor” would have made the inpatient experience better than it was. Max also talked about not having enough to eat and remaining in dirty clothes during his stay. Always one to see the humour in situations, however, he said:

[I] was very depressed in the mental health ward because I’d expected very interesting people – *One Flew Over the Cuckoo’s Nest* – and instead I met a lot of very boring people who are hamstrung by routine.

Several participants besides Jenny talked about the overcrowding in inpatient units and said there were too many service users for the available space. Max was told by staff that he had been kept in ICU longer than necessary because there were no available beds in the open ward. “They said I shouldn’t be in ICU so long, it wasn’t the best thing for me at all.”

The lack of space inside the units was exacerbated by a lack of outside space.

James-Jim, who was an inpatient for five months, described hospital as “really horrible”. He particularly disliked ICU, where he stayed

\(^2\) Seclusion, essentially solitary confinement, is where a service user is locked in a bare room on their own.
for three weeks. He said, “A large number of people [were] put in a small space ... the rooms weren’t that big and the outside area wasn’t very big either, we were banging into people, it was horrible.”

Any small outside space was often taken up with smokers which meant there was nowhere to go if you wanted fresh air. Further, outside space was often not big enough to expend energy, as many of the young men wanted to do. Toby said there were “too many walls ... I felt there was a sense of seclusion and confinement ... we need a bit of outside ... there’s the balcony but only the smokers go there ... [we need a] space to run around and play ball”. He commented that some “tranquillity” and “being out in nature” would have helped to settle his thoughts. Victor commented that he “was not allowed to go for a walk and had been cooped up inside for months ... there was nothing to do and nowhere to go”. Lack of space, both inside and outside, was a particularly stressful aspect of the young adults’ inpatient experience, especially for those who were held against their will and had to remain in inpatient units for several months.

Most of the young adults who spent time in an inpatient unit commented that they felt extremely bored, due to a lack of activities. This was depressing, especially when they were there for months at a time and were not permitted to go out, except on rare outings with staff. This lack of activity and restriction on the young adults’ movements became demoralising for many participants after weeks or months inside an inpatient unit.

David, who was in hospital for four months under a CTO, and was usually an active person, said he was basically “just in there doing nothing ... just sitting there getting bored ... there was nothing to do ... I hated it ... it was disgusting conditions ... and really dirty”. Similarly, Lorraine said that “there was absolutely nothing to do there ... [people] sat around and smoked all day”. Toby commented that he and another service user would “just walk around and not do anything, I wish there was something to do ... there were some games ... [but] ... people were quite closed ... I think I was closed myself”.

Johnie who was used to working, said, “It’s quite a waste of time [in hospital] ... [I] got to do nothing all day ... [and] because I sat there for so long it’s probably ... made me more unmotivated now.” Jenny, who was used to working long hours in a highly pressured job, told us about being compelled to engage in mindless and demeaning activities that she referred to as “popsicle sticks and pasta”. Many participants indicated that the extreme boredom they experienced while residing in inpatient units contributed to the depression and despair that they felt, and instilled a sense of hopelessness and lack of motivation.

**Experiences of Compulsion in the Inpatient Units**

We have described how a number of our participants arrived at an inpatient unit under compulsion, sometimes with police as well as crisis team intervention. Those who were compelled were particularly likely to describe their inpatient experience as awful. Jenny, who was a teenager at the time of her first hospital admission, was subject to a compulsory treatment order. She told us that she had not understood what it meant until she was prevented from leaving the unit and told she had to take the prescribed medication. Lorraine was 15 years old when she was first admitted to an adult inpatient unit. She said the order was not explained to her, and she did not feel as though she had any rights at all. She commented that it “definitely raised the stress levels”.

Once on the unit, compulsion occurred in a number of ways. As well as having to accept medication, some participants were put into seclusion, where they were on their own in a distressed state in a low stimulus environment which they could not escape. James said he had been “a bit of an idiot ... [and] got sort of out of hand”, and he described being “tackled and locked up” by five nurses. The staff “stripped down my clothes ... they gave me pyjamas and locked me up in the room”. “Being locked up in the room is the worst”, he said, talking to us about having a longstanding fear of being locked up in prison or a psychiatric ward.
In the same inpatient unit, Joe described feeling afraid that someone was going to hurt him. He was accused of attacking a nurse, though he denied that this occurred. He subsequently got into “a scuffle with one of the nurses” and “they locked me in isolation ... and gave me needles”. He felt angry about being accused of something he did not do and being punished for it.

Victor was a teenager when he was compulsorily admitted to ICU. He remained an inpatient for a year: “I was there for ages man ... it seemed like about ten years.” He described feeling “pretty retarded” when other service users came in and later left, and he had to stay. On his first day, he was told he would be put in “lock up ... if anything [untoward] happened”. Victor said some people stole his possessions, so he fought to get them back. He was subsequently “locked up” and said, “it’s like prison ... weird doctors ... look at you ... through a window and ... then walk off ... like they’re prison wardens ... it made me feel pretty angry.” Victor was locked up many times for repeat “nuisance” behaviour. He thought it was “shocking” to lock people up in this way and said, “I felt like an inmate, just for schizophrenia.” Victor had often been held down while staff forced him to take medication or extracted blood. He had sustained multiple injuries as a result of the amount of force used by staff.

Fiona, who had several lengthy inpatient admissions, including six months in one unit, thought that there was an overuse of seclusion and that it was often used as a disciplinary measure, especially against young men. She described the way “boys will be boys” in terms of scuffles and minor fights with one another on the ward. When incidents of this kind occurred, the young men were put into “solitary” and she thought that this was “wrong”. She commented, “The disciplinary actions that they used were just over the top.”

The young adults often thought they had spent a long time in seclusion. Although some said they could not accurately recall just how long, the times quoted varied from days to weeks. These experiences compounded with the boredom, inactivity and confinement on the wards, along with lack of human communication, to became quite traumatic.

**Describing Nursing Staff in Inpatient Units**

Some participants spoke about individual nurses in inpatient units who were “good”, “choice” or “fantastic”. Staff described in this way were respectful, listened and took time to talk. They were not rigid about rules but were accommodating and flexible. Bob, one of the few Pacific young adults who talked about their inpatient experience, said, “The staff were really kind to me.” Max spoke positively about one nurse who went out of his way to ensure he had enough medications when he left hospital, identified potential problems, and talked through possible solutions.

Mary, who had been in two different adult inpatient units, talked at length about the positive way staff treated her in one of the units:

> You’re not just a patient, you are a person ... everyone knows your name ... they joke around and take your mind off things ... they talk ... they’re personal, they will hug you ... and [ask] if there is anything [they] can help you with ... the nurses were really supportive, they were with you when you felt low and didn’t judge ... I found them very useful.

She also said they followed up and got back to her with information, did not enforce contact with her parents, and helped her with sleep when she had insomnia.

However, most participants related stories of an institutional culture characterised by negative staff attitudes and interactions. These ranged from a lack of caring and lack of interest, to provocation and blatant abusiveness.

Fiona spoke about the way staff “gossiped” in the nursing station, socialised with the other nurses, spent time on the phone talking to friends and generally ignored service users
unless there was an incident. She felt they were “not that interested” and did not take time to talk or listen. Johnie thought the inpatient unit was “like a business ... the nurses come and do their shifts and go, [and] as long as there’s no trouble, it’s okay”. James-Jim said that some nursing staff were judgemental and dismissed his physical pain as psychosomatic. Max talked of staff who were “patronising” and “authoritarian”. Mary described staff in one unit as “too clinical”, “impersonal”, “uncaring and unsupportive”. She was “told off” and “blamed” for self-harming, and no one asked why she had cut herself or how she was feeling. Mary commented that staff repeatedly failed to listen to her. She commented, “I know myself better than they do ... I think if they just listened ... and helped me ... I would get better.”

Lizzie, who spent months in an inpatient unit, had observed nurses laughing at patients. She described some of the nurses as “bad personalities”. Lorraine spoke about nurses who made disparaging comments, for instance, telling her that she was “costing $600 ... a day”. She also said there was no one to talk to and no one who was interested. Jenny spoke about the way some staff would “antagonise” service users and “try and get a reaction out of them”. She said the staff would “poke fun at them [and] they’d take away their cigarettes ... hold things back from them or not allow them to drink coffee ... so they’d get more and more wound up ... ”. Further, Jenny reported being yelled at by one staff member for no apparent reason other than that he was having a “bad day”. Finally, she commented that from her perspective the staff were “just big and scary ... they were just scary”.

Several participants commented that because they were young, their views were dismissed by staff. Pippa told us, “It seemed like because I wasn’t old, enough my opinions weren’t valid ... it was [seen as] me going through a phase ... if that’s the case, a year later I was still going through that phase.” Likewise, some young adults did not want their parents involved and found it distressing when staff enforced parental involvement. This was particularly so for some of the young women who had experienced a lifetime of emotional abuse and/or neglect from parents. Pippa told us about a meeting at the hospital involving her family: “I felt that it didn’t work, it just made things worse. I was basically told how I felt and told what I thought.” She said that this was how it had always been with her parents and that some mental health professionals also behaved in this way.

### Associating with Other Service Users in the Inpatient Unit

The young adults repeatedly told us that they found it stressful being around other service users during their inpatient stay. In particular, they spoke about how disheartening it felt being in the company of older service users whom they perceived as “really crazy” and as having no hope of recovery. This adversely affected the young adults’ own sense of hope and expectations about their own recovery. Moreover, the large numbers of older service users who were distressed and “zombied” were a constant source of stress to many participants.

Lorraine found it “scary” and “unhelpful” being around older service users. Toby said, “There were some elderly people and I find it really hard to relate to them, just by the fixations they have ... trying to communicate with them is quite challenging.” David, who did not like the company in the inpatient unit, told us that “everyone else was flipping out ... it wasn’t really the type of people I wanted to hang around”. Some people talked about the unpredictable or objectionable behaviour of other service users. For example, Lizzie, who described feeling very frightened in the adult inpatient unit, said “You don’t know what’s going to happen around the corner, [whether] someone is going to strike you or jump on you and scream at you.” Max told us that he was really offended by a service user who urinated in the corner of a room each day.

Some participants said that they had their belongings taken by other service users. Max’s books were taken; James-Jim had his electric
toothbrush and razor taken, and items were removed from his bag.

A few said that they had found being around other young service users helpful. This primarily related to having some companionship and someone to share their mental health experiences with.

Almost all of the young women who had been inpatients spoke about the stress they experienced being around male service users. This is addressed in the next section on safety for women service users.

Safety for Women, Sexual Harassment and Sexual Abuse in Inpatient Units

Nearly all of the women who had inpatient experiences spoke of feeling unsafe during their inpatient stay. Their fears were based on events that occurred while they were in hospital, and they were fearful of both male service users and male staff.

Several women told us that they had been harassed by male service users. Lizzie said she was constantly “hit on” by a male service user, who also asked other women if they would have sex for money. Fiona was also followed around and harassed. She spoke of men coming into the bathroom while she was having a bath. She was not allowed to lock the bathroom door. Fiona also described recurrent sexual activity between men and young women service users in isolated parts of an inpatient unit when staff supervision was limited. She thought this was “dangerous” for some of the young women, whom she described as “quite vulnerable”. Jenny had spoken to us about literally being “landed on in the middle of the night” by a male service user, and on several occasions having men wander into her bedroom. All in all, the women reported having little privacy or sense of safety from male service users.

Some young women spoke of inappropriate sexual innuendo, sexual harassment and sexual abuse by male staff members. Jenny told us about a male nurse who repeatedly stood too close in behind her and some of the female nurses. The female nurses were “a bit wary of him ... [and] ... wouldn’t leave you in the room with him”. Although there was non-verbal communication about the staff member concerned, the issue was never talked about.

Fiona was sexually abused by a male staff member. He took her to the “judge’s room” where there was no one else around. This was the same room where she had been placed under a CTO. She never laid a complaint because she thought no one would believe her. Fiona also talked about being told by staff to “get a room [to have sex]” when her boyfriend visited. She found these comments offensive and hurtful. Pippa, who spent six months in an inpatient unit, was sexually abused by a male staff member on a day when other staff were distracted with a particularly distressing event that occurred in the unit. Although a consumer advocate helped Pippa lay a complaint, and the staff member concerned was demoted, he continued to work at the hospital. Pippa said, “Ever since [the abuse] I just hate going anywhere near the place.” She had so many negative experiences as an inpatient that “the only way you’d get me to be admitted is compulsory”.

Treatments: Focus on Medication and Absence of Talking Therapies

A focus on medication and the absence of talking therapies was a dominant theme in the young adults’ narratives of inpatient units. Many participants described being trialled on many medications, often multiple medications at once, and sometimes in high doses. Most reported negative side effects and the need to change medications several times before they found one that was effective. About half said that once the right medication was found, this approach to treatment was helpful. However, the other half told us that medications were not effective or made them feel worse. A minority of participants were against taking medications, but were forced to do so because of the threat or presence of a CTO.
Max said:

The first week, though, using the medications on me, they’d try things like [named drug] and other things, which made me slur, and I’m quite articulate and quite loquacious, and my family came out – my father, anyway – and I found it incredibly embarrassing. I couldn’t talk to them properly. And it was just awful. I could see them looking at me, thinking, “Oh, God, he’s really fucked up now.” And the pity. There is nothing worse than pity. And I’m trying to tell them, like, “Nuuuhh!”

Pippa, who had lengthy hospital admissions, was given several different antidepressants which were ineffective. She was told by staff that she was “willing it not to work” or “wasn’t taking it”, and one staff member said that “perhaps [she] likes feeling [depressed]”. Some of the medications caused vomiting, depleted her energy and caused agitation. Pippa said she had “pretty much wiped out” the SSRI group of medications.

Gillian spent five months in an inpatient unit. She saw a psychiatrist whom she described as “terrible … he was just horrible and blunt”, and he prescribed a high dose of antipsychotic medication. Gillian thought this was bizarre, as she had a diagnosis of depression, and was of small stature and underweight. The antipsychotics made her “wasted and dozy” and were not effective.

Bob was placed under a CTO, held in an ICU and stayed in hospital for four weeks, following a suicide attempt. He said, “I had drugs pumped into my system”, and was never offered anyone to talk to. Outlaw was given “heaps at the start, heaps of different ones … it was blank for a couple of weeks … I never liked taking the pills”.

Toby, who was under a CTO, wanted to understand why he was taking the prescribed medication and how long it would be for. He wanted to see “different alternatives” and “really didn’t want to feel forced into taking it”. David said, “they’ve locked me up and made me take medicine ... [that’s] all they’ve done for me ... they don’t seem to know what to do.”

Finally, one young adult who had tried several medications that were not effective was given two complete courses of Electro Convulsive Therapy (ECT) during their inpatient admission. That person said that the staff refused to talk about it, and it was “a very lonely feeling”. The ECT impaired the person’s memory and was not effective. This person was not offered a psychologist or therapist, which they thought would have helped.

None of the young adults who stayed in an inpatient unit were offered a psychologist or therapist, despite long inpatient stays and/or recent trauma. The exception was one participant who had a one-off talk with a psychologist, whom they thought was an intern.

Many said that while they were inpatients, they had wanted someone to talk to about how they felt and the adversity they had experienced. Some people had never had anyone at all to really talk to throughout their lives, and had described a build-up of thoughts and feelings until they “lost the plot”. Although some people occasionally had chats with a nurse, they also indicated that what they needed was an ongoing relationship with a suitably skilled mental health professional. Jenny had a traumatic experience immediately prior to her first hospital admission, and had a history of childhood abuse. She told us that although she was admitted to the inpatient unit on several occasions and had repeatedly asked for a psychologist, she was never given one. Fiona commented, “I think all of my illness is around emotional pain – everything goes back to that.” She would have found talking therapies really helpful following a traumatic incident and series of adverse life events. Toby said he had never had any trauma therapy where he “could just talk about [his] trauma”. He commented, “How can you forget something so traumatic without having some help.” This theme, which was articulated in a range of ways by participants, was echoed throughout the participants’ earlier and later experiences of services.
Although most of the young adults told us that they would have found it beneficial to have someone to talk to, two said they did not want to talk to a psychologist or therapist because experience had shown that it “triggered” them into another crisis, or because they felt they had dealt with issues themselves.

The Need to Be Somewhere

Some young adults who reported a more positive experience in the acute unit were making a contrast with a previous adverse environment. Tiare, who was a young mother, described being scared for her life following an altercation with her stepfather, who had sexually abused her for many years. She took herself to the police and asked, unsuccessfully, to be admitted to an inpatient unit. Later she was “beaten up” by her mother, as often occurred, and sustained a “black eye”. Her mother then called the police and ambulance, and Tiare was placed under a CTO. Tiare stayed in hospital for six months. She said she had “heaps of friends ... got a lot of free clothes ... from patients ... and there were a lot of guys who wanted to go out with me ... “ While there, she established some goals involving her young child, a job and living independently.

Others mentioned that they had needed somewhere safe to be for the period of their crisis. Although the inpatient experience was typically negative, it had provided some escape from the stress of parents or family and the demands of everyday life.

Leaving Hospital and Returning

Most young adults were referred to other mental health services after their time in hospital, and their experiences of these are the focus of the next chapter. Several of them, however, described returning to hospital two or three times, sometimes within a short space of time after discharge. Some of them were of the view that they had been discharged prematurely, either because they were seen as “okay” by staff, even though they personally did not feel ready to leave, or because of high demands on beds. Some of this group had inadequate support once discharged, and/or did not gain access to a community based mental health service or psychological assistance.

Some participants said they had a further crisis, due to factors such as not being given medications when they left hospital, stopping prescribed medications themselves, resuming alcohol and drug taking, and/or experiencing an adverse or traumatic event following discharge.

OTHER FORMS OF ACUTE PROVISION

Some participants described services provided for them when they were in crisis that were alternatives to acute inpatient services, but were nevertheless, were organised around crisis provision, rather than being what we have described as “post-crisis” services. These alternatives were described in far more favourable terms, in most instances, than the acute inpatient services.

