# Māori experiences of bipolar disorder: Pathways to recovery



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#### He maimai aroha

One of the participants, Antonio, passed away during the data collection period. Members of the Māori and Psychology Research Unit drove up north to attend his tangihanga (funeral). The night before Antonio was buried his family and friends sang songs, delivered eloquent speeches, played the guitar and recited poetry to him. Antonio was surrounded by family, friends and, importantly, his children and mokopuna – something he would have been happy to know – Hoki atu rā e te tama a Hine-nui-te-pō ki ōna ringaringa awhiawhi, ki ōna ringa ūkaipō.



## Pua

One of the wāhine who participated in this study – *Zemara Waru Keelan*, referred to as *Pua* in this report, was kind enough to have her art work presented/illustrated in this booklet. The beautiful creations below reflect an important aspect of Pua' journey towards recovery.

"I wish no shame or stigma for the mental health community that I have become a part of. So I share my story like a badge of pride" – Zemara Waru-Keelan".



"In the year I was diagnosed I made a hieke, like a rain cape out of corn husk, and I dyed them all black, called one **Te Pango** o te Pō because I was in that kind of state.

And then the year after that I made a contemporary korowai out of rainbow emu feathers all different colours, and I called that **Te Uenuku Harikoa**. Quite a bit of a transition, through that process I did heal, creating things" – Pua/Zemara



# **Executive summary**

The findings of this research highlighted pathways into mental illness for Maori that could have been avoided earlier. The pathways to recovery however, showed the critical importance of maintaining connections with significant family members over the lifespan. Exposure to varying levels of childhood adversity, such as sexual and physical violence, parental mental illness, multiple and/or abusive foster care, and abandonment issues led to acute levels of post-traumatic stress, substance abuse, poor relationship choices, depression, anxiety and safety issues.

More often, whānau pointed to adolescence as a difficult period where anxiety, depression and substance abuse dominated. Of note is that females tended to have had multiple diagnoses ranging from depression, anxiety, substance abuse, personality and eating disorders and postnatal depression. Male whānau described co-existing diagnoses of anxiety and depression, substance abuse and addiction disorders. The narratives showed clearly that some whānau did not seek help until they were in serious need or that some sought help early and were treated for other conditions.

In relation to mental health diagnosis, all whānau had been diagnosed with bipolar affective disorder at some point in their lives. The narratives collected from each whānau¹ revealed chronic levels of unmet need that began (for some) in childhood, adolescence and, for others, in early adulthood. What is relevant is that some whānau had mental health issues that were unresolved for much of their lives. The level of unmet need created a cycle of health disparity, placing whānau at a significant disadvantage resulting in a loss of productivity and lost potential. Moreover, that need crept into the senior years, as whānau became primary caregivers to their grandchildren or were disconnected from their children and grandchildren.

Across the study whānau experienced unstable and inadequate living conditions, poverty, low education and difficulties in attaining and maintaining employment. Gender issues were a particular concern as female whānau were often powerless in their intimate relationships and during pregnancy and childbirth. Women lived in fear of losing their children, had their children taken from them, or were told not to have children. Each of those women described a deep sense of loss or trauma about not being able to raise their children. Several male whānau, who were fathers or single-fathers, were equally concerned about losing their children and that they were not able to provide for their families, which challenged their notions of being a husband, partner and father. The consequences of losing a child, or being the child who was removed, signifies a serious gap in support systems for parents with mental illness.

The level of unmet need for many whānau created a landscape of hardship and adversity that was barely tolerable. Whānau became unwell when their right to self-determination was compromised in any way or when their support systems were fragmented. At times, due to the

<sup>&</sup>lt;sup>1</sup> The term whānau has been used instead of participant. See the Methodology on p 27 for more information.



repeated and severe nature of multiple stressors, whānau reached breaking point, causing them to react. In many cases, those reactions were used to confirm the presence of bipolar disorder, which shifted the focus from external factors to biological causes. Medication was the primary treatment choice for all whānau—and all three whānau saw a psychologist.

The journey towards recovery for whānau emphasised the pivotal role played by family and social supports. Opportunities to live balanced lives, engage in leisurely pursuits and enjoy social connections were identified as protective elements. When whānau were in healthy relationships and connected to significant family members, they were better equipped to incorporate wellness strategies into their lives. Conversely, unhealthy relationships and disconnection from family contributed to illness, exacerbated stress levels and prevented whānau from seeking wellness.

The overall finding from this research clearly points to the urgency to provide additional support to strengthen families throughout their developmental lifespan. Whānau Ora has emerged as a unifying concept that encompasses Māori aspirations of good mental health as being rooted in cultural identity (Mental Health Commission, 2007). Recognising the significance of whānau as agents for change and a catalyst for Māori development has been at the heart of Māori paradigms of wellbeing for many decades (Mental Health Commission, 2007). While whānau configurations and dynamics may differ, whānau as a fundamental construct in Māori society remains the same. Prioritising collective wellbeing for whānau, in the many ways it manifests, provides an environment where security, connection, support, belonging and identity can be nurtured (Irwin et al., 2011).

When external and internal factors to achieving wellness were optimal, whānau were more productive in their lives which included reconnecting with, and enjoying their family and personal relationships. The external factors that contributed to and maintained wellness for whānau were: treatment of co-existing mental illness, correct diagnoses, access to stable and appropriate medication, prevention and early intervention, and timely and detailed mental health information.

A trauma-focused approach to assessment and treatment could have made a difference for the whānau and their families. Furthermore, recovery strategies could have included access to talking therapies and kaupapa Māori services. In particular access to Māori-led and culturally appropriate services and supports provided the best outcomes for whānau.

Recovery strategies require collaborative responses from the whole health sector, the broader social, education and justice sectors, as well as the mental health and addiction sector. Improving access to and the effectiveness of all services for Māori is a priority, and a competent mental health and addiction workforce is critical to achieving that goal. Of importance is that all policy directives emphasise the importance of whānau receiving timely, high quality, effective and culturally appropriate services.



## Recommendations

#### **Cross-sector**

- 1. The primary and secondary health sector, the broader social, education and justice sectors, Child, Youth and Family, mental health and addiction sector and Work and Income New Zealand provide collaborative responses to whānau.
- 2. These collaborative responses seek to address unmet need related to child protection, suicide risk, adequate housing, adequate nutrition, employment, family violence, and drug and alcohol addictions.
- 3. Services supporting senior whānau to live well with healthy families are provided.

#### Mental health and addiction sector

- 4. Consider that bipolar disorder may be symptomatic of chronic co-existing or underlying mental health concerns and that the implications for whānau and their families may be extensive.
- 5. Provide training to highlight the role of co-existing disorders and unmet need from a broad systemic perspective to inform assessment and treatment options.
- 6. Provide Māori with access to parental mental health services that operate from a kaupapa Māori and Whānau Ora worldview, taking into account the roles of fathers, extended families and grandparents.
- 7. Deliver psychological and occupational therapies in combination with medication.
- 8. Closely monitor and record medication use to identify unmanageable side-effects and note medication spikes as related to medication not a mental illness.

#### Policies to address inequalities

- 9. Recognise that poverty, inadequate housing, low levels of education and unemployment place whānau at greater risk of developing mental health and addiction issues.
- 10. Address these social determinants of mental health.
- 11. Provide financial support and rental assistance when whānau are unable to pay rent due to frequent hospitalisation or job loss.

#### Resource development

- 12. Develop online or app-based resources for adolescents that describe mental health, relationship and substance issues, and provide options for accessing help.
- 13. Develop resource packs to provide a range of culturally relevant causal theories and assessment and treatment options. Support the workforce to discuss these as best practice.

#### Further research

- 14. Collect primary care and NGO service user information by improving PRIMHD, the Ministry of Health database.
- 15. Conduct further research with whānau and their families to address intergenerational experiences of unmet needs.



## Introduction

...I had all of these terrible things happen in my childhood. It would have been a miracle if I hadn't ended up with bipolar or a mental illness (*Niwareka*).

The comment above reflects a feature of bipolar affective disorder where it is not always known whether situations within a person's life act as triggers to an existing biological vulnerability or whether the symptoms are normal reactions to intensely distressing life events. In either case there is a clear need to provide appropriate and timely supports to ensure that Māori live in ways defined as important to them. Within the mental health system, Māori experience significant and unnecessary disparities in outcome compared to non-Māori. Since 2006 diagnoses of mental health disorders for Māori have increased (Māuri Ora Associates, 2006; Ministry of Health, 2012; Waikato District Health Board, 2008).