Crisis Houses

Tommie was very high, not sleeping or eating and spending lots of money. He was sent to a crisis house where he spent a few days, but he would get a taxi into town and go and see his friends in order to pass the time. He was then sent to a lodge where there was more intensive nursing and which he was not supposed to leave, although those there were allowed on half hour walks, as long as they returned at the right time. Tommie did use one of his walks to go and buy something that was very expensive and unnecessary, and he also went to a nearby car dealer to buy a car. He was not under compulsion in the facility, and he did want to go home, but “they just told me to stay and I was the type that would listen”. While there, he was put on medication and he began eating better and sleeping. Early intervention team members visited him there, and he was taken out to see the psychiatrist at the mental health centre.
Home-Based Treatment

Two or three participants in the Young Adult project had contact with a home-based treatment acute service (HBT), in every instance after they had experienced hospitalisation. All spoke highly of the service and the calibre of its staff. Max, who said he had been “lost in the system way too long,” said that it would have helped him if he had been referred to HBT at the time of his hospital admission (which was “a nightmare”) after a suicide attempt. However, he got HBT services on discharge, when he arranged to go and live with a friend because neither his mother or father could offer a suitable home:

... because there’s this history of mental illness in my family, particularly on my mother’s side. My mother has wigged out a couple of times. She’s had suicide attempts, so I couldn’t go live with her. She’s ... she’s quite mad. Lovely lady. Good mother. Mad as a fish. And my father ... my father took it worse than I did ... he was a mess ... .So I went to live with [my] friend. And the home-based seemed cool – it was actually their choice, because they saw my parents and they were like, “Yeah, no.” Home-based was brilliant—I can’t say enough ... . I got a psychologist who I felt confident talking to.

Jenny said HBT was “really good”, in that people were available out of hours, weekends, and when you needed them. Like Max, she had an appalling inpatient experience, then HBT services on two different occasions during later crises. She told us that because she had used the service twice, she would not be permitted to use it again.

Some young adults went to respite at the time of a mental health crisis, instead of to hospital, although most had been sent to hospital at the time of their first crisis. Their experiences of respite varied, but most said respite was better than being in hospital. James-Jim was sent to respite following a physical fight with a sibling. He said it was “a relief” to be away from ongoing conflict. James-Jim said the staff at respite were “quite good”. Jenny went to respite twice and described these services as “nicer than hospital”. She commented, “you’d still get strange people all around you ... but it was better than being in hospital.” Other participants were offered respite services after an inpatient admission. These experiences are detailed in the next chapter under community mental health.

Children or Young Person’s Units

Several other participants spoke of experiences with children’s or young person’s units. Lorraine had been to the day service of a youth acute unit, and wished that the facility had been there when she had her inpatient admissions to an adult facility.

Taylor spoke favourably of her experience in a youth inpatient service. Although her admission to the unit felt “very swift”, she said, “I did understand I probably needed [to be there].” Although Taylor described feeling extreme fear, due to the distressing thoughts she was experiencing, she said the staff “were obviously very good”. She said, “I had lots of help with my thoughts” which was “good” because she had become very “paranoid”.

Two of the Māori young adults had been in contact with a unit for children and young people during their adolescence and prior to their initial contact with adult mental health services, and this would have shaped their attitudes to inpatient settings.

Chris stayed at the children’s hospital for three months. He described being asked the “very best question” during his initial interview when the staff said, “What has been going on for you the last few years? What’s been happening for you? You can tell us.” Chris liked the anonymity of talking to staff. He said it was like a Catholic “confessional” so he felt free to talk openly, whereas it was difficult to “tell all these secrets to my Mum”. Chris told us that “it felt great” to have an opportunity to tell his story. He and his mother had difficulty communicating and
had “drifted apart”. Although Chris found some nurses “rigid in the rules” and “quite strict”, others were “really, really cool”. However, he also commented that some staff “just turn up to the job, do the paperwork ... or not even that, sit around having coffee and a smoke, talk to staff ... they’re not there for the journey with someone, they’re just cruising along”.

Overall, he had appreciated staying there because he “needed the security” of taking his medication, “having three square meals a day” and “being around people that were actually willing to sit down and talk with me”. Finally, Chris told us of “one bad experience” he had at the time of leaving hospital. His dose of medication was incorrectly increased beyond the maximum permissible dose by a locum psychiatrist. This excessive medication resulted in Chris being unable to control his motor function, walk down stairs, get around the house or concentrate. Eventually he was seen by his usual psychiatrist, who adjusted the medication to the dose originally prescribed.

In contrast to Chris’s generally positive experience, Victor said he was “mistreated” at the same facility. He was an inpatient for more than six months without his mental health improving. Victor told us that he was prescribed multiple medications during that time, including “Olanzapine, Clozapine, Risperidone, Seroquel” and another two – sometimes in “strong” doses. The medications caused him considerable discomfort due to an array of negative side effects, including a thick tongue, slurred speech, weight gain and “the way your whole mind gets bogged out”. Victor said he had little improvement in the whole time he was an inpatient, but was compelled to take the medications due to staff threatening a CTO and seclusion. Victor told us that he had been held in seclusion for several nights. He said there was one “good nurse” there. She listened to him and ensured that the medications Victor was prescribed were reviewed, so that he experienced less intense side effects.

Most participants spoke very negatively of their adult inpatient experience. This was particularly so for those subject to compulsion and seclusion, or coercive treatment. For many of the young adults, the inpatient stay was described in ways that suggested it had been a traumatising experience. For those with histories of childhood abuse, the experience had compounded their trauma. The acute inpatient experience was particularly distressing for those who were physically or sexually abused, sexually harassed, verbally abused or otherwise treated in a negative manner by staff. The lack of safety for young women service users was highlighted through a range of situations where they were abused, harassed or lacked privacy and safety from male staff and service users while inpatients.

Staff interactions with the young adults often seemed disrespectful, and lacking in empathy or interest. Although there were some individual staff members who were particularly helpful, and the occasional service that young adults spoke about in a positive way, the overriding organisational culture in adult inpatient units was negative and created considerable distress for the young adults.

Many of the young adults remained in acute inpatient units for months. Despite frequent reports of childhood or recent trauma or adversity, the experience of trauma while inpatients, and the ineffectiveness and adverse effects of medication, none had access to psychotherapy while they were inpatients.

The young adults emphasised that they found being around older service users particularly distressing and disheartening in terms of their own future prospects of recovery. The behaviour of some older service users, especially men, was disturbing and created fear for some of the young adults.

A minority of the young adults gained access to alternative acute services. For those who did so, these services were typically regarded much more favourably than inpatient services.
In particular, the Home-Based Treatment Service and the staff who provide these services were regarded more favourably than any other acute service which the young adults spoke about.

Many of the young adults said that at the time of their mental health crisis, they had needed to stay somewhere they could be kept safe. They often also wanted to be away from parents or family and to be removed from the demands of everyday life. Although inpatient units provided “somewhere to be”, they were often not a safe place and did not create a sense of security for most of the young adults.

The young adults’ largely negative experiences in adult inpatient units and the lack of alternative acute services highlight the urgent need for attention to the provision of acute services appropriate to the young adult age group. We return to this issue in Chapter Eight, as part of a broader discussion about the future provision of mental health services to young adults.
After the mental health crisis situation had settled, participants in our study found themselves developing relationships with mental health services designed to help them on the road to recovery. During the crisis, two-thirds had experienced hospitalisation and were then referred onwards – or back – to community-based services. Those who were not hospitalised began a relationship with community-based services that was initiated during their crisis, but most of their contacts with services occurred post-crisis.

A striking finding of this study was that mental health services had an overwhelming impact on the experience of mental health problems amongst these young adults who had newly become service users. As the last chapter showed, the inpatient experience, usually encountered at the very start of journeys through mental health services, gave an initial flavour – and it was often a sour one – to people’s understanding of services, mental illness and their role as service users.

Further on in their journeys, the people we interviewed described the range of services that they had accessed after the acute situation. Their individual roads to recovery, as we shall see, were profoundly shaped by what was made available to them and the extent to which services met their needs.

This has been a difficult section of the report to organise, although it is central to our understanding of the service experiences of young adults. Between them, participants in the study experienced a wide range of services; individuals often told us of experiences with four or five or more different types of service. After much thought, we decided to organise the material around the following types of service:

- adult community mental health teams
- early psychosis intervention (EPI) services
- intensive programmes
- culturally based services (Māori and Pacific)
- other specialised services such as eating disorders, maternal mental health, and a youth-oriented service
- accommodation providers: hostels and other residential services.

There were only 40 participants in our study, and we were led to our participants mainly through the generosity of particular services in particular DHB regions. Therefore, participants’ descriptions of service experiences are weighted towards those services that helped us obtain participants, and are not evenly distributed across a characteristic range of services. Therefore, the material in this chapter does not amount to an evaluation of any form of service. However, through paying attention to participants’ experiences of different service types, we begin to see how the structures, values and practices particular to each type service impacted on them. More generally, themes emerge about what kinds of service interaction and provision helped and hindered recovery, and these are discussed later in the chapter.
ADULT COMMUNITY MENTAL HEALTH TEAMS

Community mental health teams are the backbone of mental health service provision in New Zealand. They have a number of functions, not always arranged in the same ways. Assessment during crisis is often, but not always, part of the community mental health service; and other functions include referrals and regular support, especially with medication.

Community teams were not referred to as often, or in the detail, that we expected in the interviews. The crisis assessment functions of the teams have already been discussed in Chapter Four, where their gatekeeping role in access to mental health services generally was identified. Young adults’ narratives of first hospitalisation were also examined, with the crisis teams often playing a prominent role.

The young adults we spoke to received a variety of mental health services in the post-acute situation. Most of their narratives focused on the treatment and support they received from more specialised services, such as early psychosis intervention (which provided a range of supports that were similar to, although more extensive than, that provided by generic community teams), cultural services and intensive programmes. It seems likely, however, that their local community mental health team had played a significant role, once again, in gatekeeping and referral onwards to these services.

When community mental health teams were spoken of, the focus was on regular visits or attendances to the base, being supplied with medication, getting support from key workers or case workers, and appointments with a psychiatrist via the team. There were few references to any strong relationships that had developed with community team members.

Gillian found a distinct lack of relationship from a community team when they took her into respite care following an overdose. They visited her every day there, but did not explain their role:

They didn’t seem to get that I am still pretty low and a week ago I had just taken 50 pills and, like, maybe I wasn’t ready to tell them how I was feeling…I didn’t really understand what they were there for, different strangers who came every day and said, ‘What are your thoughts like?’, and [would stay] just for a little while and then they would just leave, and when I did say it was bad, they wouldn’t listen…I was trying to tell them that it was dangerous, but they sort of said, “Oh, no, you will be all right”.

Gillian had to find accommodation independently when the month in respite finished. The team did not help her with staying any longer, even though she said she was not ready, was not eating or sleeping properly, was crying a lot and refusing to see her parents. “I was still saying I felt alone, and I was still hurting myself.” One positive was that the team got her a psychologist, which was better because “she listened a lot more”, and it was better “having one person that you could get to know a little bit, not just strangers that expect you to say how you felt”.

One issue raised in several narratives was around significant delays in referral to or back from more specialised services, and the need to be on the books in order to get these referrals. One narrative in particular spoke of delays of months in accessing the community mental health team, following a serious overdose and a crisis assessment that had recommended follow-up.

Sarah, who had made several suicide attempts, had self-injured, and had damaged her house, had an immediate and helpful assessment with the crisis team, but waited five months for the team to get her an appointment with a psychiatrist after that. Because she had just found out that she was pregnant, the psychiatrist immediately referred her on to maternal mental health, and this took another couple of months
(her experiences with maternal mental health are discussed elsewhere). After her baby was coming up to a year old, she was due to be discharged from maternal mental health back to the community team; but after finding that getting an appointment with the community team would take six to nine months, maternal mental health arranged for her to see a private psychologist instead.

EARLY PSYCHOSIS INTERVENTION (EPI) SERVICES

Early psychosis intervention services, staffed by multi-disciplinary teams, are designed to provide assistance to young adults early in the development of a psychosis spectrum disorder. In New Zealand, different EPI services have each developed their own focus and criteria, although they are strongly linked. Overall, they are founded on the (evidence-based) belief that providing early assistance, including medical, educational, counselling and family interventions, will lead to better outcomes, in terms of the course and severity of disorders, as well as their impact.

In our study, 26 out of the 40 participants (20 men and six women) reported that they had experienced some kind of disorder within the psychosis spectrum. Of these, 16 (12 men and four women) had contact with an early psychosis intervention service. Of those who did not have contact, two lived in a rural area where they did not have access to such a service, although there was a staff member in their service allocated to an EPI role (we have excluded them from this discussion). In terms of ethnicity, seven of the EPI users identified as Pacific, four as Māori, two as Asian and three as Pakeha/New Zealand European.

Ethnicity was strongly linked, in our study, to access to EPI services. Most Pakeha, Asian and Pacific participants with psychosis accessed them, but only four of the ten Māori participants who seem to have been eligible (i.e., psychosis disorder, and living in an urban area where there were services) were referred. Nor were the six others referred to a Māori service during their early contact with mental health. However, this is a small qualitative study and is not the vehicle for any strong claims about the ways in which ethnicity might influence pathways through mental health services.

Most of those accessing EPI services were referred after an acute crisis and an inpatient admission and some had more than one and as many as three inpatient admissions before they saw EPI; only some accessed EPI from the community or through a direct referral from a crisis team. Earlier access could well have been beneficial for the majority.

Most participants spoke favourably of EPI services and staff, and all who had been inpatients indicated that their experience of EPI was very much more positive than hospitalisation. EPI staff were seen as supportive, “really good”, “cool people” and “reliable” by many, though reactions from Pacific participants were a little more mixed.

Participants valued the frequent and ongoing support from EPI, in the form of appointments at the service and weekly or fortnightly visits from team members. James, for example, said he received “counselling” from a case worker, fortnightly “check ups” from a support worker, and saw a psychiatrist “every couple of months to get a prescription”. He said “it’s great” and that this type of support suited him. Shane, who accessed an EPI team without previous hospitalisation, said that the service was “really good”. He was able to continue with his apprenticeship and have weekly visits from a caseworker at a time to fit in with his work:

She always asks me how I am, I just tell them how my week’s been ... pretty much like counselling, doctor sort of situation, one on one ... [she gives] ... advice on how to make my week or my month easy ... they give me a few pointers ... it’s really helpful.

Tommie, who stayed in a crisis facility rather than an inpatient unit when his psychotic episode was at its most intense, was managed
there by the EPI service. He had a case worker who would come to his home to “follow up and see how [he] was going”. During a time when he was thinking about suicide, EPI rang him every day to check that he was all right. Tommie commented, “They were looking after me, very friendly and they knew what was going on.” The EPI service also provided information and support to his parents and partner, which he found very helpful.

Jenny “didn’t click” with her first case manager, who she said was “patronising” and spoke “like I was thick”, but the service arranged for a replacement who suited her. She had “check-in” calls and fortnightly visits. She described the staff at EPI as “intelligent” and said, “I can talk to them about things not just related to mental health issues ... they’re just there, you can ring them up ... they’re just really good.”

Pacific participants were a little more ambivalent about their relationships with EPI staff, particularly at first, although they also appreciated the ongoing support. Bob was initially unsure about talking to EPI staff because he thought they were “nosey”; he said that he did not realise he had a “mental illness”. The staff came into his home, and he found this invasive. He had thought they might sit in a car or somewhere outside. However, once he got to know the Pakeha staff, he said they were “cool”. Bob had never had anyone to talk to until he came into contact with EPI, and told us that his case worker “helped me by talking to me”.

Toa and Tevita liked the EPI staff, too. Jerry told us that EPI supported and talked to him, provided help with getting employment, and had helped him to write his story which he found very beneficial. Although he described the support as “good”, he said that he could not talk openly about how he was feeling, because he thought the staff who came to his home did not have much time. He commented, “They could’ve been better, [they could’ve] listened more.”

Rocky noted that there were no Pacific staff or Samoan speakers in the EPI team. Rocky described a support worker who came to his home as “this white dude” and said, “He was bugging me ... he goes ... how’s your day been? are you still drinking? are you still doing drugs? ... it was like one question after the other, he couldn’t even let me speak ... then ... I never see them again.” He commented, “There’s a big difference between EPI team and [his Pacific service] ... Pacific people, they helped me big time ... the EPI team, they just come and see how I am, that’s it ...”

Participants described the variety of treatments they received through EPI. Most participants talked about their case manager or support worker, who offered advice or education about mental illness, particularly in the context of ongoing support, as the above accounts show.

All participants were seen by a psychiatrist, who prescribed them medication. On the whole, interactions with psychiatrists seemed to be brief, occasional, and focused around medications; the participants did not have very much to say about them. James-Jim saw an EPI psychiatrist monthly. He was not happy with the psychiatrist because he did not think he was given sufficient information, and always “felt on the back foot”. James-Jim would have liked an advocate to help him communicate and receive appropriate information.

Tommie said his psychiatrist “talk[ed] to me a lot, and I seemed to be talking a lot, and he explained to me about the [bipolar mood] graph”. The psychiatrist was reassuring and helped him through a depression, a time when he had become afraid and “started crying a lot [and] having breakdowns”.

Several of the Pacific participants resented the singular focus on medications. Tevita, who described EPI staff as respectful and “smiling all the time”, responded differently when asked what help EPI had been. He said “just the drugs”, which was the only treatment he had been offered. Samuela said he only saw
a psychiatrist and there was “not much talking, just prescribing”. Rocky commented that EPI in itself had not helped: “the only thing that helped me was the pills ... they just come round and [see] you’ve got pills ... that’s it”. He also told us that the case worker he now saw used “tricky” words which he did not like and he was not given information about the side effects of medication, especially weight gain.

Several participants, all Pakeha, attended social/educational groups with other young service users, although not all who knew about them chose to attend. Jenny said that the one group she had been to was mainly attended by young guys into Eminem music. She described it as “cuzzy bro culture” which did not suit her. Toby attended an educational group where he learned more about psychosis. He said the group was “really great” and he continues to use the information he learnt there when talking to others, including his mother, who also has mental health difficulties. She has apparently never received this kind of educational support from mental health services. Toby also was able to go to an adventure based group which provided an opportunity for service users to “go canoeing, rock climbing and ... the beach”. Although he gained enormous benefit from this group, he thought it would be helpful if the group leaders encouraged more interaction amongst service users.

The need that was clearly not being met amongst participants was for psychological or therapeutic treatments from a specialist. Only four out of the 16 people who had contact with EPI services said that they were allocated a psychologist or psychotherapist, and all four indicated that treatments they received from these sources, allowing them to explore feelings, were central to their recovery process. This was a striking lack, because of the overwhelming level of psychological distress, including distress about past trauma, described to us by participants.