There are significant inequalities among the various ethnic groups in New Zealand, particularly for those who come from lower socio-economic groups. Māori feature disproportionately across all health statistics and experience the highest rates of health disorders among ethnic groups in New Zealand (Baxter, 2008; Māuri Ora Associates, 2006; Neilson-Hornblow, 2009; Oakley Browne, Wells, & Scott, 2006). Baxter (2008) concluded that significant unmet mental health needs exist among Māori, reflecting differences in: access at a primary care level, diagnostic practices and referral to secondary care. Bipolar disorder is a mood-related disorder that produces extreme contrasts in mood and in functioning (Urosevic, Abramson, Harmon-Jones, & Alloy, 2008). People with bipolar disorder are known to experience elevated levels of life stress even during asymptomatic periods while individuals who live with significant, negative life events relapse faster and take longer to recover from bipolar episodes than those without such events (Jones & Tarrier, 2005). While Māori are known to experience a higher burden of mental health and addiction problems compared to non-Māori (Baxter, 2008), little exploratory research has been conducted into Māori experiences of bipolar affective disorder.

The aim of this research was to gather information about the experiences of Māori who were diagnosed with bipolar affective disorder. In particular this research aimed to contribute to the realisation of Māori potential by explicitly shifting from deficit-focussed frameworks to a focus on systemic factors that influenced Māori wellbeing.

## Purpose and objectives

- 1. To explore trends in the rates of Māori with bipolar affective disorder accessing primary and secondary mental health services.
- 2. To explore and gain a better understanding of the experiences of Māori living with bipolar affective disorder.
- 3. To identify the priorities, issues and information gaps in Māori experiences.
- 4. To make recommendations to improve support and service delivery for Māori with bipolar disorder.



## Literature Review

#### Conceptual framework

This research seeks to add value to outcomes for Māori and contribute to the realisation of Māori potential by explicitly utilising a conceptual framework that rejects deficit theorising about Māori mental health. In doing so the shift takes into account the need to address systemic barriers that occur for Māori, their whānau and their communities, and the need to develop solutions acceptable to Māori (Bishop, Berryman, Tiakiwai, & Richardson, 2003).

Deficit-based frameworks or the problem-focused approach tends to individualise issues, with risk factors conceptualised or pathologised in terms of the individual and/or family deficiencies and dysfunction, resulting in increased susceptibility to poor outcomes (Bishop et al., 2003) and the proliferation of separate, problem-specific intervention programmes. The construction of issues and problems in a particular way heavily influences the type of responses considered appropriate and overlooks the inter-relations and connections between factors associated with mental health outcomes (Ball, 2010; Guerra & Bradshaw, 2008).

A value-added approach seeks to understand Māori experiences of bipolar disorder beyond positioning individual or environmental deficits as primary causes of poor outcomes and disparities. Such an approach privileges the rights of Māori to determine their pathways to optimal wellbeing and includes recognition that individual health and wellbeing is determined within a whānau context.

The Whānau Ora model is also used as a framework from which to conceptualise positive pathways for Māori who have a diagnosis of bipolar disorder. The framework is particularly relevant as it considers the interrelated needs of all whānau members and does not focus solely on diagnosis or treatment in isolation from the wider whānau, community, social, political and medico-legal context of Māori lives.

## Whānau Ora

Health and disability sectors are charged with recognising that health and wellbeing are influenced and affected by the 'collective' as well as the individual and need to recognise the vital importance of working with people in their social contexts, not just with their physical symptoms (Ministry of Health, 2002). Holistic Māori models and approaches to wellness are affirmed and supported, as are the aspirations of Māori to seek our own solutions and to manage our own services (Ministry of Health, 2002). The Mental Health Commission (2007) emphasises that a holistic approach to mental health service provision means mental health providers will not be concerned with mental health needs in isolation, but with all needs fundamental to wellbeing.



The Government's expectation for Māori health development is Whānau Ora, in which Māori families are supported to achieve their maximum health and wellbeing (Ministry of Health, 2002). The Mental Health Commission (2001) identified that recovery and Whānau Ora constituted a robust base for describing aspirations in mental health and assessing progress made to achieve them. However, they also emphasise that attempting to understand Māori concepts of recovery on the basis of Eurocentric cultural concepts will inevitably lead to a limited understanding and incorrect application of the concept of Whānau Ora.

The Mental Health Assessment and Outcomes Initiative (MH-Smart) Tāngata Whaiora Roopu conceptualises recovery as, "recognising the importance of whānau in the process of recovery, diversity of whānau, contributors to whānau breakdown and the importance of rebuilding whānau" (MH-SMART Tāngata Motuhake/Whaiora Roopu, 2005, p. 1). A principal source of connection, strength, support, security and identity, whānau comprising kuia, koroua, pakeke, rangatahi and tamariki play a central role in the wellbeing of Māori individually and collectively (Ministry of Health, 2002). Although underpinned by a philosophy of collective wellbeing, Whānau Ora explicitly recognises and encompasses the diverse needs of all population groups: pēpi, tamariki, taiohi, mātua and kaumātua.

#### The outcomes sought for whanau include:

- whānau experience physical, spiritual, mental and emotional health and have control over their own destinies
- whānau members live longer and enjoy a better quality of life
- whānau members (including those with disabilities) participate in te ao Māori and wider New Zealand society (Ministry of Health, 2002, p. 1).

#### These outcomes are more likely when whānau:

- are cohesive, nurturing and safe
- are able to give and receive support
- have a secure identity, high self-esteem, confidence and pride
- have the necessary physical, social and economic means to participate fully to provide for their own needs
- live, work, and play in safe and supportive environments (Ministry of Health, 2002, p. 1).

With these views in mind, understanding Māori experiences of bipolar disorder requires recognition of the multiple intersecting pathways into unwellness and recovery. Although conceptualised as an individual process focused primarily on the attainment of individual autonomy, recovery for Māori must be conceptualised within the broader context of Whānau Ora, with an emphasis on inclusiveness, collectiveness and interdependence.

Recovery is not conceptualised as an individualistic process, focused solely on the attainment of individual autonomy. This context recognises that pathways to wellbeing need to be focused on building whānau capacity (MH-SMART Tāngata Motuhake/Whaiora Roopu, 2005, p.1).



The journey of recovery for tangata whaiora is encompassed within the recovery of rangatiratanga or empowerment inclusive of whanau, hapu and iwi. Within this conceptualisation of recovery, an important challenge is to respond to the diversity that characterises what it is to be Maori. Whether this diversity relates to socioeconomic circumstances, cultural affiliation or differential access to te ao Maori, no two Maori journeys will be the same and as such, accommodations need to be made.

#### Policy context of mental health for Māori

In the past 15 years national mental health policy goals for increased Māori participation and improved responsiveness of mental health and addiction services have remained consistent (Mental Health Commission, 2007). With this focus on the responsiveness of services, a broadening of the range, quality and choice across mental health (and addiction) services for Māori is evident. However, improving the system of healthcare requires deep knowledge of the lived experiences of the people within, or outside, that system (Torrey, Rapp, Van Tosh, McNabb, & Ralph, 2005). Māori, in particular, experience significant and unnecessary disparities of outcome in relation to mental health issues (Oakley Browne, Wells, & Scott, 2006).

Te Puāwaitanga: Māori mental health national strategic framework (Ministry of Health, 2002b) emphasised the effectiveness of solutions that reflect Māori cultural contexts, priorities and realities, and build the capacity of Māori service providers. Te Tāhuhu: improving mental health 2005-2015: the second New Zealand mental health and addiction plan (Ministry of Health, 2005) positions Māori mental health policy within the context of aspirations for Whānau Ora; recognising the strong link between health and culture and that the wellness of tāngata whaiora both depends on, and is affected by, the wellness of whānau.

Te Tāhuhu and Te Puāwaiwhero acknowledge that improving Māori mental health and reducing inequalities cannot be achieved by health services alone, with social and economic factors such as employment, housing and poverty all impacting on mental health, wellbeing and recovery (Cram, 2011a; Durie, 1999; Kingi, 2011). Tangible mental health for Māori requires access to te reo Māori, land and marae, and ready access to primary health care, education, housing and employment opportunities (Ministry of Health, 2005).

Explicit recognition of the complex interrelationship between mental and physical health and the wider determinants of health is evident in current policy directions. Attention is directed to a person's social and cultural context, with a focus on how history can shape and influence mental health outcomes. Also recognised is that inequity in access to health services across the life-span prevents the full realisation of wellbeing for Māori (Mental Health Commission, 2012). The life-span approach requires responses from not only the health sector but also broader social, justice and education sectors (Mental Health Commission, 2004).

The Mental Health Commission (2012) takes a 'life course' approach based on the premise that early responses are critical and opportunities to make a real difference exist through early intervention. This ensures people can access the right services when they need them via



interventions undertaken in the least intensive way to achieve the best possible outcomes. The relevance of including a focus on policy documents within this study is apparent as Māori experiences of bipolar disorder highlighted multiple opportunities for implementing strategies that could alleviate disparities for Māori and aid their pathways to recovery.

The presence of mental illness is largely associated with disruptive life situations, thus impeding on an individual's ability to live well, and affecting social relationships (McGorry, 2005; Ramon, Healy, & Renouf, 2007), working life and physical health (Adrian & Hammen, 1993; Ministry of Social Development, 2010). Of importance is that all policy directives emphasise the importance of whānau receiving timely, high quality, effective and culturally appropriate services. Improving access to and the effectiveness of all services for Māori is a priority, and a competent mental health and addiction workforce is a goal. The focus on non-Māori responsiveness and competency when working with Māori is not new.

Baxter (2008) collated and reviewed research into Māori mental health providing a comprehensive evidence base in which Māori mental health needs can be established and addressed. Baxter's (2008) findings concluded that Māori are 1.7 times more likely to develop a mental disorder compared with non-Māori, and also predicted that three in five Māori are likely to experience a mental illness at some point in their lifetime. Furthermore, her findings raised concerns for mental illness in Māori between the ages of 15-35, with this group holding the highest prevalence rates in New Zealand. Young Māori males were also featured as presenting with the highest rates of youth suicide. Baxter's findings highlight a serious concern as suicide risk in the bipolar population is well documented (Beautrais & Fergusson, 2006).

Additional barriers to Māori accessing mental health services are that entry criteria are often restrictive and Māori have limited choice about psychological intervention or medication. Other research shows that Māori are more likely to have prior psychiatric inpatient treatment than non-Māori and are more likely to experience misdiagnosis and multiple diagnoses, have poorer prognosis and have limited knowledge about the mental health diagnosis (Durie, 1999; Dyall et al., 1999; Ferguson, Collings, Blakely, & Allan, 2005; Ministry of Social Development, 2009).

## Mental health for Māori

Māori, the indigenous people of New Zealand, make up approximately 15 per cent of the total population (Māuri Ora Associates, 2006; Statistics NZ, 2013b). Mental disorder is common in New Zealand with 46.6 per cent of the population predicted to meet criteria for a disorder at some time in their lives; 39.5 per cent having already done so and 20.7 per cent having a disorder in the past 12 months (K. Scott et al., 2006). Despite service improvements over the past 10-15 years, Māori still tend to access mental health services at a later stage of illness with more severe symptoms (Ministry of Health, 2005; Ministry of Health, 2012).

Research conducted from 1990-2007 shows an alarming trend of unmet mental health need for Māori; Māori admission and readmission rates to hospital for psychiatric and alcohol-related



problems were higher than non-Māori and non-voluntary admissions for Māori were double those for non-Māori (Dyall et al., 1999; Gaines, Buckingham, Eagar, Burgess, & Green, 2003; Johnstone & Read, 2000; Wheeler, Robinson, & Robinson, 2005). Māori were also more likely to have court-ordered treatment, to be incarcerated and to have co-existing mental health and addiction needs.

Co-existing substance use typically impacts on assessment and treatment and may precipitate psychiatric disorders (Beautrais & Fergusson, 2006). Suicide risk is also higher for Māori compared to non-Māori, particular in the age range of 15-24 (Beautrais & Fergusson, 2006; Ministry of Health, 2006). Suicide studies show that age, childhood adversity, personality characteristics and biological, social, cultural and inequalities, act to determine individual vulnerability to suicidal behaviours. However, the major risk factors for suicide are mental disorders, stressful life events and substance abuse (Beautrais & Fergusson, 2006; Blakely, Collings, & Atkinson, 2003).

As stated earlier, the multiple influences on health status also include knowledge of the social and economic realities of Māori. Studies show that low educational levels and socio-economic issues related to unemployment and literacy levels, poor housing conditions and lower physical health were also more prevalent among Māori (Baxter, Kingi, Tapsell, Durie, & McGee, 2006; Ihimaera, 2007; Mancall, Robertson, & Huriwai, 2000; Milne, 2001). Housing issues such as loss of accommodation during acute illness or hospitalisation affect between 10 and 20 per cent of tāngata whaiora (Peace & Kell, 2001).

The implication of housing displacement and lack of housing stability impacts on whānau health and can disrupt social networks. Consistent with other authors (Ball, 2010; Cunningham, 2011; Gluckman, Low, & Franko, 2011), Baxter (2008) suggests that findings regarding significant unmet mental health needs among Māori may reflect differences in patterns of access to services at a primary care level, diagnostic practices and/or referral practices to secondary care.

Māori with mental health needs were more likely to access general medical services (primarily general practices), highlighting the central importance of primary health care as a source of assistance (Baxter, 2008). However, services are under pressure to engage in gate-keeping or prioritisation processes which include discouragement of primary sector referrals and the maintenance of a narrow focus on those with psychotic disorders (Mental Health Commission, 2007).

There are significant inequalities among the various ethnic groups in New Zealand, particularly for those who come from lower socio-economic groups. Key findings from the New Zealand Health Survey (Ministry of Health, 2012) identified diagnoses of mental disorders for Māori have increased from 12 per cent in 2006/07 to 16 per cent in 2011/12, and approximately 20 per cent of all Māori admissions are drug and alcohol related (Māuri Ora Associates, 2006). The Waikato District Health Board documented that between 2000-2006 a total of 1,568 people were



hospitalised due to an episode of bipolar disorder, of these 31 per cent were Māori (Baxter, 2008).

Studies relevant to this research are *Te Rau Hinengaro: the New Zealand mental health survey* (Oakley Browne et al., 2006) which included 12,992 people aged 16 and older living in permanent private dwellings throughout New Zealand and *Te Rau Matatini mental health needs profile* by Baxter (2008). The Te Rau Matatini study gathered together and analysed quantitative data relevant to Māori mental health and highlighted priorities for attention. In light of this study we now need to better understand how Māori configure the experience of bipolar disorder in their lives and how they navigate mental health services to receive appropriate support to continue as active and well members of their communities and whānau.

#### Key findings about Māori from Te Rau Hinengaro:

- Mood disorders were common among Māori: 24.3 per cent (one in four) had experienced a mood disorder. The most common lifetime mood disorders in Māori were major depressive disorder (15.7 per cent) followed by bipolar disorder (8.3 per cent) (p.152).
- In the 12 months before the interview 11.4 per cent (more than one in 10) of Māori experienced a mood disorder, with major depressive disorder the most common (6.9 per cent). Bipolar disorder was also present in 4.6 per cent of Māori.
- In contrast to other groups surveyed, the prevalence of bipolar disorder was higher than that of other groups (Māori, 3.4 per cent; Pacific people, 2.7 per cent; others, 1.9 per cent) (p.210).
- Three out of five Māori (56.9 per cent) with a mood disorder had no contact with a service provider; one in two Māori (48 per cent) with a serious disorder had no contact with any service, and Māori with substance use disorders had the least contact with services.

Māori rates of depression and anxiety were found to be so high that Baxter recommended they be emphasised as key priority areas. Higher rates of social and material disadvantage do not explain all differences in the rates of diagnosed mental disorder for Māori, with a series of systemic factors related to ethnicity contributing to differences in diagnoses and experiences of care (Tapsell & Mellsop, 2007; The MaGPIe Research Group, 2005).