A few participants talked about having cognitive therapy-type interventions or basic supportive counselling from case workers or nurses. This was mostly found useful, though one participant did not like the way the psychiatric nurse would “repeat” his problems back to him.

Four did access a psychologist or therapist using early intervention. Lorraine said she did not like talking much, but she appreciated help from a psychologist with anxiety and stress management; she was offered sound advice and educated about social models of psychosis. She has been with EPI for three and a half years and has had no further inpatient admissions.

Jenny told us that despite repeated requests for a psychologist, it had taken more than two years for EPI to provide her with one. She said to EPI staff, “I can’t keep what’s in my head in my head too much longer, it’s just going to keep getting worse and worse and worse ... I basically kicked up a stink until they got me [a psychologist].” Jenny emphasised that the assistance she received helped more than anything else, because it had enabled her to work through trauma, deal with childhood abuse, identify triggers and gain support for an holistic understanding of mental health difficulties. She was surprised and angry that no psychological assistance was available to her from the time of her first contact with mental health services.

Toby was allocated a case worker who offered supportive counselling from the very beginning of his contact with EPI. He described this person as “great because he had a really good personality, someone I could relate to”. The case worker got his family together and provided them with information. Toby found this very helpful, because he felt his family lacked any understanding of mental health issues, and his parent had given him the idea that, “Oh I’m too busy and my work is more important than your health.” Toby also saw an EPI psychologist who he said was “really good to talk to ... [and] not judgemental”. However, Toby did not like writing down “a journal of bad thoughts” or undertaking tasks set by the psychologist. He commented that he had “never had any trauma therapy ... it would certainly take away a lot of baggage.” Overall,
Toby was generally pleased with the support he received from EPI and was looking forward to returning to academic study.

Jennifer was referred to EPI following several acute inpatient admissions that occurred in the context of sustained trauma, complex living circumstances, and alcohol and drug use. Jennifer was allocated a woman psychologist, whom she found really helpful:

[I]t was ... a lot of listening ... helping me to work out my problems ... if I had something I didn’t know what to do about ... I’d tell her about it and we’d plan out a way to deal with it ... we had to make plans each week to ring one person and she supported me to do it ... just to get out there a bit more because I was really afraid of people.

Other than Jennifer, none of the Pacific or Māori young adults attending EPI services mentioned being offered a psychologist or therapist, although most of them had talked to the interviewer about significant grief and/or abuse issues that were troubling them. Neither did any of them mention attending educational or support groups at EPI services, and only one mentioned any form of employment support.

INTENSIVE PROGRAMMES

More than a quarter of our participants attended intensive programmes, which were usually of some weeks or months duration and might include a residential period, for at least part of the programme. The programmes were each organised very differently, with different target groups, different philosophies and different kinds of treatment. What they did have in common was that they enabled participants to spend a considerable part of their day in comprehensive programmes involving structured activities and therapies that were designed to assist recovery.

An Intensive Psychotherapeutic Programme with Optional Residential Facilities

Six of the women participants, all of whom had non-psychosis diagnoses, and all of whom were Pakeha, had access to an intensive programme offering a comprehensive range of psychotherapeutic services. Diagnostic categories given to people who use the service include, for example, post-traumatic stress disorder, major depression, bipolar disorder and anxiety disorder. The underlying philosophy of the programme is one of self determination, responsibility and recovery, and a key focus of therapy is on enhancing self-esteem and confidence. In conjunction with one-to-one psychotherapy, clients are offered a range of options, such as a Trauma and Recovery Group, an Interpersonal Focus Therapy Group, a Skills Group and art therapy.

All of the young women who had contact with this programme spoke very favourably of it, indicating that the service was “awesome” and “life changing”. They appreciated the philosophy of the service, the theoretical orientation that underpinned therapy, the treatment options they were offered, and the attitudes and interactions of staff members. All of them had described to us many negative experiences they had had with other mental health services, and had told us of the ineffectiveness of treatment they had received prior to their contact with this programme. They all had complex histories, including backgrounds of abuse, neglect or lack of emotional connection from parents, had engaged in self-harm or self destructive behaviours, and had been suicidal or attempted suicide at some time before entering the programme.

Access to the programme had not been easy for some, who spoke of a lengthy and sometimes frustrating process. Referral could occur only through a community mental health team, and one person described a lengthy delay arising from the fact that her GP had to refer her to this team first. Further, when referral processes
had been sorted, there was often quite a wait for a new intake to occur, as only a specified number of small therapeutic groups operate at any time, and some are closed groups. It took ten months for one of the women to commence the programme. She had taken time off work to undertake the programme, and when the waiting time was extended three months she found this “devastating”, particularly since she had a lot of time on her hands. Another woman also talked about waiting months to gain access to the intensive psychotherapeutic programme, with the mental health service she had been seeing not offering any psychotherapeutic help, but only a nurse visiting once a month.

Gillian had problems with the age criteria. She was too old for child and youth services, but too young for entry to this programme. She commented, “I guess that’s when I found there was a distinct lack of services for 18 to 25 year olds.” Gillian talked about “a very long process of reading through applications and interviews ... I had to have a care worker ... and ... the one [I had] ... was terrible ... just awful ... then there was the whole process of getting into [the programme] and that was delayed ... I was just hanging out for [it] ... before starting [it] I self-harmed more”. Others also mentioned that if the programme at the intensive psychotherapeutic service had been available to them at an earlier age it would have been of considerable benefit, and could have meant pre-empting a mental health crisis and avoiding the distress associated with hospitalisation.

The programme required a comprehensive contracting-in process. Pippa spoke about the contracting phase as a time when she was introduced to some of the key concepts, kept a daily mood diary, and conducted a behavioural analysis of times or events that were distressing. She said, “You just dissect it bit by bit and then you think about what will help prevent that in the future ... [and you] get a taste of what the DBT [Dialectical Behaviour Therapy] is like.” She also completed “a whole heap of tests” and entered the programme about six weeks after this contracting phase. During this period there was a visit to the residential lodge associated with the programme, and someone spoke of one-to-one psychotherapy being arranged at this time.

Cassandra described the intensive psychotherapeutic programme as group therapy three times a week, Dialectical Behaviour Therapy skills group twice a week, mindfulness meditation once a week, and individual therapy as well. She gave a comprehensive account of the theoretical orientation, Dialectical Behaviour Therapy, and said, “[The programme] has taught me to regulate emotions and use the skills to keep [my]self close to baseline...feel with feelings, but not letting them blow your head off.” She found the key components of DBT particularly useful: “interpersonal effectiveness which is looking at how to talk and deal with people, asking for things and saying no...[t]here’s stress tolerance skills, keeping yourself safe and riding the wave of emotions...and emotional regulation skills”. Cassandra emphasised how valuable she found feedback. She commented:

You’re given feedback a lot...you could get feedback every day, or in group therapy.... and also once every six weeks you get a review...then all the therapists...discuss how far you’ve come and what you’ve done really well and what you need to work on.

The reviews involve individual clients writing their own notes, therapists providing review, and then discussing the reviews together. She said this “keeps you encouraged to keep going”.

Gillian talked of participating in “full on therapy, group therapy and art therapy”. She gained particular value from the Eastern philosophical approach and ideas about developing a “life concept”, which had been important in working out “some purpose and meaning” in her life.

Claire spent one and a half years at the intensive psychotherapeutic service, following a life-time of sexual abuse and neglect. She was
involved in different groups, including a coping skills group where she learnt “different ways to respond to stressful situations ... basically equipping you with emotional skills to get through the day ... so you don’t catastrophise when things go wrong”. She had also learnt ways of coping with anxiety, such as “keeping yourself focused, people counting, or counting your breathing, centering yourself so you don’t spin out with different emotions”. Claire told us that “one of their really hard and fast policies is that you are not to abuse or self-harm while you are in the programme ... taking drugs or suicide or cutting ... is not acceptable”. During her time there she did take drugs. However, instead of being blamed or banished from the programme, she was required to talk to the group and complete a behaviour analysis. This “was all about what led up to it, what I was thinking at the time, how I was feeling, what could have been done differently and what the effects on me were, what were the effects on the environment and the people around me”.

Michelle said that group therapy was particularly helpful for her, as it provided a forum in which to “share...and realise there’s other people out there”. The programme had helped her to explore the ways in which her childhood experiences affected her mental health.

Susan started off with a skills group which, she told us, participants are advised to complete twice because “anyone starting off is very confused ... and preoccupied with their stress”. Second time round, she said, “It’s really good because I have learnt the skills heaps better and [am] definitely more aware of the mood that I’m in ... before it would all be in retrospect.” She found the group particularly useful because participants are “taught different skills that in any situation you can use to overcome stress or ... a problem or when you feel so sad that you just don’t want to get out of bed”. She liked the focus of this group on the here and now, because “I’ve gone through the last two years of telling everybody from day one [first contact with services] what’s happened in my life ... it’s quite a long story ... [and] I didn’t have to tell any more people about what happened”. Susan planned to move on to a trauma group where participants “discuss in-depth trauma [they] have been through and how to get through that”. She also hoped to do an interpersonal group, “where they teach you skills to help you improve your interactions with other people”, and was looking forward to art class where “you can express yourself” and get help from a therapist as you go.

Pippa described the programme as small, with a timetable like school, and therapy every day using DBT, “which has definitely been the most useful of all”. She told us that she was given a book of handouts that included practical suggestions, such as for distress tolerance, and “a hundred things you could do to keep yourself busy ... so you’ve actually got ideas as to what to do”. She liked the daily community meetings “which was all of us together and [we] basically talked about how the night went or what we were doing”. Pippa said, “It was just accepted as fact that that’s how it was for you, they weren’t trying to put words in your mouth ... you were listened to ... we were treated as people, not just self-harmers.” For Pippa, being actively involved in treatment and having a sense of control was important, as this had never occurred before during her long history of contact with mental health services. She noted that although the programme might implement a safety contract if anyone was at risk, “you’re the one who comes up with what’s in it ... you’re the one who decides what action to take ... and they’ll just support you with it ... they’ll suggest things, not force things on you”. For her, the programme was “the best thing that’s happened”.

People spoke favourably of the way staff interacted with service users at the intensive psychotherapeutic service. One of the participants said that one staff member in particular “had a tremendous amount of empathy and would go out of their way to help me ... they would do alternative medicine that most therapists wouldn’t do, they provided extra support and they always had time for me”. That person also conveyed considerable “empathy, trust, respect and rapport”. The
participant said that being of the same sexual orientation, and having similar past experiences and some reciprocity, was especially useful and helped her “feel that they’re human as well!”.

One participant referred to the residential staff as “empathic” and said there was always someone available to talk to and to provide support through times of distress. Another said that when a service user was suicidal, a staff member would sleep in the same room with the young woman, rather than locking her up, as would often occur in an inpatient unit.

Over time, intensive, regular therapy sessions became less frequent as participants were encouraged to become increasingly self-reliant. Cassandra commented:

[They give you heaps of guidance and support and care at the beginning, and then they slowly pull back, letting you make your own steps...[you] become more responsible for your own life...by using the skills they taught you to make life worth living.]

The service also runs groups for “graduates”; Cassandra described this as providing a feeling of safety during the process of exiting the service. In addition she could attend a monthly graduates group which was available for a year.

Pippa spoke of how “you phase yourself out bit by bit” and by the end of the period, the staff ensure “you’re fully involved in the community mental health centre”. She still sees a psychotherapist provided through community mental health. Cassandra and Gillian also told us that arrangements had been made for them to see therapists once they completed the programme. This means service users are not left without psychological assistance, and recognises the complex mental health difficulties that brought them there.

Sadly, there were clearly other participants in our study who sought psychological help and who might have benefited from this kind of programme, but were not able to access them, particularly those who lived in cities where no such programmes were offered. Pippa finished her account by saying that this programme was one of “the first good experiences of mental health services” that she had experienced. Gillian, who had self-harmed regularly, had “a terrible quality of life” before she entered the programme, despite her regular contact with other mental health services. After her time at the intensive psychotherapeutic service, she had not self-harmed again. Cassandra concluded her account by saying, “It’s totally changed my life.”

Two Programmes with a Variety of Therapies and Activities and Residential Facilities

Several Māori participants described using two different day programmes that offered a variety of therapies and activities, as well as residential accommodation.

Victor, who had very negative and disturbing experiences of adult inpatient and other residential services, spoke positively of his experiences at one of these services, which he described as “relaxed” and having “good staff”.

Lizzie told us about an adventure trip to the mountain. The group stayed for a week and lived in a hotel in dorm rooms. Lizzie found the physical environment and company of other young service users uplifting. She commented, “It was just cool being in the snow, the atmosphere when you wake up in the morning ... and the sun glistening on the snow ... it was cool new food, you can wake up to the nice new food, the new place in the middle of nowhere ... we were all like family.” This was her best memory of adult mental health services.

Chris also loved his trip to the mountain, with five other young service users who he referred to as “all my mates, you know, with my flatmates, my mates, it was great, it was like an adventure”. He told us that he “got some good photos [of] a “good experience with my
friends, [we] got to stay in a lodge for a couple of days ... [and] got to snowboard which I had never done”. Chris particularly enjoyed the recreational pursuits:

Every week we knew we’d be doing something cool, so there was something to look forward to ... every week it was either windsurfing or paintball or go-karts ... and it was all friends ... it was just a good experience ... a great place to be at that time.

Overall, he described the service as “choice” and liked the fact the houses he stayed in were all “brand new”. He thought that the programme offered a place that is about “getting people on a safe road to recovery”. While he did not have any individual therapy, there were group therapies and group discussions. He described the groups as being like “a whole bunch of your friends sitting around” and said “it’s not always that helpful, always someone wants to crack a joke” but that the groups were “fun” and “choice”.

The other residential programme was also attended, and mostly liked, by three participants of Māori and Pacific ethnicities. Tevita, one of the Pacific young adults, said that the range of activities offered, such as woodwork, auto courses, exercise group and cooking courses, “fills up my days” and was important to his recovery. Another participant was Chris, who was transferred to it from the previous programme. From the very beginning, he was involved in a performing arts adventure based learning programme. He said “I just gobbled it up ... it was great.” He had photos taken abseiling, doing a stage performance, and a video doing Māori Tai Chi. One of “the best” things about this programme for him was that the manager hired a lot of Māori staff, and this enabled him to learn about his iwi and history.

Chris told us that these programmes had provided him with opportunities he might not otherwise have had in his life. However, he was somewhat less enthusiastic about some of the staff who worked at the residential services in the second programme. He talked about negative staff attitudes towards him and feeling under scrutiny, and that this had worried him a lot. Chris commented, “Sometimes I wouldn’t be met with a very warm welcome at all ... staff attitudes were a big thing for me ... you know, how they perceived me and how the non-verbal communication was going on.” Sometimes he coped with hearing negative comments about himself by being “passive aggressive”, such as not doing his chores or leaving a pile of washing.

Chris thought some staff “didn’t look like they were really there for the people”. He said “they were just coasting ... it made me feel like I was a burden on them ... they seemed to get frustrated really easily with me and I never really understood cause I was living at the place for Christ’s sake, they got to go home every day”. Staff would “gossip rather than do handover ... it was like an ‘us’ and ‘them’ thing ... they got to chat and laugh and tell stories about us ... which happens quite a lot”, and often the service users could easily hear what was being said. However, he did point out that some staff would challenge other staff about the derogatory way they spoke about service users.

**CULTURALLY BASED SERVICES**

**Pacific Services**

Five out of the seven Pacific young adults were in contact with a Pacific service, and two other Pacific participants had infrequent contact from an individual Pacific staff member connected to such a service. The Pacific young adults’ accounts of their experiences with Pacific services were largely positive, with one saying, “I hope to God the Pacific care will always be there.” Some participants preferred a particular Pacific service over others, and this was primarily to do with the age of other service users and the activities available through the service.

Rocky, who had nothing but praise for the service he used, said the people “helped me
big time”. He knew all the staff at the service and mentioned the names of five people he found particularly supportive, including one everyone called “aunty” and another who treated him “like his nephew”. Rocky’s parents both had contact with the service and his father “grew a bond” with one of the key mental health professionals there. The same staff member had liaised with Intensive Care Unit staff and provided translation services for Rocky’s father when Rocky was first admitted to hospital. As noted previously, Rocky said the only help he received from the EPI service was “the pills”, and he felt he could not talk to them as he talked to the staff of the Pacific service. Rocky said the Pacific service “took me out to touch [rugby] ... to sing talent ... we did an umu together ... and we ate together”. “When I’m with [the service] I can be who I am, they allow me for who I am, they understand why I went to the ICU.” He commented several times that “the people ... are really, really, caring people” and told us that the reason he “liked them better [than EPI] is because they treated me like a human being”.

Over time, Tiare had contact with two different Pacific services. Of the first, where she was referred from the inpatient unit, she said they were not her “type of people”. “I was the youngest one out of all of them and I was like, ‘this is not me’, I’m not supposed to be here.” Here she was assessed for her ability to cook and undertake other daily living tasks, which felt inappropriate to her. At a later point in time, Tiare took herself to a different Pacific service. She liked the support system there, and the fact that other service users were also young. They also helped her find a place to live. Samuela did not like mixing with “mainly older” service users, either, although he did say that the staff member he had contact with seemed like “a real kind person”. He said that having more activities like “working and sports” would make it a better service.

Tevita talked about being taken out to the church and the home of one of the key staff members – experiences which, he said, made him feel “more compassionate”. He found that being spoken to in his first languages calmed him down. Comparing his experience of the Pacific service with his prior experience of EPI and an inpatient unit, Tevita said that although he was unwell while he was at the Pacific service, if he had been at a Pakeha service he would have been “more isolated” and “moodier”.

Bob was one of the two Pacific young adults who did not attend a Pacific service, but instead had intermittent contact from an individual Pacific mental health professional. Although Bob saw this staff member only a few times, he appreciated the help he had received following discharge from hospital. Bob said the staff member “just talked to me ... gave me some male advice and that was cool ‘cause I was dealing with a lot of ... female nurses ... it was just good to hear some male advice ‘cause that’s what I need, like all my life ... that’s all I needed really”. The staff member also provided practical help, such as forwarding mail to Bob and helping him get some furniture and items for his room: “He’s been there for me, he’s been good ... a lot of support.” Bob said he related to this person because “we’re both Pacific Islanders,” and after some reflection commented, “I’ve lost contact with my cultural side”.

Māori Services

Six of the 14 Māori participants were in contact with a Māori mental health services provider in a city at the time the research interviews were conducted, and four were with a rural provider which was not specifically a Māori service, although it included some kaupapa Māori principles (and so is discussed elsewhere). A further four were not in contact with a Māori mental health service. Two of these participants never had been; and the other two had been at some time, but said little about these services during the interview.

Little information was gleaned about particular Māori mental health services during the interviews, sometimes because the service acted as a point of liaison with other services;
sometimes because it was not clear which service the interviewee was referring to (one provider referred to a range of residential services, some of which may have been specifically Māori and others not, and these are discussed under the section on accommodation provision); and sometimes because they had been in contact with a succession of other mental health services, and had only recently being put in touch with a Māori mental health service.

However, Māori participants did address the importance of cultural factors, such as being seen by a tohunga, having contact with a koroua, gaining ancestral knowledge, going on a whakapapa trail, connecting with whānau and iwi, being exposed to tikanga, te reo and waiata, and being involved in kaupapa Māori or te reo courses or learning environments. They also sometimes referred positively to interactions with Māori staff in mainstream environments, contact with other Māori service users, and situations in mainstream environments where Māori tikanga was observed.

Joe spoke animatedly about his experiences with a Māori service where he became involved in a te reo Māori course. He continued going to kaupapa Māori courses provided through the Māori service on a daily basis. He said “my whole life just turned around” from when he began the te reo course. Joe also enjoyed residential care provided through the Māori service, as he made friends, laughed with others, played guitar and got to hang out with “a whole lot of other guys”. Joe, whose mother died when he was young also appreciated the fact that “there were people there that were taking care of you”. He described this service as “awesome”.

Kelvin stayed in a kaupapa Māori service, where there was a koroua who he described as “funny” and a “hard case”. The koroua focused on Kelvin as a whole person. He described the service as “pretty cool”, particularly because they had some DJ music equipment which he could use; he put on a show for the whānau and used his talent writing songs. They also did waiata together, and Kelvin said, “When I sang the Māori songs they made me feel happy...made me feel better inside...I want to do more.” He also connected up with other Māori musicians in the area. A drawback at the service was that other service users would take his belongings from his room, such as jeans, money and CDs. Kelvin thought the house he stayed in was “beautiful”.

Victor, who was using a kaupapa Māori service, said that although he attended a short course that was run by doctors, he was not doing anything like kapa haka or te reo Māori. He said, “It sucks, nothing to do, nowhere to go, it’s not an average lifestyle that you’d like to enjoy being in.”

OTHER SPECIALISED SERVICES

A number of participants were referred to a range of specialty services, including maternal mental health, eating disorders, and a youth mental health service in a rural area. On the whole, accounts of specialised mental health services were quite positive, and referred to the development of much better relationships with staff than those described with community mental health teams.

Maternal Mental Health

Chrissie had a lot of trouble accessing mental health help, and she was pregnant and on medication from her GP when her referral to maternal mental health came through. She found them good in terms of providing information about the medication, “seemingly basic things that I just hadn’t been told along the way”. They also talked to her partner about noticing any changes, and were supportive through fluctuations in her mood state after the baby was born. There were issues, as mentioned earlier, when policy meant that she had to be referred back to community mental health because her baby was coming up to one year of age and she was no longer eligible, but the maternal service dealt with these sensitively by arranging for her to see a private psychologist, which she did find really helpful.
Michelle also found the maternal mental health service useful, especially since they were able to provide her with a psychotherapist. When she shifted across town, she had transfer difficulties, and when she was feeling bad, “no one” from the crisis team from either region would talk to her. It took about a month before she was with the new maternal team. From them she was no longer able to access psychotherapy, but the team was “great”. A doctor visited her several times at home, and a nurse from the team visited regularly. She was able to access a post-natal depression support group, and given encouragement to sort out issues with her ex-partner through Family Court counselling. Eventually the team arranged for her to continue with her previous psychotherapist until she was transferred to an intensive psychotherapeutic programme. That was useful, but after another shift, she was declined by the maternal mental health team in her new area as “too well” and referred to community mental health, whom she had not heard back from at the time of the interview.

**Eating Disorders**

The one participant who was referred to an eating disorders service found it helpful in dealing with self-harm and an eating disorder. Although she had a speedy referral, she then had to wait three months to be allocated a therapist following her initial assessment. She liked the availability of different treatment approaches including individual counselling, group therapy and seeing a nutritionist. The group therapy she attended mainly included older service users who were at a different stage in their life from her so she felt like “an outsider”. However, Julia and the therapist did not get on well, partly because Julia thought the therapist imposed her own reality onto Julia’s experience. Although Julia was offered another therapist, she decided to leave the service after three months. A drawback about the service was that it was a long way from town, and took a long time to reach using public transport.

**A Rural Service for Young People**

Four Māori participants were identified through staff connected to a child and youth mental health service in a rural area. The two men came into contact with the service after being transferred from other services. The two women had been referred to the service for counselling.

Outlaw was referred to this service in his local area from another DHB, following an inpatient admission. A “Māori person”, who was possibly a counsellor or social worker attached to the inpatient unit, liaised with Outlaw’s whānau during the transfer from the inpatient unit and travelled with him to his home when he was discharged from hospital. Outlaw said he saw the staff member twice and “she sussed everything out, sussed out my family and then came over and gave me a talk”. He then had a couple of visits from a Māori staff member attached to the child and youth service, but the person came only about once every three months. Other than his aunties and the person from the service, Outlaw had no other support.

Outlaw, who spoke little during his interview and had been heavily medicated during his inpatient stay, said he would have enjoyed doing carving and participating in kapa haka if this had been available. Like many participants in this project, Outlaw described the time he spent in the inpatient service as “boring”, and said that being allowed to have longer visits from his whānau would have helped. During discussion after the interview, Outlaw indicated that getting back to his roots, returning to his home area and being around whānau were important to his recovery. Further, being cleared of a community service obligation helped Outlaw feel that he had a “clean slate”, and the child and youth service had helped by arranging a driving course.

Hine was referred to the child and youth service following an overdose and admission to hospital. She had not been in contact with any other mental health services. Hine was allocated a non-Māori counsellor who, she
indicated, was significant in her recovery. Hine said she had found it difficult expressing her feelings as a teenager, and the counsellor had helped her “feel better” by providing someone to talk to. Hine told us that the counsellor had “a lot of sympathy for me, she just let me talk and after I’d finished whatever I wanted to say she would say, well if you do this...or maybe you could try this”. Hine indicated that she had liked the counsellor offering suggestions, but then being able to decide for herself what action to take. Hine also described a situation where she was extremely distressed, called the counsellor, and was able to see her straight away. This had helped her deal with the crisis situation in an effective way.

Lolly was also referred to a non-Māori counsellor at the service. Like many participants in the project, Lolly said she had “no one else to talk to”, so being able to talk to the counsellor in a one-to-one setting had really helped her. Further, the counsellor had insisted on separate counselling for Lolly and her partner, as Lolly was in a violent relationship. She did not recall the counsellor talking about power and control models of violence, but said the counsellor was “just trying to let me talk”. Prior to seeing the child and youth service, Lolly had gone with her partner to Christian based counselling. Here she was encouraged to stay with her violent partner, who had beaten her up outside the counselling venue. Rather ironically, the approach taken by the Christian counsellors resulted in Lolly “seeing the light” and leaving her violent partner.

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Some participants had positive experiences in hostels or residential services; for others, the service was a source of considerable distress. For instance, there were reports of belongings being stolen by staff or service users, and one young adult experienced sexual and physical violence perpetrated by staff members.

Joe was referred to residential care from a Māori provider, and described the place where he stayed with other young men as “awesome”. Bob said he was “quite happy” staying in a hostel with other service users, because “when I’m feeling down I can just run to the dude and just be like, “Help me out!”.

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“paranoid and really psychotic”. This resulted in Victor damaging some property. He also had an altercation with a staff member, who he felt was provoking and “eye balling” him, and who swore and spoke abusively to him. When she was “eye balling” him, “she was taking a part of me away ... and trying to belittle me”. His relative also said that new clothes and expensive items they had purchased to occupy Victor’s time were also stolen while in this service.

This series of events led to a shift to another Māori residential service. In this service there were karakia before breakfast and kapa haka. However, the staff would “sit round on the couch and watch TV ... they used to just take it over and watch the rugby on the weekends”. In the first few days, Victor got a “hiding” from other service users for not sharing cigarettes. He suffered “bruises down his face and his neck was all scratched”.

In a later incident involving a staff member, Victor had “bruises on his face again”. He told us that the staff member would “grab me around the collar ... [he] used to drag us around and one time he dragged me and pushed my mate down first and then tried to push me on top of him”. The staff member said “you’re two effing faggots”. Victor said that after this incident, several staff members “grabbed me and they put my arms behind my back and folded my legs up and crushed me and pushed hard up against me until ... I started crying ... and everyone was just sitting there watching this happen”. Victor said to staff that he wanted to phone his relative, but was not allowed to do so. Staff threatened him not to tell anyone about the incident. On another occasion, staff who were involved in the violent incident came into Victor’s bedroom, held him down and sexually violated him. His relative said about this service, “it was almost like a prison the way you were getting punished”.

Not so many women described living in residential accommodation, but Gillian lived in supported accommodation when she was discharged from the inpatient unit and while she was studying at university. The residences she was in were for youth, and there were positives, but she found one aspect particularly difficult: “I found it quite hard to live with some of the people in there who were going to kill themselves – brandishing knives or all sorts of things.”

When she turned 20, they said she was too old for a youth house, and although she did not think herself ready to go, they told her that she was. “I just could not live with my parents.” She found her own independent accommodation in a flat, where she began self-harming again. Gillian was also too old for the adolescent mental health service she had been seeing: “That’s when I became aware of the distinct lack of services for 18-25 year olds. People were bending the rules so that they could continue seeing me.”

**HOW POST-ACUTE SERVICES CAN HELP RECOVERY**

This section is organised around themes relating to treatment, peers and social support, mental health services staff and being an active participant.

**Treatments**

Some general themes around treatment, crossing different types of service, emerged from the stories and here we discuss young adults’ views on more general approaches to treatment.

**Biomedical Approaches**

All the young adults were exposed to biomedical approaches to treatment during their journeys through the mental health services, because this is the model that most strongly prevails across the services.

All but two participants were prescribed psychoactive medications during their journeys, and most were still taking medication.1

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1 The two who did not receive medications experienced non-psychosis spectrum disorders, and attended a rural programme for young people, which had a Māori focus and a more holistic approach.
Medications featured quite strongly in many of their stories, with the predominant themes being:

- being forced to take medications, particularly in acute inpatient units
- medications sometimes being experienced as helpful in lessening symptoms and leading people to feel better and function better
- side-effects of medications, mentioned by most who discussed them, including quite extreme adverse effects
- interactions with mental health professionals, involving trying to get the most helpful medications in the most appropriate dosages
- being over-medicated, and on multiple medications at once, feeling “zombied out” and finding it hard to function normally because of medications
- decisions around continuing to take medications and concerns about how long this would go on for.

Overall, around half of the participants found medications helpful, and the other half conveyed the impression that the costs were greater than the benefits.

Issues around diagnoses were the other main theme in terms of biomedical approaches to treatment. Once again, there was a range of views about diagnosis. Some participants found them helpful, in that the long period of distress building up to a crisis and being accepted into services was now seen as somehow meaningful, because they had a diagnosable mental health problem. It was not just that they were “badly behaved”, as some had been perceived, and it had become clear that their level of distress was out of the ordinary. Certain diagnoses, such as depression, eating disorders and bipolar illness, seemed to make more sense to the participants, than other diagnoses, such as schizophrenia or borderline personality disorder. As one participant said about “depression”, the term is good because it explains how one feels.

Of those who felt uncomfortable with diagnoses, those who had been told they had schizophrenia often showed a reluctant rather than a keen acceptance of the diagnosis. They gave the impression that this diagnosis was not a key to understanding their experiences at all, and could cause stigma. Others were concerned that a diagnosis seemed to imply a lack of hope for the future. As Gillian said:

[Being diagnosed with] personality disorder, it’s horrible to get because it’s just kind of stuck with you and it suggests that there’s something intrinsically wrong with you and it’s not something you can change.

Another participant said, “I’m a person, not a diagnosis.” Most participants saw psychiatrists in relation to being prescribed medications and being given a diagnosis. Interactions with psychiatrists were not a strong feature of most of the narratives, and people gave the impression that they were remote figures with whom strong relationships did not usually develop. This was partly because appointments were infrequent, and it was not unusual for someone to see a different psychiatrist on their next appointment. There were also several complaints about trying to understand psychiatrists for whom English was a second language.

Overall, psychiatrists were not involved in day to day interactions, unlike other mental health service staff in some of the programmes, and it was unusual for them to engage in psychotherapy with clients. There were a few stories of really positive interactions that conveyed care and concern, and where the psychiatrist gave careful explanations of what was going on.

**Psychological and Psychotherapeutic Approaches**

We have emphasised a number of times so far that many participants would have liked someone to really talk to about issues from childhood, adolescence and their “going downhill” period. Psychological help was often requested, but was very hard to source. It came in a number of forms, including Cognitive Behaviour Therapy and Dialectical Behaviour Therapy approaches,
which emphasised cognitive and emotional skills; and psychotherapy and counselling approaches, which emphasised delving into emotional issues from the past and giving support over current life issues.

Some mental health staff, as a matter of course, used elements of these approaches, somewhat informally, in their dealings with clients, but in-depth psychological help was not provided unless a client was referred for sessions of psychological therapy or therapeutic groups—and very few, overall, received such help. The most rewarding service experiences described in this study involved the intensive psychotherapeutic programme, already mentioned.

A striking finding of this study was that, despite the extensiveness of trauma histories reported by participants, they were seldom offered trauma therapies, and seldom given a chance to talk about trauma in mental health settings. “You can’t recover if you have to keep it to yourself,” said one participant.

**Holistic Approaches**

Young adults really liked participating in services and programmes that gave them options and viewed them as a “whole person, not a diagnosis”, seeing them in the context of their broader lives.

People who participated in the intensive psychotherapeutic programme came away with the belief that a range of interventions can be very helpful. Some participants were interested in alternative health or Eastern philosophies, and found it helpful when different values and ways of thinking were encouraged in a programme.

A number of people, particularly the men, really liked programmes with activities involving the outdoors, adventure and trips. A number mentioned artistic and musical activities as a relevant and effective means for tapping their emotions and expressing their feelings. They liked being occupied and active, and participating in activities with meaning and purpose, and wanted opportunities for growth, change and personal development.

Participants liked mental health staff to inquire about and take into account their living circumstances, their histories and their aspirations, and to be concerned about their overall wellbeing. They wanted to be encouraged to maintain and expand their normal lives and social networks, and have useful support for career and education aspirations, as well as sensitivity to housing arrangements. They liked to be seen as individuals, with their own values and cultures.

**Cultural Approaches**

What participants found helpful about culturally-based programmes overlaps to some extent with what was helpful about holistic approaches. In relation to Māori services, participants liked being involved in waiata, kapa haka, te reo Māori, and sharing kai with staff as well as other service users. Emphasis on whanaungatanga and their cultural heritage was appreciated. In Pacific services, people said they liked being treated like a nephew or niece by staff, music and singing, eating together and umu. Participants liked being given services by people of the same ethnicity, and being alongside service users of the same ethnicity.

**Peers and Social Support**

A number of participants were offered groups involving other young adult service users, particularly through early intervention services. Some people found support services useful; others declined the opportunity to use them, usually because of the inconvenience of travelling to them. In one or two instances, the support group did not meet their needs (for instance, the woman who went to a support group which was mainly composed of younger men of a different ethnicity).

The one group described that was independently peer run was seen very positively by the couple of participants who had access to it. That group engaged in mental health advocacy and public education as well as peer support, allowing participants to get involved in some of the broader issues around mental health.
Otherwise, there was very positive talk about engaging in activities or therapeutic endeavours with peers, even when these were run by mental health staff. Peers were also preferred in residential settings.

**Mental Health Services Staff**

Participants liked staff who showed an interest in them, who were warm and friendly, who were approachable, who listened and appeared unhurried. They wanted to be recognised and greeted, for example, by the receptionist for a service. They appreciated staff who genuinely wanted to know how they were, as opposed to asking them how their day or week had been in a formulaic manner. Recovery was helped by staff validating people’s experiences, respecting them and treating them as a human being.

An important aspect of interactions with staff for young adults was to be treated as if they were intelligent and had something to contribute. They appreciated it when staff were empathic and shared something of themselves, treating them as equals in the human condition. Continuity was also important, so that people could develop relationships with staff and not have to tell their story over and over again to strangers.

They appreciated practical advice and suggestions about how to manage symptoms. They also appreciated education and information about mental illness, especially if it was relevant and tailored to their situation. They wanted staff to encourage self-determination, so they could take control of their lives.

Above all, they wanted staff to believe in them, to focus on their strengths, and to believe in their potential to contribute and achieve. They wanted staff to believe that they could back to normal again (with or without ongoing mental health conditions), and to make it clear that they were optimistic and hopeful for the young adults.

**Being An Active Participant in Services**

A strong theme throughout the interviews was people’s desire to participate actively in their own treatment and care. They wanted self-determination and choice. Often participants experienced lack of choice, for example, in receiving services compulsorily via the Mental Health Act, being forced to take medication and being put in seclusion. Force was seen as detrimental, even though many were aware that they needed active help and needed safety to be provided.

They wanted to be able to choose amongst services, and to be able to have some choice about people who worked with them. For instance, if they did not get on with a particular professional, they wanted to be able to change. Participants wanted information, and they wanted to be able to discuss and query what they had been told. Feedback on how they were doing, and review, were seen as helpful, as was being an active participant in any planning that was being done, such as discharge plans or recovery plans.

A number of participants mentioned needs for advocacy and some were actively involved in advocacy themselves. Their passion for this area grew from their own experiences of not having information or choices.

Above all, participants wanted to have a say in what happened to them!