The health status of Māori has become a priority health concern for New Zealand (Baxter, 2008; Oakley Browne et al., 2006; Tapsell & Mellsop, 2007). Understanding the way in which Māori present and the significance of that for clinical assessment and care is critical, not only in relation to the contributions of specific cultural variables, but also in relation to the validity of standard Western approaches to diagnosis and classification for Māori. The issue of how mental health clinicians interpret psychiatric phenomena was identified as being particularly relevant when diagnosing mood and psychotic disorder for Māori (Taitimu, 2008; Tapsell & Mellsop, 2007; Wharewera-Mika, 2012). Since *Te Rau Hinengaro* (Oakley Browne, et al., 2006), a review of the literature suggests there have been no significant qualitative explorations of the experience of



Māori people living with mental health issues or their experience of mental health service provision.

## Bipolar disorder

One of the purposes of this study was to identify why Māori have high rates of bipolar disorder, therefore a full description of bipolar disorder and the subtypes is warranted. In considering the characteristics of bipolar disorder the presenting features overlap markedly in disorders such as substance abuse, anxiety, depression, schizophrenia, personality disorders and trauma. Bipolar onset tends to occur around 19-21 years of age, when individuals seek independence (Jones & Tarrier, 2005). Early-age of onset (prior to age 17) is associated with a more severe course and poorer outcomes (Waikato District Health Board, 2008).

Bipolar disorder is a mood-related disorder producing extreme contrasts both in mood (hypomanic/manic euphoria and irritability vs. depression) and in functioning (Urosevic et al., 2008). The disorder impacts on emotional regulation producing affective highs and lows with some states combining feelings of mania, depression and other moods or emotions concurrently (Gruber, Eidelman, Johnson, Smith, & Harvey, 2011; Power, 2005). The description of bipolar disorder has changed with the new *Diagnostic and statistical manual of mental disorders 5* (*DSM-V*) released by the American Psychiatric Association in 2013 (American Psychiatric Association, 2013). However, this study was conducted prior to 2013 and the previous version of the manual has been used (*DSM-IV*) (American Psychiatric Association, 2000).

Bipolar disorder (also known as manic-depressive illness) is a prevalent, chronic, serious and complex psychiatric disorder that is particularly difficult to treat and is often misdiagnosed or underdiagnosed, often going unseen for many years (Montoya et al., 2010; Royal Australian and New Zealand College of Psychiatrists Clinical Practice Guidelines Team for Bipolar Disorder, 2004). Around two-thirds of individuals diagnosed with bipolar disorder experience delusions which often accounts for misdiagnosis of schizophrenia (Cosgrove & Suppes, 2013). Delusions and grandiosity is also common in substance abuse disorders (Knowles, McCarthy-Jones, & Rowse, 2011). The implication here is that care is needed when whānau present to health services with psychotic or manic features and are also under the influence of substances.

Mania is an intense high where the person feels euphoric, almost indestructible and often leads to extreme over-spending, rash business and personal decision-making, dangerous sexual behaviour, and/or misuse of drugs or alcohol. Decreased sleep accompanied by increased energy, changes in mood and judgment, and impulsivity are also features of mania. The emotional experience of mania while appearing as a 'high' typically consists of dysphoria, anxiety, irritability and emotional liability (Power, 2005, p. 1102). As the high fades, the consequences of the manic activities become apparent leading to relationship difficulties and extreme depression.

Several subtypes of the disorder are recognised.



*Bipolar I* disorder (full-manic episodes) involves disrupted affective functioning, including periods of abnormally and persistently elevated mood (ie hypomania/mania). Patients also experience periods of depression.

*Bipolar II* disorder (without full manic episodes) has features of bipolar I with mild hypomania. Bipolar II disorder is distinguishable from bipolar I as it has recurrent episodes of depression and hypomania (without ever experiencing a manic or depressive episode). While the symptoms are similar, they are not severe enough to cause marked impairment in social or occupational functioning and typically do not require hospitalisation to assure the safety of the person (Benazzi, 2007). They are, however, sufficiently distinct in terms of chronicity and severity to warrant separate classifications (Baek et al., 2011; Judd, Akiskal et al., 2003).

*Bipolar type schizoid-affective* disorder is seen as a mid-way point disorder between bipolar and schizophrenia and is characterised by recurrent mood changes and periods of schizophrenia-like symptoms such as psychosis and delusions (Cosgrove & Suppes, 2013; Craddock & Sklar, 2013).

Cyclothymia is defined by frequent swings between depressive and manic symptoms that do not develop into full-blown episodes and is often misdiagnosed as borderline personality disorder. Considered by some to be the precursor to bipolar II, cyclothymia has an early-age of onset and features histrionic and passive-aggressive characteristics (Akiskal, Hantouche, & Allilaire, 2003; Perugi, Toni, Travierso, & Akiskal, 2003). The relevance for Māori and, in particular, women is that personality disorders and substance abuse disorders are common in victims of sexual abuse (Brown & Anderson, 1991; Mueser et al., 1998; Spataro, Mullen, Burgess, Wells, & Moss, 2004). Given the impact of sexual abuse in the mental health population, accurate and empathetic assessment is needed at all times.

Bipolar Disorder, Not Otherwise Specified (BD-NOS) is reserved for when symptoms are similar to bipolar disorder but they do not meet the threshold or duration criteria of the other types (American Psychiatric Association, 2000). The Not Otherwise Specified category appears to act as a 'catch-all' which can be problematic when rapid mood changes are also features of adolescence, trauma, personality, anxiety and substance disorders. Martinez and Fristed (2013) argue that BD-NOS is commonly diagnosed in youth, yet as a disorder it is imprecise, unstable and heterogeneous. Once again Māori youth in the under-25-age group are significantly affected as this is the period when they are testing boundaries in their everyday lives, including experimentation with drugs and alcohol, risk-taking and sexual encounters (Cunningham, 2011).

Bipolar disorder also features characteristics of creativity, spirituality, art, empathy, realism, resilience and humour. Indeed artists, poets, writers, musicians and designers are well known in the bipolar population. Researchers argue that clinical and research attention is needed to preserve and enhance those traits to improve outcomes in bipolar disorder (Galvez, Thommi, & Ghaemi, 2011; Murray & Johnson, 2010).



## Co-existing mental health

Bipolar disorder has a very high incidence of co-morbidity. *Te Rau Hinengaro* found Māori have the highest rates of comorbidity in New Zealand even when controlling for age, sex, education and household income (Baxter et al., 2006). Bipolar disorder shares clinical features with major depressive disorder but the episodes of hypomania or mania are distinct. Comorbidity with personality disorder, substance abuse and anxiety disorders has a heightened prevalence in Māori, in contrast to the general population (Freeman, Freeman, & McElroy, 2002; Vieta et al., 2000). An overwhelmingly high incidence of comorbidity has been documented in New Zealand, with those with bipolar being found to have as high as 93.7 per cent prevalence for having another *DSM-IV* diagnosis during their lifetime (Wells, McGee, Scott, & Oakley Browne, 2010).

Research to date indicates the high rate of comorbidity between anxiety, mood and substance use disorders has implications for the way services are managed and delivered (Scott, McGee, Oakley Browne, & Wells, 2006). Furthermore, the importance of accurate assessment and diagnosis is needed to ensure vulnerable individuals, such as the substantially over-represented and under-catered for Māori population, receive the attention they need and are not inappropriately misdiagnosed (Royal Australian and New Zealand College of Psychiatrists Clinical Practice Guidelines Team for Bipolar Disorder, 2004; Wolkenstein, Bruchmüller, Schmid, & Meyer, 2011).

#### Prevalence

Bipolar disorder is more common than previously thought with life-time prevalence estimates (in the United States) of 1.0 per cent for bipolar I, 1.1 per cent for bipolar II and 2.4 per cent for sub-threshold BPD (Nivoli et al., 2012). Subthreshold bipolar disorder is considered to common, significant and undetected in treatment settings (Merikangas et al., 2007). In an international epidemiological study, Soutullo et al. (2005) reported that New Zealand has an estimated 2.4 per cent life-time prevalence of bipolar in adults. Most people experience several episodes (an average of 0.4–0.7 per year), each lasting three to six months.

#### **Aetiology**

Research has shown a strong biological component for bipolar disorder, with environmental and social factors playing a role in the exacerbation of symptoms (Johnson, 2005; Weinstock, Keitner, Ryan, Solomon, & Miller, 2006). While there are a number of theories (in particular genetic studies) on the origins of bipolar disorder this review focuses on psycho-social determinants such as life events and stressors. The diathesis-stress model suggests people have, to different degrees, biological, cognitive and personality-based vulnerabilities or predispositions to developing mental illness.