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To conclude, people found it helpful to be offered choices from a range of accessible services, designed around the needs and values of their age group, with opportunities to meet peers. Services that helped most with recovery were intensive or at least regular and reliable, were based on coherent philosophies and values, and treated participants as people with lives outside diagnoses or services. Recovery-oriented services were delivered in a respectful manner with opportunities for input and feedback, by optimistic staff who listened, cared, offered useful support and advice, and gave hope for recovery.

Mostly, what was wanted are the common themes in recovery narratives from all age groups, as discovered in the recovery research cited in the introduction to this report.
Recovery Journeys

The last two chapters examined the ways in which the participants experienced, tried to make sense of, and found their way around mental health services. In this chapter we look at their recovery journeys, focusing on the way young adults moved towards “living well in the presence or absence of mental illness”, to use the Mental Health Commission’s definition of recovery (Mental Health Commission, 1998, p.1).

In our earlier narrative study (Lapsley, Nikora, & Black, 2002) people were interviewed long after they saw themselves as recovered from disabling mental health problems. That study included a section on “life after mental ill health”, in which participants reflected on how having a mental health problem had impacted on their lives. In contrast, here the focus is on younger people who were relatively recently in crisis, and most of whom are still in contact with mental health services. Inevitably, they have a shorter perspective on their experience of mental ill health, and they are at earlier stages of their recovery journeys.

We struggled with the approach to this chapter, which does examine issues and experiences that are still very much in process. For this part of the interview, our interviewees have switched from telling us about the past, in a narrative voice, to telling us how things are for them now. After much discussion, we decided to organise this chapter around how our interviewees see themselves placed now in relation to their hopes and dreams for the future.

Being able to articulate and move towards the realisation of hopes and dreams is central to recovery. Most of the young adults spoke freely of their hopes for the future, and discussed the barriers and roadblocks, as well as the ways in which they found themselves moving forward.

After analysing “recovery talk” in the project, we decided to highlight predominant recovery themes by examining them in relation to three groups that emerged as relatively distinct:

1) “Surviving day to day”: those who were having difficulty in moving towards realizing their hopes (around a quarter of the participants);

2) “Moving forward”: those who are moving on recovery, and taking some concrete steps to achieve their more immediate goals, but who are still relatively close to the disruptions that a mental health crisis had caused in their lives (around half of the participants),

3) “Living well”: those who already are “living well in the presence or absence of mental illness” and fully engaged in the recovery process. (around a quarter of the participants)

HOPES AND DREAMS

There were many commonalities across all participants in terms of their hopes and dreams. Overwhelmingly, people wanted to recover from mental health problems, overcome the disruptions that the mental health crisis had created, and lead what they regarded as
“normal lives”, working towards achieving goals common to their age group.

Many young adults wanted to engage with, or resume, education and training. The range of educational involvements that they were engaged in, or planned to undertake, included studies at undergraduate and Masters level, as well as certificates, apprenticeships and training courses in a wide variety of topics, including arts, sport and recreation, small business management, mental health support work, music, building, and art therapy.

Most wanted to increase their work participation, whether studying or not, in order to better their financial situations, which were often dire. Quite a few found it difficult to engage in working towards the goals they had in mind when they were on the very limited income of a Work and Income benefit. For some, living on a benefit with no other support meant being unable to participate in the community. They could not freely engage in sports, go to the movies or go out for a coffee. For others, living on a benefit meant they could not live the kind of life they wanted and saw some of their peers having, such as running a car, flatting or providing well for their children.

A very few in the group had managed to hang on in and avoid severe disruption to their work (a teacher, an apprentice), and they expressed renewed determination for success. Many others had already resumed education and training, and/or work (often part-time). Participants did have career goals, although some were more concrete and immediately realisable than others. People saw themselves as working in professions or skilled jobs, running businesses, or at least earning enough to save money, live the way they wanted to and support families in the future.

On the whole, the experience of a mental health crisis had not changed the direction of young adults’ career interests (unlike the older participants in the earlier study, for whom a mental health crisis often meant a change in life direction). Some with already developed careers were keen to get back into the same line of work (for example, graphic design and engineering). For a certain number of participants (right across the range of ethnicity and gender) there had emerged a passion for mental health work, combined with a strong commitment to improve the experience of services for others. Mostly these people had already been interested in working with people, but now focused on mental health careers.

In terms of living arrangements, quite a few of the young adults lived autonomous and independent lives. Those who were living with their parent or families of origin, or who had returned to parents or families due to financial circumstances, usually wanted to live independently. So did most of those in supported living situations. A key theme amongst the young adults in relation to living circumstances was the desire to choose whom they lived with. Usually this meant living alone, or with a partner or child. They also wanted to have enough money to support themselves to live in the way that they wished.

In terms of families and relationships, quite a few young adults were estranged from their families, or had only irregular superficial contact with one or two family members. Sometimes parents did not want much contact with their son or daughter, and were not available to support them with recovery. Some who had difficult relationships with family members were reestablishing or hoped to establish better relationships; others were completely autonomous, had little contact with families, and were finding other networks of personal and social support. Others had great support from families/whānau, especially from their mothers.

Most of the young adults (more than 80%) were not in an intimate relationship with another adult. Seven participants talked about being in a relationship. Only six (15%) had children whom they were parenting. Participants were sometimes surprisingly reserved in expressing hopes for a future partner, with some recognising that the time was not right, that hurts had
occurred in the past, and that they needed to be strong in themselves to make a relationship that would support rather than hinder them. However, many, especially women, thought that in the future they would like to have children. Those who had children wanted to be better parents, and it was not uncommon for participants to say that they wanted to do a better job of parenting than their parents had done for them.

These were the young adults’ hopes and dreams. In the next section we show how these hopes and dreams, and participants’ lived experiences of distress, are linked to recovery narratives.

RECOVERY STORIES

“Surviving day to day”

The young adults we characterized as “surviving day to day” seemed to be in a murky place following the aftermath of a mental health crisis. They talked about their lives mostly in terms of surviving day to day. Most in this grouping were young men and included people who identified as Pakeha, Māori and/or Pacific. Most had been given psychosis spectrum diagnoses. With some difficulty, the young adults in this group were trying to make sense of their mental health crisis, and their contact with mental health services. Most talked about their lives before the mental health crisis, and saw their experiences then as contributing to their current mental health difficulties. They were engaged in the task of making sense of their mental health crisis in the context of their lives as a whole, but were still trying to figure out their inner world in terms of what was happening now. For some, the situation felt overwhelming; for others it just seemed bewildering. They were still in the position of not really understanding the shape or meaning of their mental health experience.

People who we characterized as “surviving day to day” were typically isolated, lonely, unoccupied and had no sense of purpose. Some had literally only one person in their lives, such as a mother or friend, other than the mental health professionals they came in contact with through services. Most were estranged from families or whānau, and did not have support from extended families. Some were alienated from their cultural background and ostracised in their communities. Some lived with significant material hardship, and this impacted on all facets of their lives, making it difficult to participate in the community even if they had felt able to. Most could not choose where or with whom they lived, and were unable to live independently at this time. The lack of social and emotional support was a key theme amongst this group.

Mental health services were a key focus of talk for this group, as their lives were integrally entwined with, and often nearly limited to, contact with services. This group, on the whole, had not received appropriate or effective help from mental health services. Most had been hospitalised, and although some had found aspects of the inpatient experience somewhat useful at the time of initial crisis, the overwhelming experience of the units was negative, frightening, on occasion abusive, and, at the very least, extremely boring. Despite many telling us about childhood abuse and/or recent trauma during the interviews, none of this group had received psychotherapeutic interventions while they were inpatients, and all but one had not been offered this kind of assistance from other mental health services since. Indeed, medication seemed to be the dominant or only focus of treatment for this group, and many seemed heavily medicated, had difficulty concentrating, and lacked energy and motivation.

The young adults in the “surviving day to day” group had unanswered questions and fears about how their immediate futures would unfold. Indeed, few could see much that was positive in the future, and no one talked of feelings of hopefulness from mental health workers. It was difficult for them to find hope in the face of their day to day experience of despair. Although most told us at least one hope or dream, they did not seem well positioned right now to move forward towards
achieving these hoped for futures. Participants in this group varied in terms of the length of time they had been stalled on recovery, but some seemed to have been in a similar position for as much as two years.

The overwhelming feeling we were left with from talking to the young adults in this group was that they had nothing to look forward to, no means to move forward and little sense of hope for the future. Sadly, most of these young adults seemed to have no one in their lives whom they felt had instilled hope and who could support their recovery in a positive and meaningful way.

**Victor**

Victor, who was in his early 20s at the time we interviewed him, had lived in inpatient units and mental health residential services for several years. He had experienced compulsory treatment, seclusion and physical violence from staff, and described feeling like “an inmate for schizophrenia”. He told us that he did not connect with other service users.

Victor had recently tried to commit suicide. He talked about feeling very depressed throughout his teens, hearing voices, and having nothing to fill his days. He had resorted to drugs and alcohol to cope. Although he has been in contact with mental health services for several years now, he has never been offered any therapy. He also told us that the medication had never been explained to him and he would have liked information about it. Victor had been given a diagnosis of schizophrenia, which he did not think was “that bad”. He talked about what it meant in terms of “paranoia…hearing things, seeing things”. He had been taken to a tohunga who did “foot massage and …traditional greenstone mirimiri”. He said that this was very painful and caused his leg to swell. He now lives with his mother, and commented, “Our [wider] family doesn’t even exist to us”. There is no whānau support and Victor has no friends.

He had done well at school but left early, and has no qualifications or training. Victor told us that the only thing that curbed boredom was watching television and listening to the radio. Otherwise he said he had “nothing to do and nowhere to go…it’s not an average lifestyle you’d like to enjoy”. When asked what could make his life better, Victor said the only things that could really help him would be a Play Station, boom sounds and a car, but he had no idea about how to get hold of them. When asked about his hopes and plans for the future, he could not think of anything other than wanting to “get pissed” on his 21st birthday. Victor’s negative life experiences, current mental health problems and the gross abuses he was subjected to while staying in mental health services have left him with little hope for the future.

**David**

David was under a Compulsory Treatment Order at the time of the interview. He had been in contact with mental health services for over a year, and had several compulsory admissions. He told us that he had been taking drugs and feeling strange for about a year before the mental health crisis. He had lost one job and left another. Since being locked up a couple of times, he had since stopped taking drugs, and found that abstinence helped him remain more on track. Although David was told he had a drug induced psychosis, he said, “It didn’t mean a lot, I didn’t really understand what it was about”. He had been given information about psychosis in the form of pamphlets, but said it “didn’t really cover much”.

David said he no longer heard voices and was “a lot better now”. However, “I never really understood what the voices were about or how they came about…it’s just beyond me…I just can’t understand it…I still don’t understand how to take it”, and he seemed bewildered by the whole experience. When asked whether he thought he was in recovery now, David said “the doctors seem to think so…they just put me on another three months Compulsory Treatment Order the other day”, but personally he did not think he was in recovery. He has contact with a doctor occasionally and a nurse once a week, but otherwise had no other contact or...
support from mental health services. He had not been offered therapy, despite recent traumatic experiences. David has limited company and little to fill his time.

When asked if he had emotional support from his parents, David said he was “under control emotionally…it’s not really much of an issue”.

David is currently in receipt of a Sickness Benefit and lives at home with his parents. He has been offered admission to a rehabilitation service, but declined this on the grounds that he would rather get a job, as it would help him get his life back on track. He viewed a job as an “income” and “stability”. He also talked about enjoying his chosen work and wanted to be doing that again soon, although he had no set plans for achieving this, and was afraid that if he got unwell again he would lose another job. He did not know “what to do if it [the psychosis] comes back again”.

David told us that the way he tried to “get better” was by doing some exercise and taking medication, although he qualified this by saying he did not notice any positive effects from the medication.

David was one of the few young adults who, when asked, said he did not have any hopes and dreams, although he expected to “carry on with [his] lifestyle, earn money and have a good time in the weekend”. He also wanted to get off the medication as soon as possible. Lack of hope permeated his interview.

**Mary**

Mary was staying in a non-acute hospital inpatient setting at the time we interviewed her. Her story is quite different from the others in this group, as she was one of the few women in the “surviving day to day” group and she did not have a psychosis spectrum diagnosis. She had recently been admitted, on two separate occasions, to acute inpatient units following overdoses. In between these admissions, she had been in respite care and had then been discharged into the community without follow-up. At the time of discharge, she had told staff that she was scared, felt alone, was cutting herself and felt suicidal. She told us that she had never lived on her own, had no skills and was not in a position to handle finding independent accommodation. She subsequently overdosed a second time and was readmitted to hospital where she has remained.

Mary was different in that she wanted to be in an inpatient setting (despite very negative experiences in one unit) because she “could not cope” and “was not ready” to survive on her own, and had no suitable family support. Although she had seen a psychologist on only a few occasions, it had helped her to understand her mental health experience and think about things differently, Mary did not think she had learnt any coping strategies. Furthermore, at no time had she been offered access to intensive psychotherapeutic services.

Factors she had found helpful during her time in the “good” inpatient unit included empathic and supportive staff, and structure and participation in ward activities, which had helped her immensely. She had gained more confidence to deal with her parents, had activities to distract her, and had a reason to get out of bed. She told us she had also been coming off the overdose, so the distractions and activities had been beneficial. Things had just started to get better and she was getting “stronger and more in control” when she was discharged, and immediately went downhill until the second crisis a short time later.

One of the youngest participants, Mary talked about the high level of distress she felt when her parents visited, and how this prompted her to self-harm and go “backwards”. She described her father as an alcoholic who “tells us his problems”, and her mother as neglectful and abusive. She did not experience them as supportive and did not want them involved in her life at this time. She had no other family support, although she described some close friends as her “community”. However, her friends were not counted as “family” by hospital staff.

At the time of the interview, Mary told us she felt “unwell”, had difficulty sleeping, experienced severe anxiety and feeling out of
control, self-harmed, felt depressed, cried a lot and was underweight. She said she just needed some support, people who would not judge her and could understand why she cut herself, and acknowledge that she “obviously felt really bad”. During the interview, Mary emphasised that she needed to be “involved” – not to just learn to cook or follow a recipe, activities taking place in the current unit.

Although she did not elaborate on this, it was clear from the interview that Mary needed to feel close to people, and to be nurtured. She repeatedly said, “I know myself better than [the staff] do” and if they “just listened to what I said…I would get better…otherwise it’s going to drag out longer because it’s just going to put me back into the situation I was in”. When asked if she regarded this as recovery time, Mary said the first inpatient experience had been, but that the situation now was “not therapeutic or a recovery place”. She expressed little hope for her immediate future, but said she was just “trying to think…I will get through it and that it will get better”. She hoped to “live a normal life and be able to go flatting, go to uni and get a job and do something with my life”.

“Moving Forward”

Participants we characterised as “moving forward” were the largest group, accounting for around half the participants in the research. They conveyed a sense of forward movement in their recovery journeys, even though this was often a gradual process. For many in this group movement was often slow and sometimes involved setbacks. However, most of the young adults in this group spoke of feeling better than they had done at the time of their first contact with mental health services, and they were taking some positive steps to get their lives back on track.

Living circumstances varied. Some lived with family members (often due to restricted financial circumstances), some flatted alone or with friends, a few lived in supported accommodation, and several of the women lived alone with their children. Like the young adults in the “surviving day to day” group, quite a few still seemed isolated, had little purpose to their lives and found it difficult to occupy their time in a meaningful way. However, most spoke of having hope, had made forward movement in some key aspect of their lives, and could foresee things getting better at some time in the future.

For many of the participants, the mental health crisis had been a catalyst for positive personal change and development, and a greater understanding of mental health difficulties generally. Most had begun to identify factors that helped or hindered their progress. Some had come to the realisation that taking medication consistently and not using drugs and alcohol helped their progress forward. For many, contact with mental health services had meant being able to talk to an adult and feeling listened to for the first time in their lives. Some had gained a greater understanding of contributors to mental health difficulties, personal triggers and ways of managing stressors in their lives more effectively. Although some of the young adults in the “moving forward” group had “made sense” of mental health services, and had been able to access services that seemed to be working for them at least to some degree, most had not accessed psychotherapeutic services, even when recent trauma and childhood abuse was part of their history.

The type of service participants accessed impacted on the young adults’ understanding of their mental health crisis, and the meaning they could make in terms of their ongoing recovery. For those who received services that focused primarily on medication and offered little in the way of understanding mental health beyond a medical model, there was often difficulty in making sense of their experience, and they expressed fears about “it” (i.e a mental health crisis) happening again. In contrast, those who accessed psychotherapeutic services, or who had regular and ongoing contact with a mental health professional working with a holistic and comprehensive recovery based framework, seemed to have a much clearer and more comprehensive understanding of their mental
health problem in terms of their histories and the broader social and cultural context of their lives. For these participants, “making sense” of their mental health experience had been part and parcel of what they learned through therapy. For some, though, stigma and a lack of understanding about mental health difficulties by family members or local communities remained a barrier to recovery.

Some of the Māori and Pacific young adults talked about experiencing an insecure cultural identity. However, through their mental health experience and contact with Māori or Pacific services, they had gained an understanding of the importance and value of their cultural landscape in achieving a secure sense of self.

While some of the young adults in the “moving forward” group had made moves in terms of work, education and/or training, others had yet to make plans and actively work towards such goals. For some, recovery seemed to be hampered by a lack of money and resources, and the ongoing impact of family dysfunction and/or estrangement. Some of the young adults still had a way to go in terms of developing social relationships, engaging with others and gaining a sense of connectedness to their communities. Indeed, many remained isolated, had little social or emotional support, and had little to fill their days in a structured or meaningful way.

Most young adults in the “moving forward” group spoke positively of their hopes and dreams for the future, and some had concrete plans that could provide a bridge to reaching these hopes and dreams. Listening to these young adults’ stories highlighted the complex interplay between the day to day reality of living with mental health difficulties, the provision of accessible and effective mental health services, and the wider social, cultural and material context within which recovery occurs.

In contrast to the “living well” and “surviving day to day” participants, there was considerable variation in terms of background experiences, living circumstances and recovery stories in this group. Indeed, this group represents a diverse spectrum of experience along the recovery journey. To describe this range of experience, we present three stories that capture some of this diversity.

**James**

James, who is in his late 20s, first had a mental health crisis and came into contact with mental health services about three years ago. He was early in his recovery journey, and although there were fewer elements of recovery in his story than for others in this group, he conveyed a sense that some aspects of his life were beginning to move forward.

James told us that he had spent time in seclusion and been under the “Mental Health Act”. He could not think of anything positive that happened during his lengthy stay in hospital. He recalled being tackled to the ground and locked up.

He has been on medication for about a year and said that it “definitely helps”. He described “feeling better slowly” and no longer hearing voices. At the time of the interview, James said he knew in himself that he was getting better and realised that he needed his medication. He has been strongly encouraged to continue with it, though he hoped the mental health professionals would say he was “normal” and “could get off [it]”. James talked about times when he had stopped taking the medication and resumed drinking alcohol. This resulted in weight loss and becoming “a bit unwell”. His parents or mental health caseworker usually recognised these changes and helped him to realise them too. He continues seeing a doctor once a month, and has a support worker who visits him weekly or fortnightly.

At the time of the interview, James was in receipt of an Invalids Benefit and lived with his parents. He described the lifestyle as “easier” than if he had been living independently. He expressed fears about shifting out on his own or being around different or unknown people and wondered whether his health would be all right if he did.
James is Māori and has a supportive whānau. He had drifted away from the tikanga when he left school, and did not have the patience to do kapa haka and other kaupapa Māori activities. However, he had benefited considerably from bush walks and the Māori knowledge he learnt through the Māori service he is in contact with.

At the time of the interview James was due to start a part-time job. He saw this as vital to recovery, emphasising how he needed “to be doing something”. Otherwise, he was “just getting bored and not making money, spending all my time smoking cigarettes and drinking coffee”. James has a car, and his father bought him a gym membership. He said he has no hobbies. He no longer associates with his old friends, who consume drugs and alcohol and get into trouble with police. Instead he is making friends with other service users who go to a drop-in centre. James spoke of his old life and recognised that he had had “to try and change”.

Although James had moved forward in some aspects of his material and cultural life, he could not understand why he was ill, and said that this sometimes caused him anger. He said he did not know what he had learnt in terms of his mental health experience, other than learning that hearing voices was “wrong” and “that you shouldn’t do that normally”. James said, “[I’m] probably not completely back to my old self, but doing all right”. He described his “old self” as generally happy and enjoying things, enthusiastic, motivated and excited about things. He also talked about what he wanted in the future, including “a good career, a good job, heaps of money, a nice house”. James conveyed a sense of optimism during his interview which is somewhat lost in the printed telling of it. He had reconnected to aspects of his cultural history, was motivated, had found work, was establishing new social networks and had a secure material base from which to further his recovery.

Bob

At the time we interviewed Bob, he was living in a hostel with others, some of whom were service users, and was in receipt of a Sickness Benefit. He had tried to kill himself at the time of the mental health crisis, and when we saw him he had been out of hospital for only a few weeks. He had been diagnosed with bipolar disorder. Bob told us that having his experience named as “mental illness” had been helpful, as it helped him understand that there was a “real” problem and that it was not just him “behaving badly” as his family and others had thought. Prior to contact with services, he had never understood what was “wrong” with him.

He spoke about now realising that his thoughts were often not “reality”, and said having a “mental illness has changed how [he] think[s] of people”. Here he was referring to understanding mental illness better, realising the person is not to blame, and being more compassionate towards others. He had gained considerable benefit from an Early Intervention Service because he was able to talk to a staff member on a regular basis, and she had helped him understand his experience and feelings. Bob had never had anyone to talk to while growing up. He described the services as “awesome” and said they had been central to his recovery. Bob had also benefited from research and educational tapes about bipolar disorder and psychosis, and a recently released Early Intervention Service DVD about four young people talking about their experience of psychosis. This resource had helped him understand other people’s mental health difficulties, and helped him to identify what makes him feel better or worse. Bob said, “I gotta try and balance my life out” to prevent getting too depressed or too speedy. Bob’s mother, who is a key source of support and encouragement, had also benefited from watching the DVD, as it enabled her to understand Bob’s mental health difficulties and to realise it was not due to “bad behaviour”.

Bob spoke of having “tons of mates”, but said they were not people he could talk to. He conveyed this clearly when he said, “I can’t talk like that [about feelings] with them, eh,
they’re mates who I can confide in if I need to know the score...or to have a beer.” Bob said he was “quite happy” staying in a hostel with other service users, because “when I’m feeling down I can just run to the dude and just be like, ‘Help me out’...he just like talks to me...[and says]...’ They’re just thoughts, but they feel so real...you believe in them so much you’re not in this world anymore’”. Bob stressed that the only way to get over thoughts of this kind was to get help, like the help he had received from early intervention. He said he would stay away from his old friends while he still hears voices and gets depressed, because he did not want to be a burden to them or go out drinking. Although Bob tried to be active every day, he was not involved in any structured activity, as he had been used to, and said he did not have anything “solid”. This lack of purposeful activity and involvement with others made some days especially difficult.

Bob told us that his mother had experienced a lot of blame and stigma from others about some of the behaviour associated with Bob’s mental health difficulties. It was therefore important for him to be autonomous and not to burden her further with his problems. Living independently was central to Bob getting his life back on track and feeling as though he could cope.

Although Bob identified as Pacific, he had been immersed in Māori culture and said, “I lost a lot of my inners from trying to cancel out what truly was [i.e being Pacific] and trying to be something else.” Other than his mother and siblings, Bob has little whānau support, and said “I’ve just lost contact with my cultural side because I’m still trying to work on myself.” Part of his recovery was realizing who he is and trying to gain a strong identity.

Bob grew up in a Pacific culture believing he was at fault, and people had told him he was “useless”. He said this probably contributed to feeling so bad about himself. He talked about how his Pacific community’s lack of understanding of mental health difficulties had “really hurt” and created a barrier to his recovery. This meant being blamed and stigmatised by others. He said, “Most families, they don’t wanna know their family has mental illness, ‘that’s not from us...you put this onto yourself’.”

Despite dealing with this hurt Bob was highly focused on getting himself back on track. He said:

I’m not gonna...do anything else except work with myself until I’m able to go back out into the work force or do my music...so at the moment it’s just working on myself, balancing out...I still hear the thoughts with the medication, some days...I feel depressive...but...I know who I am now, I know what I have...I’ve been through enough shit, I can do this.

Bob spoke passionately about the music he makes. He had firm plans to commence a music course later in the year, and hoped to use his music to help people with mental health problems in the future. Throughout the interview, Bob reiterated that he was not going to let the mental health problem “keep me down”. His positive and proactive stance was a powerful reminder of the agency and hope many of the young adults in the “moving forward” group conveyed during their interviews, despite living with few resources and in difficult material and social circumstances.

Michelle

At the time we interviewed Michelle, she was living alone with her baby. She was supporting the two of them on a Domestic Purposes Benefit, and said it was always a financial struggle to have enough food in the fridge at the end of the week. She has no family nearby, but has two close friends, one of whom supported her through the pregnancy and birth. Since the birth of her child, Michelle has established regular phone contact with her mother who she said was now supportive in a way she did not use to be, and was interested in the baby.

Michelle told us she had gained considerable benefit from a post-natal depression group via Maternal Mental Health and from therapy
through intensive psychotherapeutic services. The intensive therapy had helped her to understand how adverse childhood experiences contributed to how she felt as an adult, and she had learnt new ways of coping with her feelings. She said she was currently working through some of her “childhood... unpleasant stuff”. This helped her understand depression and the mental health crisis she experienced. She had also benefited from sharing her experiences with others, and had made some connections with other service users. Visits by a support worker during the early weeks following childbirth helped to ease the loneliness of this time. She had since received Barnardo’s support to assist with parenting and budgeting. Michelle described being “a big fan of exercise” and said this helped her recovery. However, having to have regular contact with the baby’s father was one of her ongoing biggest stressors, and this made it “hard to move on”.

Michelle’s hopes included developing better self-esteem, meeting people and getting more support. Her biggest hope was to be “a good parent”, which included showing affection and praising her child – expressions of love that she had not experienced as a child. Although Michelle’s circumstances were difficult, she was moving on recovery and hopeful about the future. Her story is an example of being some way along the recovery journey, while also needing continued support to achieve her hopes and be able to live well in the future.

“Living Well”

Young adults whom we characterized as “living well”, about a quarter of the participants, conveyed a strong sense of agency, determination and desire for personal change. They expressed hope for the future and talked about having gained meaning and purpose in their life that provided a firm foundation for their recovery and future lives. These young adults showed a clear understanding of their mental health issues, and had made significant progress towards piecing their lives together following a crisis. They expressed acceptance of mental health difficulties and their experiences were understood as part of their whole identity, which was multifaceted. Most of the young adults in this group saw their overall mental health experiences in a positive way, as “gifts” or “sensitivities” that they could use in a proactive way to help others.

The “living well” group spoke in a concrete way about recovery, and had clear goals and plans for achieving their hopes. They had made significant steps towards gaining some security in their material lives, such as housing, and/or employment/training/education, and they had clearly defined career aspirations. Some were committed to working in the field of mental health with the intention of being advocates and educators, and/or improving mental health service provision and delivery. They had also developed social networks and personal support, and were able to participate actively in their communities.

A common theme amongst this group was that they had (eventually) accessed comprehensive recovery based mental health services that were appropriate to their needs, such as gaining access to intensive therapy, or therapeutic rehabilitation programmes or being offered a comprehensive range of services. Few of the young adults in the “living well” group had been diagnosed with psychoses, and not many had been hospitalised or had endured the trauma that often accompanied an inpatient admission, especially where compulsion was involved. Though “living well”, these participants continued to deal with some mental health difficulties and the associated stressful social worlds they sometimes occupied.

The young adults characterized as “living well” were primarily Pakeha women, although they also included some Māori men and women. None of the seven Pacific young adults in the study were included in this group.

Here we tell three recovery stories from the group we defined as “living well”, to illustrate how elements of their recovery journeys have contributed to realizing hopes and dreams.
Sandra

At the time we interviewed Sandra, a Pakeha woman, she was flatting with friends, studying at university and working part-time. Sandra had told us that her childhood was characterised by emotional abuse and neglect, and lack of emotional warmth or attachment. She had left home at 16 and supported herself through high school and university. She continues to have little contact with her parents, and they are unable to support her emotionally.

Sandra’s experiences spoke volumes about the importance of an holistic approach to recovery from the mental health problem which led to self-harming, hospitalisation and time spent in mental health services. She sees recovery as a process that may be life-long. For her, the integration of an Eastern philosophy in her everyday life means being able to discover a deep meaning and purpose. Being a role model to a younger sibling, whom she loved and looked out for, and living with a pet she could take care of, were examples of purpose.

Sandra told us that having hope, motivation and knowing how to develop goals that give her something to live for are central to her recovery:

The motivation to recover is hope ... [this] is fueled by having good stuff in all aspects of your life – living where you want to...with people you want to, having a social network is huge, having a job you can enjoy...or some educational...or vocational goals...hobbies, things you like doing and that make you feel good.

Sandra identified key factors that have been, and remain, significant in her recovery process. She referred to these as internal (things she feels and believes) and external (things others do or believe about her). The most important factor in her recovery had been the work she had been able to do in the intensive therapeutic service she attended. Here she found staff members who instilled hope and were committed to a respectful and self-determining process of recovery. Sandra told us that one of the biggest barriers to recovery was “people who have no hope for you or don’t carry any hope for you”.

Gaining an understanding of her mental health experience within the theoretical framework of Dialectical Behaviour Therapy had also been instrumental in the changes she achieved. Through intensive therapy and artistic expression, she began to change a fundamental belief that she was not a “good person”, to identify triggers to feeling bad and self-harming, and to learn new ways to manage intense emotions.

Sandra is currently realising her hopes and dreams, and has made significant advances towards achieving her desired future career. Having completed a Bachelors degree and gained acceptance to a Masters programme, she is currently undertaking advocacy work in a health field, which she described as “liberating and empowering”. Her goal is to work in mental health in a way that is meaningful. She is also involved in other youth and gay community initiatives that are both personally and professionally fulfilling, and has developed a strong social network. Although Sandra conveyed a high level of motivation and determination, she did not paint her life as “rosy”. She continues to struggle with overwhelming feelings and the desire to self-harm. However, her story highlighted many ways in which she has worked hard, and with the hope, commitment and support of others, has created a life that she feels is worth living.

Shane

At the time we interviewed Shane, a man with Māori and Pacific heritage, he was living with his partner and their child, and working full-time in an apprenticeship. He said he had been “pretty messed up”, and understood his mental health crisis as a result of “an overload of stress or being depressed”. He spoke about the role the Early Intervention Service had had in helping him, especially in terms of having regular contact and giving him “pointers” and advice to think through issues and find solutions to difficulties. He said they were “really helpful”
and had taught him to “deal with it and carry on with life”. The Early Intervention Service had also supported his family.

Shane talked about being on medication that was mostly effective in reducing the voices, improved his mood and sleep, and was a “light” enough dose so that he had energy to work and get through the day. He said that staying on medication in a consistent way, not drinking too much, and avoiding dope had helped him regain some balance in his life. For Shane, seeing things out of the corner of his eyes created fear and a sense of always having to be alert. He said this was “the worst”. It meant he was scared of the dark and made him feel, at times, that he couldn’t protect his family. However, his partner was understanding and used humour to help in these situations.

Since his mental health crisis, Shane’s family, who used to “fight” a lot, had “moved closer to each other” and they visit regularly. His mother, whom he had not been close to, provided support and showed an interest in his child; and his brothers and sisters were “really supportive”. He and his father both hear voices, and his father was able to talk to him about how he manages. Shane said that his family’s support “played a big part” in his recovery.

Shane is working full-time in a new position with “better money” than his previous job. He has not told his current work mates about hearing voices, because he thought they might think it was “strange” and he wants to wait until they know him better. His previous boss was aware of the problem. Shane said the Like Minds advertisements have been useful and have given him more understanding towards others, because “they’re just normal people that have problems, personal problems”. Shane described a life that was full and busy and gave him a sense of purpose. In particular, his young child was a source of joy and hope. Shane’s sense of recovery and humour was captured in his closing comment: “I don’t get depressed these days, if I do it will be the All Blacks losing.”

Jennifer attributed her recovery to a range of factors, including mental health service support, tikanga Māori and whakapapa connection, engaging in mental health work, and a personal commitment to make positive changes in her life. She spoke enthusiastically about the help she received from Home-Based Treatment, Early Intervention Services, and a psychologist whom she has seen for two years. The combination of psychological help, medication, hypnosis and Māori healing methods (including rongoa and mirimiri) had been significant for her. With this range of help, she gained an increasing awareness that she could have a better life and did not have to live in abusive or destructive circumstances. Jennifer said, “I changed everything…I started thinking I wanted to change for my [child]”. She began eating properly, stopped smoking marijuana, and moved in with her mother whom she gets on well with, and where she is safe from her child’s violent father. Together Jennifer and her mother work, study and share the care of her child. This environment is nurturing and supports Jennifer’s passion for learning. Jennifer emphasised that a key factor in her recovery was “people letting me make the decisions [about] what’s best”.

Since being involved in mental health work, Jennifer has also been immersed in tikanga Māori. Jennifer said that being in contact with the person who did the rongoa had provided her with knowledge of her whakapapa, and had provided “a bit more culture in my life”, which she had not had growing up. She said this made her feel “happier inside”, as she realised she could make “connections” with her whanaunga. Jennifer also said that she finds prayer helpful when she is feeling “scared or down”.

Jennifer talked about the study she has been doing for the past two years and spoke proudly of an award she had won for her diligence. Although there have been times when Jennifer has had “relapses” and has been in respite care, she has maintained her study throughout
and has “never been back to ICU”. She has a couple of close friends and has disconnected from people in her life who were involved in drugs and alcohol, and caused her harm.

One of Jennifer’s hopes is to work in the mental health field, and she is currently actively engaged in this vocational aspiration, working full-time as a support worker and studying mental health. She has been involved in educational work, conferences and Māori mental health hui. These forums have provided a framework for understanding anti-discrimination work and have drawn on her experience of recovery. Jennifer told us that her role as a support worker and the kaupapa Māori workplace gives her “motivation in the morning”. She described the work as challenging, stimulating and diverse, and she enjoyed the people.

Although Jennifer continues to face “trials some days”, she said, “I can cope with them a lot better now, I know I can ring people if I need help, my son is thriving, I can make decisions that affect our family, I get along with my mum and I never used to, I’ve got savings [and] a car.” Jennifer hopes to get a house in the future, but in the interim feels established where she is living, and wants to continue working and studying. Jennifer finished by saying that one of her main goals in life “is to stay well”.

FAMILIES, WHĀNAU AND FRIENDS SUPPORTING RECOVERY

Although some of the young adults and their families and whānau were estranged, disconnected or had difficulties getting on, others were well supported, and family/whānau support was often reported as a key theme in recovery, as some of the above stories show. Moreover, some families, like Shane’s, pulled together and were more helpful to participants after their mental health crisis than before.

Sarah was particularly well supported by her partner, and her mother and father who had been helpful over the years, through many incidents of self-harm and extreme distress. Her mother had noticed evidence of self-harming and the overuse of non-prescription medications, and was concerned about changes she had noticed in Sarah’s well-being and behaviour. Her mother had come along to an assessment with a psychologist, which helped in providing family background information. Sarah’s partner, who had stuck by her over many years, was an ongoing daily support and took an active role in finding ways to help Sarah strategise ways of reducing self-harming. He was her main support once the crisis team refused to provide ongoing assistance following further self-harming incidents. Sarah was one of the few participants who talked about making decisions about her recovery process as a family.

Some of the young adults with little or no support from family and whānau had familial type support from close friends. Max, who was referred to Home-Based Treatment, had close friends who helped him after his discharge, as his parents were unable to support him. “I’ve got the coolest girlfriend right now who I can talk to about it,” Max said.

Julia, who flatted with friends, had two friends she was particularly close to. One of them provided monitoring of Julia’s bulimia and self-harming. Julia’s friend supported her to “cut down” the incidence of these events. She eventually stopped altogether. Sandra, who had no support from her parents and had left home at age 16, had been supported by some very close friends whom she had maintained through and beyond high school.