The diathesis-stress model proposes an association between life stressors and onset of bipolar episodes, a finding that is consistent with research conducted over several decades (Johnson, Winett, Meyer, Greenhouse, & Miller, 1999; Waikato District Health Board, 2008). Studies show that negative life events precede increases in bipolar depression whereas manic episodes are



brought on by disruptions to social rhythms and sleep patterns (Jones, Hare, & Evershed, 2005; Jones & Tarrier, 2005).

People with bipolar disorder often experience elevated levels of life stress even during asymptomatic periods. Johnson (2005) and Johnson and Miller (1997) argue that severe negative life events, such as death and divorce, predict faster relapse and slower recovery within bipolar disorder. They concur that individuals experiencing significant negative life events were found to take three times as long to recover from an episode of bipolar disorder than those without such events. With these factors in mind, identifying low and high level stressors and coping mechanisms is crucial to managing the course of the bipolar disorder.

Expressed emotion is a term describing the affective attitudes and behaviours (eg criticism, hostility and emotional over-involvement) of relatives to a family member with a psychiatric illness. Expressed emotion is seen as a reliable predictor of relapse. Research suggests the emotional atmosphere of the family may be an important predictor of the clinical course of bipolar disorder and may be associated with an increased tendency to relapse (Miklowitz, Goldstein, Nuechterlein, Snyder, & Mintz, 1988).

Other research shows that a non-optimal rearing environment with psychosocial stressors such as abuse, harsh and critical communication style, deprivation, drug and alcohol abuse, violence, sexual abuse and neglect is associated with mental illness, with certain individuals more susceptible than others (Mason & Beavan-Pearson, 2005; Walker & Diforio, 1997). The impact of childhood adversity has been shown to contribute to unresolved feelings of loss, abandonment, lack of loving relationships and feeling different (towards others) in childhood and adolescence (Lapsley, Nikora, & Black, 2002).

The diathesis-stress model provides socio-cultural avenues for research (Taitimu, 2008; Urosevic et al., 2008; Walker & Diforio, 1997) that highlight risk factors for Māori and other disadvantaged groups who are more likely to experience poor mental health and compounding stressors associated with low socio-economic status. Within these highly vulnerable populations the presence of any psychosocial adversity seems to contribute to greater risk for depression and chronic episodes, anxiety, schizophrenia and bipolar disorder (Johnson et al., 1999).

#### Treatment considerations

Bipolar disorder is typically treated using medication to reduce symptoms and prevent relapse, and psycho-social strategies such as self-care or self-management plans. Although symptom relief is important, studies show an emphasis on social and functional recovery is needed for service user empowerment and greater collaboration among professionals (Jones, Mulligan, Higginson, Dunn, & Morrison, 2013). The treatment of bipolar disorder has progressed significantly with the use of medications such as lithium carbonate, anticonvulsants, antipsychotics, anxiolytics and antidepressants (Waikato District Health Board, 2008). The use of drug therapy alone has increasingly been challenged, resulting in more research to examine the benefits of combining drug and psychotherapy.



Lapsley et al. (2002) highlighted how participants reported adjuncts to medication including frequent hospitalisations, the use of general practitioners and community treatment settings. Around half the participants noted their experience of hospitalisation as negative with many commenting on the lack of opportunities for individual therapeutic work. Those who did use psycho-therapy found it was mostly of benefit to them (Lapsley et al., 2002).

Studies show that psycho-social interventions such as cognitive-behavioural therapy (CBT) family-focused therapy (FFT), group psycho-education, and interpersonal and self-care management programmes should be used in conjunction with appropriate medication. Results demonstrate the effectiveness of combining treatment modalities in delaying relapses, identifying stressors and triggers, reducing symptom severity, reducing the number of hospital admissions and the time spent unwell (in the community), and enhancing psychosocial and family functioning (Miklowitz & Scott, 2009; Scott, 2010).

It is important to consider the intended outcomes of psycho-education as results vary. Cognitive-behavioural therapy (CBT), group therapy, interpersonal therapy and family and marital therapy have been shown to affect different stages of bipolar disorder. For example, family-focused therapy was found to reduce re-admission to hospitalisation which individual therapy did not; however family-focused therapy did not change the likelihood of a first relapse (Rea et al., 2003). Psycho-education for spouses was found to lead to an improvement in social adjustment and global functioning, whereas group education was beneficial for social and occupational goal setting (Rowe & Morris, 2012).

Furthermore, randomised, controlled-treatment trials show psycho-education reduces relapse and is more effective at treating depression than mania (Beynon, Soares-Weiser, Woolacott, Duffy, & Geddes, 2008; Scott, 2006). This is particularly relevant as patients report greater distress about the depressive phase than they do about the manic phase. Despite the indicated utility of psycho-education for bipolar disorder, they are underutilised (Wells et al., 2010).

Te Whare Tapa Whā developed by Sir Mason Durie provides one tool for culturally appropriate assessment and treatment of Māori with mental illness. This model and its emphasis on whānau, tinana, hinengaro and wairua show what are seen as key areas for engaging and supporting Māori through their mental health journeys. Tapsell and Mellsop (2007) also highlight the works of Durie in advocating for the importance of culture and cultural connectedness in assessment; most importantly for those who strongly identify as being Māori or feel dislocated or disconnected from their identity.

Also of note are the findings of the MaGPie Research Group in 2004. This research demonstrated that although age, gender and poverty were controlled for there was differing and higher rates of mental instability for Māori that could not be solely accounted for by these variables. A cultural assessment alongside a clinical or medical examination would likely help explain and provide a clearer picture of Māori experiences.



Mitchell and Romans (2003) ENREF 90 reported those experiencing bipolar disorder showed differences and experienced confusion between the explanations of medical and spiritual advisors. Consistent with other research, their finding highlights the importance of assessing for religious and cultural standpoints and understandings of concepts of mental health to provide the best package of care for tāngata whaiora (Mitchell & Romans, 2003; Mental Health Foundation of New Zealand, 2010; Taitimu, 2007; Wharewera-Mika, 2012). Various other assessment and treatment models from a Māori perspective, or seen as having a holistic focus, would also likely aid in the utility of both assessment and treatment for Māori (Taitimu, 2007). Given this, future studies need to not only reflect differences in diagnosis and pattern of presentation, but also how to best access this information accurately and in a culturally appropriate manner.

#### Impact of bipolar disorder

#### Social impact

Bipolar disorder can have devastating consequences for individual sufferers and their families. The impact on family members needs further documentation. However, studies to date show caregivers reported significant difficulty maintaining their relationships with loved ones when they were unwell (Dore & Romans, 2001). Lapsley et al. (2002) also identified the impact on relationships with children and, for some, a sense of having failed their child or children as well as a general difficulty to make and maintain friendships.

Individuals with bipolar disorder who are supported experience less depressive symptomatology over time (Johnson et al., 1999), while having hostile or critical close others is associated with more depressive symptomatology, poorer response to treatment and higher relapse rates (Rowe & Morris, 2012; Walker & Diforio, 1997; Weinstock et al., 2006). An understanding of the role of family/whānau within a culturally relevant context is needed to identify the behaviours that support or hinder recovery.

#### Attitudes and assumptions

Common perceptions and misinformation about Māori and health responsibility also have an impact on the mental health status of Māori. Stigmatisation, public prejudice and social exclusion are well-documented consequences and maintenance factors for the mental health population (Corrigan & Shapiro, 2010; Mental Health Commission, 2001). Fifteen years ago it was suggested Māori have a genetic predisposition to mental illness (Johnstone & Read, 2000). The effect of these beliefs on Māori who have bipolar disorder is not known. However, Herbert (2002) suggested high rates of psychiatric admissions are common in minority populations reflecting the inability of mental health agencies to understand the social, educational, political and economic realities faced by many indigenous populations.

The assumption that Māori are to blame for their poor position is a view widely held by society and perpetuated by the media (Nairn et al., 2012). Some of the typical social messages (or stigmas; Corrigan & Shapiro, 2010) are that a person with mental illness is dangerous (eg they



are unpredictable and potentially violent), they are at fault for their illness and they are incompetent (eg they are not capable of real work). This research also emphasised that Māori are often seen as a social burden and as threatening social order (Nairn et al., 2012). Such assumptions shift responsibility for addressing negative health statistics away from the dominant group and ignore wider socio-political influences and consequences for Māori.