Friends who had experienced mental health problems too were especially valued. “It’s not that they knew what to say, it’s like they know what not to say”, said one participant.
In this chapter, we have shown that recovery is a shifting, multifaceted and often unpredictable process. Some of the participants’ stories capture “living well” following a mental health crisis. These stories can be summarised as having a fundamental sense of “being in” and engagement within a community. People who were “living well” often had jobs or were otherwise occupied in meaningful activities, such as study, training or raising children. Most had some financial and material security, and could live autonomously or choose where and with whom they lived. Many had established social networks that involved meaningful relationships with friends, family or others. Indeed, participants in this group seemed to have a strong sense of meaning in their lives. This was often expressed not only in terms of having goals and aspirations, but demonstrating an understanding of their own mental health experience. Participants who were “living well” talked of their mental health experience as one part of their broader lives. For many, their understanding was related to developing an understanding of their crisis experience not simply as a “genetic hiccup”, but as having emerged from the complexity of earlier life experiences, often characterised by trauma, childhood adversity and/or recent stressful life events. The young adults who were “living well” seemed to have a range of resources and skills that meant their hopes and dreams had some substance in terms of the futures they could achieve.

In contrast, participants in the “surviving day to day” group had some way to go in connecting their hopes and dreams to concrete plans, and finding the resources necessary to ensure that their plans for the future could become realities. Most lacked social, cultural and material support, and were not receiving effective, comprehensive or recovery based mental health services.

The largest group of young adults, those who were “moving forward”, sometimes very slowly, into recovery, had many positive elements to their stories. They were not “living well”, though, or not living as well as one might have hoped, given the often long that had elapsed since their first contact with mental health services. Too often, participants spoke of little social, cultural and/or material support, and their days were often isolated, unstructured and felt meaningless. Many were unable to make genuine choices about where and with whom they lived, and some could make only small steps towards securing education, training or employment in the near future. Although some had experienced positive changes in family relationships, others came from historically dysfunctional families where relationships had long been difficult or a source of stress.

Irrespective of where our participants were in terms of their recovery process, the majority expressed clear hopes for the future and were able to identify barriers, as well as things that were helpful, to moving on recovery. For many, the goal of living well and being able to realise future hopes seemed dependent on more comprehensive mental health services of better quality. In this regard, there seemed some way to go in terms of services situating the person in their social context at the centre of “treatment”, rather than focusing on the reduction of “symptoms” or drug management of “illness”, as appears to be the modus operandi in many services, as reported to us.

As noted earlier, a significant group of young adults in this project had experienced abuse and trauma during their childhood and early teen lives. Some were subsequently abused while staying in mental health services, and many women felt unsafe in adult inpatient units. Few were offered trauma therapy, intensive psychotherapy or any form of psychological assistance, despite many commenting that they would have liked to have had this. Their stories highlight a strong need for mental health services to respond to the needs of young adults early in their initial contact, and offer appropriate forms of therapy as a matter of course. There is a need for services to situate social and cultural contexts at the
centre of an understanding of mental health, and offer treatment approaches that genuinely recognise the complexity of young adults’ lives in the twenty-first century.

Most strikingly, recovery stories illustrate the intelligence, creativity and determination that young adults brought to bear on grappling with severe mental health problems, understanding how their lives had brought them to this moment, and trying to harness what services could offer to help them move forward. They were very clear about what helped and what hindered. Participants from all positions in recovery tended to speak with a united voice about the importance of safety, respect, hope, friendship, work and careers, family support, meaning and purpose in life, independent housing, community participation, someone to talk to, and the provision of holistic, recovery oriented treatments and supports.
When we first examined the narratives of our 40 participants, describing their journeys through mental distress and pathways through mental health services, what struck us was that everybody’s story was unique and amazing. As researchers and interviewers, their stories had a huge impact on us. The adversity that they told us about saddened us deeply, and we were amazed and delighted by the courage, determination, intelligence and humour they displayed in their journeys towards recovery. As professionals in mental health, we were discouraged by the kinds of journeys into and through services that most participants recounted, but we were heartened by the stories we heard of individual services and staff who showed both humanity and expertise in their practice, and who ignited recovery.

In analysing interviews, one goes through a process of working through from the individual narratives to the themes, patterns and sequences that emerge. By the end of our analysis, it was clear that journeys through services deeply impacted on, and indeed shaped the course and experience of the severe mental health conditions of our participants. Moreover, as pathways into distress and pathways through services became clarified, with that clarity came the capacity to reflect on and critique New Zealand’s system of delivery of services to those who experience mental distress as young adults.

In this chapter, we present our conclusions about these journeys and pathways through mental health services, both in the text and, in a simplified form, in the diagram on p.90. We also want to present a strong critique of current pathways, in terms of the ways in which they unnecessarily foster illness and impede recovery.

**JOURNEYS INTO MENTAL DISTRESS**

It will be recalled that most participants described to us childhood adversity and/or trauma that they felt contributed to their later mental health problems. What many of them lacked, and what became central to their later distress, was a secure family life (whether with one parent or two) offering a sense of safety and predictability, and freedom from the kinds of abuses identified by the participants in this project. We cannot emphasise enough what a difference it would have made to many participants (and their siblings) if they had experienced warm and open family relationships, in which effective communication between parents and their children validated children’s feelings and life experiences.

Children and teenagers who do experience various forms of traumatic abuse and loss need to be able to communicate their grief and puzzlement to trusted adults who recognise the significance of their feelings. Their support will also include trying to get children and
teenagers access to mental health and other services where there are skilled professionals.

The participants’ stories also alert us to the need to be aware of the negative impact of bullying and harassment in schools. Poverty is also a source of stress in the day to day lives of children and teenagers, affecting their identities and their sense of fairness and opportunity. Participants also described living with parents who had mental health and/or alcohol problems as particularly stressful. Finally and importantly, the pervasive use of drugs and/or alcohol featured significantly in participants’ narratives, leading us to emphasise the need for appropriate education and intervention early, rather than later, in the teenage years.

We also noted in Chapter Three that few participants described outside interventions into childhood and adolescent situations which put participants at risk of later mental health problems, even where these situations involved ongoing abuse. Of the occasional interventions mentioned, none were successful in terms of improving situations or outcomes, with the possible exception of the mental health services received by two or three participants as adolescents, long after harm had occurred.

Our conclusion for the first part of the journey into mental ill health is that trauma and various forms of adversity were talked about by most participants, yet successful interventions, which might have improved outcomes did not occur.

Chapter Four, describing “going downhill” made it clear that serious distress (manifesting itself in early signs of mental health problems) occurred over a long time period, from months to years, without effective help being given. Participants described depression, despair, self-harm, suicidal behaviour and a range of other distressing feelings, thoughts and behaviours. Nearly all tended to abuse alcohol and drugs in attempts to alleviate their distress.

The range of experiences identified by the participants as precursors to going downhill again highlights the significance of a secure family life, where young people can live with a sense of safety and predictability, where family relationships are functional, and where young people and young adults are able to talk within a safe context about their feelings and the things happening in their lives. Their stories highlight the importance of having emotional and practical support, and having access to peers and older adults who can listen to and validate their experiences, and who do not stigmatize mental health conditions.

Those participants who were to experience psychotic spectrum disorders – although usually experiencing considerable distress – did not ask for help during this “downhill” period, although their families sometimes did, with unsuccessful outcomes. Those with “non-psychotic” mental health issues usually did seek help, but the help that they received from primary health and counselling services was insufficient. The impression conveyed was that their complex and multi-faceted problems were seen as just too difficult to be dealt with by practitioners in the primary sector.

There were not many attempts at referral from primary sources to mental health services during this downhill period, and the few attempts described were unsuccessful. Participants’ conditions were not seen by mental health service providers as severe enough to gain access to mental health services, and no doubt primary and counselling service providers were aware of the futility of referral in many instances. Our analysis of the “going downhill” period is that despite severe and obvious distress, participants were just not getting access to mental health services.

All participants described a mental health crisis, which tends to be the pivotal part of their narratives. For the participants, it was described as involving severe emotional distress. To the outsider, this crisis was usually a very severe suicide attempt, or an incident which prompted others to call for help.
PATHWAYS THROUGH MENTAL HEALTH SERVICES

Crisis led to crisis assessment in some form or other, usually by a crisis assessment team who were often accompanied by police, or who were accessed via an Accident and Emergency service. Crisis assessment led our participants into mental health services (notably, a few had been assessed and turned away on previous occasions).

It is the argument of this research that participants were driven into crisis unnecessarily. Despite warning signs over a long period of time, effective mental health help had not been made available to them.

Mental health services, in their gatekeeping role, effectively prevent access to services by people who are outside the 3% of the population who have the most severe problems, and who are therefore entitled to services. In fact, because services nationally see only around 1.89% of the adult population, gatekeeping clearly also excludes nearly half of those within the 3% of the population with the most severe mental health issues (Mental Health Commission, 2005).

Gatekeeping practices often revolve around particular diagnostic classifications. Participants with psychotic spectrum symptoms, when finally arriving at crisis, were nearly always assessed as eligible for services, whereas those with symptoms of non-psychotic spectrum disorders had a far harder time gaining access.

It might be argued that it is difficult to distinguish between the “worried well”, i.e. the 20% or so of the population who have troubling, although less severe, mental health issues (such as some forms of anxiety or depression or addiction), and the 3% categorised as having severe mental illness. Mental health services at present most probably could not cope if the gates were thrown open and services were offered to all who wanted them. This is no doubt why, on the whole, mental health services do not go out looking for clients, and why they use indications of psychosis – a low prevalence set of disorders – in their gatekeeping.

However, our pathways analysis shows that the “less severely unwell” and “more severely unwell” are not clearly distinct populations. Rather, they may be people at different places in their mental health journey. We have shown how mental health problems, without attention, can worsen over a long period of time, and suddenly blow up into a crisis. However, the sorts of responses participants had from primary and counselling services indicate, that they were in fact being identified as at the more severe end of the spectrum, and therefore in the “too hard basket” for such services. What they needed was referral to suitable mental health services so that their problems did not become crises.

Even early psychosis intervention (EPI) services, in terms of the experiences of participants in this study, were not usually “early” and were most often operating as a post-acute service, usually after hospitalisation and its associated traumas. They could have been more effective if participants had had contact with them in the “going downhill” phase, and those few who were referred at crisis, averting hospitalisation, showed good recovery outcomes.

After crisis and crisis assessment, two-thirds of our participants (especially those with psychosis symptoms) went on to acute adult inpatient units, many under compulsion. Their stories about acute units were moving and central to their narratives. Although the crisis situation lessened in the units, probably because of a range of factors including change of scene, safety from self-harm, and medications, the experiences of inpatient units were profoundly not recovery-oriented.

Most of those who experienced acute units reported that they were traumatising, particularly because of the fearful and distressing nature of the inpatient environment, the hopelessness inspired by seeing older, acutely distressed people with a long history of service use, seclusion experiences, assaults and forced...
Young Adult Pathways Through Mental Distress and Mental Health Services

Narratives of childhood adversity and trauma
(most participants told such narratives; a small proportion did not)

Successful interventions to improve outcomes of childhood trauma and adversity did not occur.

Going downhill: help-seeking occurred but was not effective
(mainly non-psychosis group)

Going downhill: no help-seeking though obvious signs of distress
(mainly psychosis group)

“Falling between the cracks”: severe distress occurred over months to years.

Mental health crisis occurs
(usually serious suicide attempt or family incident)

Participants had been driven into crisis though there had been lots of warning over a long period of time.

Crisis assessment
(mainly via community mental health teams)

Participants finally assessed as severe enough to be part of the 3% of the population eligible for mental health services at any one time.

Acute inpatient services
(2/3 participants)

Acute alternatives
(a few participants, some also had inpatient stays)

Inpatient services distress most participants, many of whom already have trauma histories.

Non-acute services
Community mental health teams (which broker the more specialised services)
   Early intervention
   Other specialty services, e.g. maternal, eating disorders, youth
   Intensive structured programmes
   Culturally based services (Maori and Pacific)
   Supported accommodation
   Peer support

Non-acute services were the first step towards recovery for most participants.
medical treatment. Many of these participants already had trauma histories, and it seems reasonable to argue, as Patrick McGorry\(^1\) and others have done, that acute stays re-traumatised them. Certainly, lack of attention to psychological wellbeing reinforced young adults’ earlier experiences of having no one to talk to about problems.

Few of our participants experienced “acute alternatives”, such as home-based treatment or crisis houses. A handful had more youthful experiences in units designed for children and/or adolescents. Far more positive accounts were given of “acute alternatives” than of adult inpatient units.

Only one-third of our participants went directly from crisis assessment to non-acute services. The other two-thirds were provided with non-acute services after discharge. It was in the narratives of non-acute service experience that we started to hear recovery stories. Services varied immensely, with the participants reporting particularly positively on early intervention services, structured (sometimes residential) programmes, culturally based services and specialised services such as maternal mental health, eating disorders and youth services.

Most of these services did not provide participants with a fully holistic approach, with the full spectrum of assistance that they might have found useful, and much more could have been done in many of the services to enhance the recovery direction of participants. Some, from the point of view of the participants, overemphasised biomedical approaches (particularly medication) and many failed to make psychological assistance available, although most participants told us how they really wanted such assistance. Peer support was fairly rare, though it was appreciated when it came from age-group peers.

However, there was a sense conveyed in the stories that these non-acute services did operate to their strengths and specialties. On the whole, they did not put up barriers to contact once participants had been accepted as their clients. They worked mostly in a friendly way, were not averse to supplying information required by participants, and sometimes spoke with family and whānau. Our conclusion is that they would have been of immense benefit to participants had they been available during the “going downhill” period.

Less positive were reports about non-specialist community mental health services, which appeared to be overly busy, with hard to access appointments, and providing the most basic of mental health services: medication, a little support, and referrals to occasional appointments with psychiatrists. They did not appear to be operating, from the young adults’ accounts, in a recovery oriented perspective; yet they were often in the position of carrying the gatekeeping function for referral to other services, thus causing immense frustration on occasions.

Housing providers, too, had mixed reports, and there were too many unfortunate incidents reported from people who used them. The people whom we judged to be advancing more slowly in their recovery processes were far more likely to be in supported housing situations, heavily medicated, with not enough to do in their daily lives, and although usually supported through visits from early intervention, cultural teams or community mental health, with not getting enough focused assistance.

PATHWAYS BY ETHNICITY, GENDER AND DIAGNOSIS

Gender, ethnicity and diagnosis all impacted on participants’ pathways through mental health services, and these three characteristics interacted with each other, making interpretive comment difficult.

Two-thirds of our group had experienced psychotic spectrum symptoms and disorders, and one-third had not. However, nearly all the men (19 out of 20) came into the first group, whereas only one-third of the women did so. Conversely, all but one of those who experienced non-psychotic spectrum disorders were women.

Of the 20 men interviewed, 17 identified as Māori, Pacific or Asian. All of these men experienced psychosis spectrum disorders. Six of the 20 women identified as Māori or Pacific, and four of these women also experienced psychotic spectrum disorders. Conversely, Pakeha women made up 11 out of 14 of those who had experienced non-psychotic disorders.

Therefore, while we have been talking about differences in pathways through services between those with psychotic and non-psychotic spectrum disorders, we have implicitly been talking about differences related to gender and ethnicity. For instance, when we report that help-seeking did not occur in the “psychosis” group during the downhill period, we are also saying that Pakeha women were far more likely to seek help than Māori, Pacific or Asian men were. When we say that people referred to adult inpatient units after assessment were more likely to be those in the psychosis group, we are also saying that Pacific participants and men were more likely to become inpatients than others were.

When we divided our participants into three groups, based on their recovery to date, those who had made most progress (the “living well” group) were more likely to be Pakeha, to be women, to be from the “non-psychosis” group, and to have avoided the adult inpatient experience. Nevertheless, the “living well” group was still a fairly diverse group. The group whom we described as “surviving day to day” were more likely to be men with psychotic spectrum disorders who had spent time in adult inpatient units, and were more likely to be of Pacific ethnicity.

Because of the overlaps of gender and ethnicity in terms of the make-up of our participant group, and because participants of different ethnicities were referred to us through different sources and therefore had different service backgrounds, it is difficult to say anything very definite from our study about pathways through services by gender, ethnicity and diagnosis. Ironically, the psychosis group had more ready access to services (once mental health conditions had led to crisis) but more hospitalisation and poorer outcomes. Nevertheless, the group was very diverse and they made up nearly half the “living well” group, despite being all of the “surviving day to day” group.

Our findings suggested poorer outcomes for men (probably because more men in our study had psychosis spectrum diagnoses) compared with women. However, the women (fewer psychosis spectrum disorders and poorer access to services) perhaps had better outcomes because one group of them did very well as a result of a particular intensive psychotherapeutic programme that was designed around women’s needs.

Pakeha appeared to have better outcomes, but perhaps this was mainly because of the predominance of women in the Pakeha group. Also, it should not be too surprising that Pakeha had better outcomes, since this is a well known result across a range of health conditions. People of Pacific ethnicities had poorer outcomes, but this may have been due to the predominance of

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2 In our study Māori were no more likely to have had an adult inpatient experience than Pakeha participants were. This feature of our study is influenced by the fact that several Māori had been inpatients in child and adolescent units; and also by how we located participants – those we interviewed from a rural location, who were all Māori, had fewer inpatient experiences.
psychosis diagnoses, and background factors such as poverty. It is difficult to say much about Māori outcomes, except that they were somewhere in the middle, with Māori in all the three of our “recovery outcome” groups. Māori participants were very diverse in terms of location and the services that they had accessed. Culturally based services provided some different pathways for Māori and Pacific participants, and were appreciated, but they did not provide early intervention or avert hospitalisation for our participants and cultural services were not notably present during inpatient stays.

RECOVERY-ORIENTED SERVICES FOR YOUNG ADULTS: HOW THEY NEED TO BE

In Chapter Five we drew some conclusions about what helped and hindered recovery in acute and inpatient settings. In Chapter Six we brought together themes around what helped recovery in the non-acute services. There was an overlap in themes, although some specifically relating to the inpatient experience.

It was very clear from our research that young adult participants would prefer the company of others in their own age group in inpatient settings. Those who had experienced youth inpatient settings had better experiences, though they were too few in number to form the basis for any judgments.

The young adults in our study did not thrive in adult inpatient units, and they recounted many distressing experiences, as well as giving a bleak view of the overall atmosphere. They found it extremely distressing if they had been taken there under compulsion, forced to take medication and locked in seclusion. They generally did not get sufficient attention or positive interaction from nursing staff, and this replicated, for many, their feelings from childhood onwards of being unable to communicate deep feelings or talk about what really mattered. They did not receive psychological help, which they would have appreciated. They felt unsafe, especially the women, in terms of the behaviour of other service users, and sometimes of staff. They found the environment arid and boring, and stayed in those environments for much longer than usual. They were horrified at the dismal prospect of having continuing severe mental health problems, which they saw in older service users.