#### Youth

The adolescent period is considered a time when youths experiment with 'risk' or 'problem' behaviours. The association between mental health disorders and health and developmental concerns is well documented (Patel, Flisher, & McGorry, 2007). Youths are required to negotiate their way through relationships, decisions about education, finances, drug and alcohol use, employment and housing. While a normal part of development, not all youths are successful in emerging through this period without having acquired patterns of behaviour detrimental to their on-going physical, psychological, social and economic development. Evidence shows psychological, behavioural and social problems can be identified and prevented early thus preventing problems that become chronic and difficult to treat in later life.

Youth most 'at risk' are those who have experienced: exposure to sexual, physical and psychological violence; exposure to drugs and alcohol; an absence of support networks; educational underachievement; mental or physical illness; death of a family member; abandonment or discrimination; and bullying. Other risk factors include poverty, poor nutrition and inadequate housing. The circumstances for youths and whānau members generally, are such that additional supports are needed to prevent the interrelated impact of: underemployment; mental health issues; suicidality; tobacco, gambling, drug and alcohol addictions; criminal records; substandard housing; poverty; sexually transmitted diseases; and unplanned or unsupported pregnancies (Bagshaw, 2011; Blakely et al., 2003; Butterworth, Leach, Pirkis, & Kelaher, 2012; Cram, 2011b). Community and whānau-based interventions that are co-ordinated across social, education, welfare, health and legal agencies are considered better able to meet the complex needs facing youth today.

#### Gender differences

Women have a different course of symptoms for bipolar disorder compared to men. Where men are more likely to experience bipolar I, women experience bipolar II (with predominant depressive episodes) more often than men (Arnold, 2003). Women also experience mixed episodes and rapid cycling more frequently and are more likely to have medication-induced manias (Burt & Rasgon, 2004). Rasgon, Bauer, Glenn, Elman and Whybrow (2003) comment that in bipolar disorder, "the premenstrual and menstrual phases of the cycle have been associated with increased rates of suicide attempts, increased severity of suicidal intent, and increased rates of psychiatric hospitalisation" (p. 48). Pregnancy, childbirth and the postpartum period, breastfeeding and menopause are also critical periods in women's lives(Zappert & Rasgon, 2010).



Blehar et el. (1998) found that of 186 women who were interviewed about their reproduction experiences, almost half reported severe emotional disturbances in relation to childbearing, with close to one-third reporting symptom onset during pregnancy; two-thirds reported frequent premenstrual mood disturbances and almost 20 per cent of postmenopausal women reported severe emotional disturbances during the menopausal transition. For women the effects of bipolar disorder and medication on reproductive cycles, foetal development, breastfeeding and symptom presentation is variable; highlighting that more research is needed.

Rates of depression, anxiety and substance use disorders are all higher for Māori who present to their general practitioner than those of non-Māori (MaGPie Research Group, 2004). To gain a good understanding of bipolar disorder, differential effects should be considered across the broader demographics of age, gender, ethnicity and social status.

Samson and Walsh (2001) reported that after an experience of bipolar disorder many people are not able to regain work to the level they were previously working at. The stigma of mental health and prevailing negative views about Māori as a population are additional burdens that impact on the course of bipolar disorder for Māori. An understanding of the impact of positive and negative societal attitudes is needed to aid in the identification of meaningful recovery pathways.

# The recovery journey

Tāngata whaiora refers to Māori who have experienced mental illness and who are managing their recovery (Mental Health Commission, 1998). Recovery is defined as:

Something that happens when people can live well in the presence or absence of their mental illness and the loss that may come in its wake, such as isolation, poverty, unemployment and discrimination. Recovery does not always mean that people will return to full health or retrieve all their losses, but it does mean that people can live well in spite of loss (Mental Health Commission, 1998).

Recovery does not mean living without illness or disease, or being asymptomatic; rather, recovery is, "the ability to live well in the presence or absence of one's mental illness...each person with mental illness needs to define for themselves what 'living well' means to them (Mental Health Commission, 2001, p. 1). The recovery approach has underpinned New Zealand's approach to mental health service delivery for more than a decade (Mental Health Commission, 2007). Recovery is negatively impacted when people are isolated from their communities, power is used to coerce people and deny choices, and people with mental illness are never expected to get better; often called the 'chronicity paradigm' (Mental Health Commission, 1998). Indeed, some argue the term recovery is overused and sets unrealistic expectations for consumers, particularly if those expectations are not met (Sterling, von Esenwein, Tucker, Fricks, & Druss, 2010).



Mental illness is seen as a journey as much as a destination with positive aspects as well as bringing challenges and loss to tangata whaiora, their whanau and the community. The term recovery features principles and aspirations such as 'social and occupational functioning', 'self-determination', 'social inclusion', 'healthy social relationships', 'hope', 'autonomy', 'understanding, supporting and strengthening identity', 'living free from stigma and discrimination', and an emphasis on social and personal responsibility for recovery (Keyes, 1998; Lapsley et al., 2002; O'Hagen, 2004; Provencher & Keyes, 2011; Ryff & Singer, 1996).

Bipolar disorder is at times regarded as a 'life sentence', with little hope of recovery. The recovery-focused, mental health literature, however, argues wellness is achievable for even the most intractable conditions (Lapsley et al., 2002; Mental Health Commission, 2001). Definitions of recovery are varied and reflect the need to consider wellbeing from the perspective of the person in need. Although the term recovery supposes that one has 'recovered' and is 'living well', it is clear that recovery refers to the episodic nature of mental illness and shifts thinking away from the chronicity paradigm where mental illness is seen as permanent and individuals or groups are blamed for their mental health status (Ramon et al., 2007, p. 109).

Living well means tāngata whaiora have the ability to pursue life goals such as living with hope, safe housing, healthy cultural identities, healthy families, adequate money, employment, intimate partners, being free from violence and discrimination and being able to make choices (Craig, 2008; Torrey et al., 2005). Having a sense of control over one's life and making choices appropriate to the way one chooses to live, is an indicator of good health and wellbeing. Conclusions can be drawn where Māori as a disenfranchised people are more likely to experience barriers throughout all stages of their mental health journey and face significant impediments to living well.

Lapsley et al. (2002) noted that in keeping with policy documents and lived experiences for consumers, recovery stories should include multiple influences on peoples' lives.

Our research waka and the subject it conveys inevitably demands that stories of recovery from mental ill health be viewed and investigated in the fullness of their social, economic, political, spiritual and emotional environments. These environments are essentially bicultural, even in some instances multicultural, and sometimes monocultural. Rarely do they involve only Māori (p. 1).

Lapsley et al. (2002) emphasised that the recovery approach is compatible with Māori mental health models in that, "balance is sought between the body, person, whānau, and the environment and ecologies within which they exist" (p. 2). Research to date shows a clear association between social, psychological and biological factors on the emergence, course and prognosis of bipolar disorder. However, what is needed is a thorough understanding of why Māori have higher rates than non-Māori. Those rates suggest personal, social, political and economic forces have an impact on individual Māori in a way that requires more exploration.



Bipolar literature is extensive with clinical, medical and psychosocial models offering a vast array of research and therapies. What is noticeable is that the bio-psycho-social literature on bipolar disorder is talked about, theorised and described from a Western dominant position. The effect of this positioning is that socio-cultural views challenging systemic discrimination and bias are overlooked.

#### **Prognosis**

Bipolar disorder is regarded as having a creative and artistic side, but this is coupled with severe impairment in many areas of functioning, such as erratic work performance, low education levels (McPherson, Dore, Loan, & Romans, 1992), high rates of divorce and relationship dysfunction (Rowe & Morris, 2012), substance abuse including nicotine, alcohol and drug-dependence (Leventhal & Zimmerman, 2010), and high rates of suicide compared to the general population (Angst, Stassen, Clayton, & Angst, 2002). Among affective disorders, bipolar disorder carries the highest risk of suicide (Oquendo & Mann, 2001), particularly for those who have made prior attempts (Grunebaum, Ramsay, Galfalvy, Ellis, & Burke, 2005); however, not all bipolar patients commit or even attempt suicide during their illness (Gonda et al., 2012). Recovery literature is relevant to this study as it describes mental health from the perspectives of the individual, community and wider society.

From a 'life-course' perspective, bipolar disorder significantly impacts on multiple aspects of people's lives. In later life, episodes may be further apart and shorter in duration and manic symptoms less problematic, however, depression, suicidal risk, drug and alcohol abuse and relationship dysfunction continue to impact on optimal wellbeing (Ketter & Wang, 2010). The experiences of an ageing bipolar population must not be overlooked; as these people can contribute with a wealth of information about their pathways to relapse and recovery (Angst & Sellaro, 2000).

#### Decision-making, clinical judgment and cultural bias

The foundations of psychiatric theorising, positivism, assessment, diagnoses and treatment from a Western, non-indigenous position must be explored for its relevance to Māori experiences of mental disorders. Culturally-nuanced decision making has been criticised as influencing the clinical judgment of health professionals who are predominantly Westernised in their views about mental illness. Indeed, it has been argued that psychiatric diagnoses serve to perpetuate the status of an elite profession that is uninterested in non-medical models of care (Prilleltensky & Fox, 1997). Such a view maintains an individualist, medical/organic understanding of human suffering that takes only secondary account of the role of structural relations and the sociopolitical context in shaping people's experiences (Albee, 2000; Hare-Mustin & Marecek, 1997; Love, 1999).

Despite these epistemological issues, research conducted on bipolar disorder, while extensive, pays minimal attention to the influence of racism and cultural bias on decision-making. The international research that exists on ethnic or gender differences in bipolar disorder shows



repeated disparities between dominant and non-dominant groups involving coercion and compulsory admission, compulsory treatment, incomprehensible diagnoses and biased decision making (Fernando, 2003; Lawlor, Johnson, Cole, & Howard, 2010; Wharewera-Mika et al., 2013).

Durie (1999) emphasised the importance of considering a Māori patient's entire sense of wairua and wellbeing enabling them to re-connect with whānau without assumption that medication or westernised treatments are the best approach for all (Mental Health Commission, 2000). His work highlights the crucial importance of avoiding a 'one size fits all' approach, or making assumptions surrounding people's sense of belonging to te ao Māori or to their own whānau, hapū or iwi, and instead working individually, without judgment, to ascertain the best way forward for each tāngata whaiora (Mental Health Foundation of New Zealand, 2010).



# Methodology

## **Ethical approval**

Ethical approval was provided by the School of Psychology Ethics Committee of the University of Waikato, the Multi-region Ethics Committee (NTY/12/06/052), the Waikato District Health Board Māori Research Committee and Te Puna Oranga, Lakes District Health Board, Te Roopu Hauora o Te Arawa and Te Nohonga Kotahitanga o Tūwharetoa. Consultation with Māori advisors associated with the University of Waikato Māori and Psychology Research Unit occurred on a monthly basis.

#### Participants/whānau:

The term whānau has been used instead of participant. Family refers to the relatives of whānau. Twenty-two whānau participated in this study: 15 wāhine/women and seven tāne/men. Ages ranged from the early 20s to late 70s. Eight wāhine had children and grandchildren and four tāne had children and grandchildren.

The majority of whānau were employed in the mental health service as support workers, administrators or policy developers. Other whānau were unemployed, or studying part- or full-time. Relationship status ranged from single, recently separated or divorced, married, in a defacto arrangement, or the status was unspecified.

#### **Qualitative interviews**

The narrative-story approach sought to understand:

- a. life before the diagnosis
- b. life changes and events leading to diagnosis
- c. the experience of diagnosis and engaging with mental health providers
- d. the experience of living with bipolar disorder
- e. life journeys towards, through and beyond diagnosis of bipolar disorder
- f. key themes and events in whānau stories across the whole group as well as between Māori women and men in different life stages
- g. whānau help-seeking experiences; their engagement and relationships with mental health service providers; and their self, whānau and workplace experiences
- h. the narratives to better understand how bipolar disorder disrupts and challenges identity and how whānau respond to the disorder in their daily lives.

#### Data analysis: thematic analysis

Thematic analysis was used to identify themes and trends in the whānau narratives. Thematic analysis is a tool that identifies, organises and describes patterns or phenomena (Boyatzis, 1998) and works both to reflect reality and to unpick or unravel the surface of reality (Braun & Clarke, 2006, p. 81). The latent thematic method was used to examine and describe stories from each whānau which allowed for a thorough life-span analysis. Latent themes relate to identifying



and examining underlying ideas, assumptions and conceptualisations, and ideologies that shape or form the semantic content of the data (Boyatzis, 1998; Braun & Clarke, p. 84). The latent method is useful for unravelling content that might otherwise go unnoticed.

Within the latent approach, broader structures and meanings are theorised as underpinning what is articulated in the narratives (Braun & Clarke, 2006). To achieve this the thematic analysis will, "…capture something important about the data in relation to the research question, and represents some level of patterned response or meaning within the data set" (Braun & Clarke, 2006, p. 82).

As researchers it is important to acknowledge any theoretical positions and values in relation to the research, our position as cultural members and as cultural commentators, and to recognise that the worldview of researchers provide the instrument of analysis through which the narratives 'emerge' or are 'created' (Braun & Clarke, 2006; Sanchez-Jankowski, 2002, p. 80). With these views in mind, it is important to show an empathetic understanding (Stiles, 1993) of whānau worldviews and their voices embedded within the narratives. Whānau were provided with copies of their narratives for review and comment which they could retain as a written account of part of their life-history. As part of the thematic analysis process, themes and results were reviewed by two researchers to check for consistency, irrelevant themes and errors.

#### **Quantitative data collection**

The Ministry of Health's PRIMHD database contains secondary care data for clients accessing inpatient, residential and community-based services (Ministry of Health, 2011). PRIMHD data is used to report on what services are being provided, who provides the services and what outcomes are being achieved for health consumers across New Zealand's mental health sector. The data is collected from district health boards (DHBs) and non-government organisations (NGOs).

DHBs and NGOs who provide publicly funded mental health and addiction services send data identifying their client referrals, activities and any outcomes (DHB only) to the PRIMHD database. It is anticipated that the information enables the integration of, and access to, different types of information to be used by a range of stakeholders to improve mental health service delivery for consumers. Outcomes data does not represent all mental health and addiction service users. NGOs, alcohol and drug teams, community skills enhancement teams and needs assessment and service coordination teams are not required to collect outcomes data, affecting the quality of the information gathered in PRIHMD (Ministry of Health, 2012).

The diagnostic data obtained for this study fell within the years 2008-2010, however, that data was inconsistently reported reflecting a problem with how the data is entered at each DHB location. While it was an important avenue to investigate in determining Māori experiences of bipolar disorder, the PRIMHD data provided limited usable information.



#### **Analysis process**

Interview transcripts were analysed using thematic analysis. Extracts from each interview were organised into categories relating to the research question. The findings showed a common sequence of events as whānau talked about their experiences. Deeper investigation into whānau experiences uncovered several common themes that occurred throughout whānau journeys before diagnosis, during the illness and through the recovery process.

Thematic analysis also involved re-examining the categories created, reading over all material concerning each of the major categories, and coding that information into common themes. As this process progressed, categories were added, changed, refined or integrated. This process assisted in the identification of consistent themes across whānau interviews, as well as the similar (or unique) experiences of living with bipolar which had a significant impact on whānau lives. After the initial analysis was completed, new categories were formed, and a narrative sequence emerged that describes the progression of whānau experiences of bipolar disorder. The themes are described below – a note here is that pseudonyms have been used throughout.



# **Findings**

## **Themes**

The narratives of whānau journeys with bipolar were divided into five key themes and subcategories to illustrate unique experiences:

- 1. Early vulnerabilities
  - Perceptions about the cause/onset of bipolar disorder
  - Unmet need: family mental illness
  - Childhood and adolescent experiences
  - Pre-existing psychological vulnerabilities
  - Vulnerable families
- 2. Significant events contextual factors and triggers
  - Drug and alcohol use
  - Adulthood
  - Leaving school
  - Intimate relationships
  - Raising families
    - Post-natal depression
  - Work and study
- 3. Onset of bipolar disorder
  - Risk to self and others
- 4. Consequences of bipolar disorder
  - Experiences of mental health services
  - Disconnection from family and friends
  - Impact on work and study
- 5. Pathways to recovery
  - Recovery and wellness
  - Reconnecting with family
  - Building trust
  - Creativity, art and being productive
  - Helping others

## Early vulnerabilities

Each whānau described a range of experiences reflecting early vulnerabilities that set the context for a later diagnosis of bipolar disorder. The life pathways of each whānau member showed that mental illness was something they could not easily avoid as they had a range of physical and psychological experiences predisposing them to later problems, largely because they did not receive adequate support.