Being in an inpatient unit did remove young adults from situations that led to crisis, kept them safe from self-harm, and allowed for the impacts of medication to be observed and adjusted (which some appreciated and others did not). Overall, the study suggests that young adults in crisis would thrive if they were able to receive treatment in smaller, more home-like settings with peers, where psychological treatments were provided. Some participants would also do well receiving home-based treatment in a crisis, although more did not have a secure and suitable home base than would be likely for older adults. Overall, the findings of this study are very much in harmony with the Mental Health Commission’s recent call for reform in the delivery of acute services (O’Hagan, 2006).

Non-acute services serve a variety of needs. Generic community mental health services did not seem to be meeting the needs of young adults, in that they were hard to access and delivered only the most basic of services. However, they were the gatekeepers for access into services, via their crisis teams, and for access to specialised services. In effect, the way the mental health system operates around access meant that young adults were forced into crisis, when they should have been able to access specialised, non-acute services in the “going downhill” phase. Also, many of our participants would have benefited from good child and adolescent mental health services. Hardly any did so, and we know that these services in New Zealand are not currently providing sufficient access (Mental Health Commission, 2005).
More specialised services were, on the whole, more helpful to young adults in their recovery. Services varied immensely, in terms of their clientele, philosophies, values, and adherence to biomedical models versus more holistic practice. What young adults appreciated were holistic, comprehensive, therapy-based, values-based services that provided psychotherapeutic help for their particular problems, and mainly dealt with their age groups. An intensive therapeutic service provided a model of a well-designed service, with many of their “graduates” having made great strides in recovery. Another residential service, with a holistic philosophy and a focus on meaningful activities and opportunities to do things with peers, was spoken of well, too. Services focusing around problems common in the young adult age group, such as eating disorders and maternal mental health, were also seen as comparatively well organised and helpful in recovery.

Participants appreciated culturally based services when these put them in touch with their cultural practices and operated from a whānau or family-like base. They made comments about recovery processes being tied into knowing their cultural origins and shaping a strong cultural identity. Māori participants, in particular, talked about becoming familiar with their whakapapa and whanaungatanga, connecting with whānau and iwi, and learning their indigenous language. For Pacific participants, it was helpful to be able to hear and use their first language or the language familiar to them as children. They also spoke of how good it had felt when they were taken back into the Pacific community with the support of staff from Pacific services, because some had been ostracised for having mental health difficulties and having been in a psychiatric inpatient unit.

Early psychosis intervention, the service aimed particularly at young adults experiencing psychotic spectrum disorders, and therefore at the largest group of our participants, was generally appreciated, especially in terms of positive staff attitudes and the regular contacts, often home-based. However, there were some factors that could improve how the service was delivered to our participants, and these are not inconsistent with the values of EPI, and indeed are acted upon in some services. First, the services needed to be accessed early, during the going downhill phase, and before a crisis followed by hospitalisation occurred. Secondly, not all our participants were able to access EPI at all (in our study, this especially applied to Māori participants, though this may not be the national picture).

The other key point was that many participants would have appreciated getting a wider range of services from EPI. Most got reasonably good quality biomedical help, education about psychosis, some family education and some access to peer support groups. More comprehensive services would have delivered a range of psychotherapeutic interventions, including trauma therapies (a few participants did get some of these services). Also, too many recipients of EPI were spending most of their time alone at home. A more intensive, structured and meaningful programme, with an activities basis, as well as employment and education support, would have been helpful.

Early psychosis intervention services definitely have a huge potential to assist recovery, judging from our findings. It is worth debating the issue of whether early intervention services should also take on people with non-psychosis spectrum disorders. However, because the psychosis specialty does allow for the delivery of very focused services, and some of the other specialty services were doing well, one would not want to see, for example, maternal, mental health or intensive psychotherapeutic services subsumed under an EI service. However, these latter services could usefully adopt an early intervention model if adequately resourced to do so.

Negative assessments were delivered of some supported accommodation providers (but once again, our study was very small and may not have been representative of experiences of this kind of service). They were sometimes unsafe, and people spent their days without anything to
do. Also, not much was heard from participants about specialised employment support, although nearly all articulated educational and career goals. Certainly, some did receive advice about employment from their services, and some were helped to access training programmes, but the specialty appeared to be lacking.

Overall, there are the building blocks in New Zealand for the delivery of good non-acute services, but they must build their philosophies, values and therapeutic options around the needs and preferences of the young adults they serve, and their developmental needs, life stages or life circumstances. Acute services should do the same.

Moreover, good transitions must be provided, where necessary, between child and adolescent services and the services that young adults use. Currently, young adults who have used child and youth services may be subjected to stress at the prospect of transitioning to adult services, which seem to them to be more impersonal, of poorer quality, to disrupt their established relationships with staff and are less likely to meet their needs. These transitions could be eased by ensuring that people who are using child and adolescent services, and have a continuing need, move on to an excellent range of recovery oriented services designed around the needs and preferences of young adults.

Overall, our study showed that services impacted strongly on, and to some extent defined, the experience of mental illness for our participants. In Chapter Seven we focused on recovery stories, using examples from participants who ranged from surviving day to day, to those who were doing well on the recovery journey. They were all, in their own ways, making sense of their own mental health experiences and making sense of what services were trying to do for them, and how they could get the most out of them. Their stories emphasised the key role of services in young adults’ recovery, although other factors, such as support from families, whānau, and friends, as well as their own curiosity, courage and determination, were part of the recovery constellation. Cassandra summed it all up when she spoke about her recovery in terms of “making a life worth living”.

References


Appendix One

INFORMATION FORM

Young Adults Who Experience Mental Illness Project

Please read the following information carefully before you agree to take part in an interview for this study.

1. What would participation in an interview involve?

This would involve talking to an interviewer in a one-to-one situation (or with your whānau, friend or support person present if you wish). The interview will be carried out by a member of the research team. You will know who the interviewer is before the interview and you will have talked to them about plans for the interview. The research team is separate from any mental health services you may have been to. You will not be identified as having participated in the research.

2. How will I know what to do?

If you decide to participate in the study, the interviewer will contact you to talk about details of the interview. Before the interview you can ask any questions that you have. Then a time and place will be arranged to do the interview. The interview will be recorded. You do not have to answer questions that you don’t want to talk about and you can leave at any time.

3. Where will the interview take place and how long will it be?

You can decide where you want the interview to take place. The interviewer can come to your home, a community centre, or another place that you feel comfortable. The place needs to be somewhere quiet so the interview is recorded clearly. The interview will take 1-2 hours depending on how much you want to say. After the interview there will be time to talk about how the interview went, how you’re feeling, and any comments you have.

4. Will anyone know that I participated in an interview and will I be identified in the research report?

No. You will not be identified in any way. Only the research team will know that you participated in the study. They are not allowed talk to anyone else about your participation in the study.

5. Can I bring someone else to the interview with me?

Yes. You can bring along anyone you choose who you are comfortable with. It is important that you feel you can talk openly about your experiences.
6. **What if I decide I don’t want to be involved in the project?**

   Your involvement in the project is entirely up to you. You can withdraw at any time before the research is written up and this will have nothing to do with your future healthcare. If you decide to withdraw from the project just let one of the research team know. You do not have to explain why you are withdrawing from the project.

7. **How will I find out about the results of the study?**

   The interviewer will ask you if you would like to receive a copy of the full research report or a summary report and this will be noted on your consent form. We expect to have the reports completed by the end of 2005.

8. **What recognition will I receive for my time and involvement?**

   The interviewer will give you a $30 voucher which you can use at a garage or a grocery shop or a music store. If you need to travel to the interview your costs will be covered. The interviewer will talk to you about travel arrangements before the interview.

9. **Who should I contact if I have any further questions?**

   You can phone or email one of the core research team members who work at the Mental Health Commission if you have any questions or concerns about this project.

   The research team includes the interviewers, transcriber/s and a research assistant. Maori and Pacific interviewers will be employed to undertake interviews with Maori and Pacific young adults. If you want to find out more about the research please contact:

   Hilary Lapsley   Heather Barnett   Hineroa Hakiaha
   hlapsley@mhc.govt.nz   hbarnett@mhc.govt.nz   hhakiaha@mhc.govt.nz

   Phone one of us at the Commission (04) 474-8900 or FREEPHONE 0800 [TBA]

**Keeping Safe**

We are aware that talking about past experiences may be upsetting. We have planned time at the end of the interview to talk about how you’re feeling and to see that you’re okay. When you leave the interview it is likely that you will think about the project. However, if you feel upset and want to talk to someone about your experiences we can arrange for you to see someone from a mental health service. We can also explain the research project to them if you want us to. However, we would only do this if you agreed to it. Please remember that you are welcome to being a support person to the interview if you want to.

If you would like advice on your rights as a participant in this study you can approach the Health and Disability Consumer Advocates on 0800 377-766.

**THANK YOU**
Appendix Two

PARTICIPANT CONSENT FORM

Young Adults Who Experience Mental Illness Project

I have read and understand the information provided in the Information Form for participants taking part in the Young Adults Who Experience Mental Illness research project. I have had the opportunity to discuss the research with my interviewer or someone from the core research team. I have also had the opportunity for my whānau/family, or a friend or support person to assist me in asking questions about the research. I am satisfied with the answers I have been given and I understand what is required of me.

I understand that taking part in this research is entirely up to me and that I can withdraw from the research up until the report is published. I also understand that my participation in this research is confidential and that no information that could personally identify me will be used in any reports arising from this research. My details and interview information will be stored in a locked cabinet. I have had enough time to consider whether to take part in the research. I understand that I may withdraw from the study at any time up until the research is published, and that if I withdraw, my future health care will not be affected in any way.

I understand that I will be compensated for taking part in this research by being given a $30 voucher. My travel expenses will also be paid for by the Mental Health Commission following discussion about this with the interviewer. I know who to contact if I have any further questions about this research.

Please read the following section carefully and circle YES or NO to indicate your response. Then SIGN your name in the space provided.

1. I agree to participate in a research interview. I have read the Information Form and understand the procedures involved. YES  NO
2. I give permission for my interview to be recorded and transcribed (typed up). I understand that parts of the interview may be used for publication purposes but all personally identifying information will be removed. YES  NO
3. I would like to receive a copy of the full report YES  NO
4. I would like to receive a copy of a summary of the research YES  NO

I _______________________________ (your full name) hereby consent to take part in an interview for the Young Adults Who Experience Mental Illness research project.

Date:     Your Signature:

Project Explained by:  

Date:     Signature:
The Research Team includes:

Hilary Lapsley
Heather Barnett
Hineroa Hakiaha
Tess Moeke-Maxwell
Nancy Sheehan

Hilary, Heather or Hineroa can be contacted at any time during working hours (9am to 5pm) on FREE PHONE 0800 55 66 44.

If we are unavailable, leave a message and one of the research team will call you back as soon as possible.

If you would like advice about your rights as a participant in this research you may contact the Health and Disability Consumer Advocates on 0800 377-766 or the Health Advocate’s Trust on 0800 555-050.
INTERVIEW THEMES

Young Adults Who Experience Mental Illness Project

In the interviews we want hear your story about the mental illness or mental health problem you’ve experienced. Although we aim to cover three broad themes there is no set format. The themes include:

a) your experience of mental illness/mental health problems and life circumstances  
b) your first adult experience of mental health services  
c) your views about what helps, or makes it difficult, to get your life back on track.

These topics overlap so you can start wherever you like. There are no right or wrong answers. You do not have to answer questions that you do not want to talk about. We want to hear your story as a young adult who has experienced a mental health problem and used mental health services for the first time.

Interview Themes

Section A:  
Your experience of mental illness/mental health problem and life circumstances

This section is about what your life was like at the time you started experiencing mental health difficulties and first came into contact with mental health services. We are interested in exploring your ideas about what was happening in your life, what changes occurred, why you think the mental health problem came about and how it affected your life.

Talking about your life might also include things like: where and who you were living with; your social relationships; whether you have any children; use of drugs and substances; what work, education or activity you were doing at the time; what your physical health was like; and how you were supporting yourself.

You might also want to talk about issues relating to your childhood or youth that you think contributed to the mental health problem, and whether you had any mental health difficulties or had contact with helping agencies when you were younger.

This section might also include things relating to wider society such as racism, sexual harassment or being harassed for being lesbian or gay which might have contributed to the mental health problem.
Section B:
Your experience of mental health services

This section is about your experience of the mental health services that you came into contact with. We are interested in hearing about what help you or others tried to get when you first experienced mental health problems, how long it took to get help from services, and whether you were refused help because of alcohol or drug problems.

Talking about mental health services might also include things like: what services and treatments you were offered; whether you were offered talking therapies; what worked for you; whether things improved once you got help from mental health services; what you think about the care you got and anything you would have liked done differently.

You might also want to talk about how you were treated by the staff in mental health services including things like staff knowledge, attitudes and interactions with you and/or your family or support people.

We are also interested in what your experiences of medication were like such as whether you think medication helped or made things worse; what information you were given about medication; whether you were you informed about possible side effects of medication; whether you were you given an option about taking medication; and whether your medication and dosage were monitored and followed-up over time.

You might also talk about any diagnoses that you were given, how it felt to have a diagnosis and what impact that has had on your life.

It would also be helpful if you could tell us whether you’ve had compulsory treatment or been under the Mental Health Act. We are interested in hearing about anything that has happened against your will, whether you’ve ever been pressured into having treatment you didn’t want, how you feel about that, whether you think it was necessary and what you think could have happened differently?

Section C:
What helps or makes it difficult to get your life back on track?

This section is about what has helped you make progress from when things were worst. You might want to talk about issues relating to your friends and/or family, experiences you’ve had with staff and mental health services that helped; contact you’ve had with other young adults who’ve had similar experiences; peer support; issues relating to housing and work; spirituality; and community involvement or anything else that helped.

We are interested in hearing about cultural factors that helped you get things back on track again.

We would also like to hear about barriers or things that made it difficult to get your life back on track. This could include things relating to staff or the mental health services you had contact with such as gaining access, being treated with respect, confidentially or privacy, feeling understood, being informed, staff knowledge and interactions, follow-up, moving between services or anything else you think made it difficult for you.
The barriers theme also relates to your wider life and may include issues relating to family or friends; culture; access to and conditions of employment, education or training; having an adequate income; affordable housing and healthcare; having a place for time out; getting support to parent children and issues relating to custody or access to children; and other things like discrimination or stigma.

We are also interested in hearing what you and other young adults’ do that helps improve how you feel and whether your own self-help approaches are supported by services and others involved in your recovery.

You might also want to talk about any good things or new opportunities that have come about as a result of experiencing mental health difficulties or using mental health services.

Finally, we are interested in how are things going for you now, whether you have any fears and what hopes you have for the future.

*Please remember that you don’t have to talk about all of these things, or anything that you’re not comfortable with, and you can leave the interview at any time.*

Thank you for showing an interest in the research.
Appendix Four

Research Criteria and Instructions for the Identification of Participants

Age limit 18-29 years

First experience of disabling mental health problem or mental health crisis

First use of publicly funded mental health services as an adult

The young adult may have come into contact with a mental health service any time in the last five years

The young adult must have been in contact with mental health services for at least three months and be well enough to engage in an interview

Include young adults with varying lengths of time in contact with services – i.e those with only a short period of contact as well as those with longer and ongoing contact with services

Include those for whom the mental health system worked well and those for whom it has not worked so well

Exclude those who have a long and continuous history of contact with mental health services (i.e over five years)
Appendix Five

BROCHURE DESCRIBING PROJECT

Greetings, Kia Ora
Talofa Lava, Kia Orana,
Taloha Ni,
Ni sa bula vanaka,
Malo e lelei

If you want to find out more about the project or would like to participate in an interview please contact one of us at the Mental Health Commission.

Work Phone: (04) 474 8900 or
Heather. Rim Ph: (04) 476 6039 or
Fax: 0800 55 66 44
Email: Hilary.Lapley@mh unhealthy or
Heather Barnett
hbarnett@mh unhealthy or
Hineana Hakaha
hhakaha@mh unhealthy

The research will include:

Young women and men from diverse backgrounds, mental health experiences and ethnic groups

People who have had their first experience of mental illness or mental health crisis as an adult

People who in the past five years have used publicly funded mental health services for the first time as an adult

WHICH MENTAL HEALTH SERVICES

Early intervention, community, maternal, forensic, impatient, kia ora or mental health, and Pacific Mental Health Services

WHERE

Wellington, Auckland, Whakatane

WHEN

Interviews will occur early in 2005

KEY INTERVIEW QUESTIONS

- what was your first experience of mental illness or mental health crisis as an adult like and what was happening in your life at that time?
- what was your first experience of adult mental health services like?
- what do you think helps you get your life on track again or makes this difficult?

WHAT’S INVOLVED

A one-to-one interview of 1-2 hours, digitally recorded, transcribed, and any identifying information removed; you can bring a friend or support person to the interview.
## Glossary of Māori Terms Used In This Report

<table>
<thead>
<tr>
<th>Term</th>
<th>Meaning</th>
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<tbody>
<tr>
<td>iwi</td>
<td>tribal grouping</td>
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<tr>
<td>kai</td>
<td>food</td>
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<tr>
<td>Kaiawhina</td>
<td>helper</td>
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<td>kapa haka</td>
<td>traditional lore</td>
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<tr>
<td>karakia</td>
<td>prayer</td>
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<tr>
<td>kaupapa Māori</td>
<td>Māori philosophy</td>
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<tr>
<td>koroua</td>
<td>male elder</td>
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<td>matakite</td>
<td>second sight</td>
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<td>mirimiri</td>
<td>massage</td>
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<tr>
<td>rongoa</td>
<td>herbal or healing remedy</td>
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<td>tangata whaiora</td>
<td>mental health service users</td>
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<tr>
<td>te reo</td>
<td>Māori language</td>
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<td>tikanga Māori</td>
<td>Māori customs</td>
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<td>tohunga</td>
<td>healer, specialist</td>
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<td>waiata</td>
<td>song</td>
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<td>whānau</td>
<td>extended family</td>
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