...I had all of these terrible things happen in my childhood. It would have been a miracle if I hadn't ended up with bipolar or a mental illness (Niwareka).



It is relevant that a precursor was evident across most whānau and suggests that, for some, the precursors were possibly the primary concern for them. Had those issues been addressed earlier Niwareka and other whānau may have avoided the long-term effects of pre-existing conditions. For example, chronic depression and anxiety, substance abuse and physical and sexual abuse traumas were common pre-existing mental health concerns for some whānau.

Zane's story shows a range of complexities he had to manage on his own. Zane's parents separated when he was four years-old and he described his father as, "never part of our lives". Zane quickly moved into a world of drugs and alcohol to combat his anxiety and, in his words, the "excessive worry" that plagued his outlook on life.

In a few instances there were anxieties. In one admission I had moved to Wellington, and there was a bit of anxiety around how I was going to make a life in Wellington and how life was going to be there. Also there had been drug use, I'd been smoking marijuana since I was 16, and when I went to Wellington I had stopped smoking, and there was increased anxiety about how my life was going to be, and I think those kind of things pushed me over the edge (Zane).

Zane's story highlights the need for better understanding about how to manage mental health issues in everyday life contexts before they escalate to the point where features of the original problem become blurred with those of bipolar disorder (this point is described in later sections). For others incorrect diagnosis or medication contributed to ongoing mental health issues. Huia said she experienced severe anxiety and depression in early adulthood and then had to convince health professionals in later life that she had bipolar disorder.

I was so angry with my doctor. I challenged him but he said that I couldn't have bipolar because if I did, I couldn't be a parent, I couldn't look after my children, I couldn't have a relationship (Huia).

Huia's account shows assumptions exist that influence whether whānau with bipolar disorder are capable parents. This section has pointed to the precursors for mental illness and highlighted that most whānau could track the events that led to a diagnosis of bipolar disorder and the consequences of the diagnosis. Childhood and adolescent trauma, anxiety, depression, suicidality and 'not fitting in' were significant features in the narratives collected. The following section describes the stories associated with a pathway to a diagnosis of bipolar disorder that began in early childhood or adolescence.

#### Unmet need: family mental illness

More than half of the whānau described a history of mental illness within their whānau and associated their experiences of bipolar disorder with psychosocial stressors or a genetic predisposition, "...my cousin is bipolar, my uncle and my father too; at least that's what my mother said" (Antonio).



Tania felt negative childhood experiences and environmental stressors set her on a path of mental illness. She also commented that women in her family were the most affected by depression and bipolar disorder.

I would say I had the potential for bipolar disorder as a result of my past experiences as well as the environmental stressors that surrounded me. My grandmother had bipolar, my aunty had it, my brother had depression; two other females in the family had bipolar. It seems to be much worse with the females in our family. I think my daughter has bipolar too (Tania).

Māpihi, Awhi and Meri also made references to whānau members with bipolar and other mental illness diagnoses.

I think my father has a mental illness, he went through a period of psychosis, it runs in my family and on my mother's side too actually (Māpihi).

My mother had mental illness most of her life. I'm not sure what she was diagnosed with...so it's not a big shock in our family, there are about three of us, my mum, my brother, and me (Awhi).

Mental health has always been present in my extended family. In every generation someone has been diagnosed with depression. My grandmother had depression. My cousin is a paranoid schizophrenic and my uncle may have had bipolar. My immediate family has never had to deal with it. It's always been someone else (Meri).

I was demanding and I wasn't sleeping, and they thought to call my mum who had had experience with my sister having bipolar as well, so she was able to call the Crisis Team to come and assess me (Zane's first admission).

Rangimārie (one of the older whānau) said her daughter also has bipolar disorder, is a heavy drug and alcohol user and has had her children removed from her care. Rangimārie said her daughter's drug and alcohol abuse and parenting issues may have been the result of her inability to be a parent herself when she was hospitalised for long periods. The suggestion here is that stressors impacting on the family precipitated intergenerational mental illness rather than biological tendencies. Rangimārie became the sole caregiver for her grandchildren until she became overwhelmed and needed help. At that point her sister stepped in and now has full-time care of the children.

The comments from Tina, Zane, Tania and Rangimārie about family members who also experienced mental illness were also evident in other whānau stories. Some, however, were not aware of the existence of mental illness within the whānau until they were diagnosed themselves.



#### Childhood and adolescent experiences

The majority of whānau were able to pinpoint specific experiences or circumstances during childhood and adolescence they associated with mental illness. Some whānau described harsh living conditions while others spoke of supportive home environments. Meri described her upbringing as loving and open. Her family ate together each night and was encouraged to talk about their day.

We were encouraged to talk about how we felt. We never yelled. We discussed problems. Life was really happy. I was never abused in any way or smacked as a kid (Meri).

Tui provided a description of her childhood in relation to that of other children.

Yeah there was nothing in my childhood. We got everything we needed and wanted, it wasn't great but it was good. The kids down the road didn't even know if they had dinner that night you know, but we never had to worry about that stuff, we were always fed and warm and clothed (Tui).

For some whānau there was no single event in their lives, other than noting a particular disposition (for example anxiety or not fitting in) or that there was an absent parent in the home, while others endured repeated and sustained abuses.

Martina, like other whānau, was parented by her siblings. The risk to Martina was that she struggled with feelings of abandonment by her father, her mother and her older sister. Martina felt hated by her sister because she (the sister) was left with the responsibility of caring for her siblings as a result of their mother's alcohol addiction.

Mum would be out partying and my sister had to look after me. My brother was my guardian when my mum was out drinking. They are my half-sisters and brothers (Martina).

Tania's story started when she was a young girl. She said her mother had a history of mental health concerns, her stepfather was abusive, and that she (Tania) was unwanted.

I'd rather start earlier where I became aware that I was different, when I was about 6 or 7 years old. When I was a teenager I knew I was different because I use to cry a lot and break down in class. I'd try to OD on panadol and stuff, you know I'm lucky, I didn't know what it could do, I still didn't know what was wrong with me (Tania).

Unaddressed psychological issues were noted for all whānau. Themes relate to life prior to a diagnosis of bipolar disorder and suggest that for some whānau the pathway to unwellness was not unexpected. The stories highlight the limited support available.



Tania's sister Marama said Tania was an emotional child and would always cry.

That could be why the family didn't want to support her (Tania) because they had a whole lot of their own crap in their closets. They hadn't dealt with their own troubles (Marama, sister of Tania).

Tui said she, "was overly emotional about a lot of things" and began to isolate herself during high school. Huia described herself, "as a child who suffered from major anxiety to the point of being unable to cope with life". Rangimārie, Māpihi and Phillip recalled some form of bullying or isolation while in school which they believed had an impact on their mental wellbeing.

We used to get the bash at boarding school just for being Māori too. At a Pākehā boarding school, they'd say you black c\*\*ts, and you're all poor. So we went through that shit, and that's why I thought it was normal (Phillip).

Meri recollected an event that shocked her family. From that moment she said she understood the connection between how she thought and how she felt. It was some years before she was able to manage those interactions.

When I was 12 my uncle committed suicide. He had an undiagnosed mental illness. If he had waited an hour a doctor would have got to him. It was thought that he had bipolar. That event scared me. It also made me feel really free. I felt I could relate to the negativity in my mind and became aware for the first time of how my thoughts impacted on my moods (Meri).

Some whānau had engaged with mental health services prior to their bipolar diagnosis in relation to other problems and received mostly pharmacological treatment, others were isolated and unsupported, and some chose to minimise their contact with peers. Tui said in hindsight there were signs that something was happening.

I was starting to isolate myself a bit in the last two years of high school. I think my family might have put it down to me being shy or something. I still had mates, but I'd isolate myself a bit. And I went nursing for a while when I was 19 before I went to Europe, and I was just overly emotional about lots of things, and I think it was sort of...talking with my brother, looking back, he could see things that were starting to creep in from about 16 onwards, then fully blown at 22 (Tui).

Tui's feelings of isolation could have been part of normal adolescent development, although she felt this was the point where she noticed she was different to others. She became unwell following her overseas experience when she was 21-22 years old.

Awhi's experiences highlight a disturbing trend where she was unable to tell others what was happening to her. She was diagnosed with bipolar disorder when she was 16 years old. At the time she was in a stressful relationship, she was living in a stressful home environment and her situation was critical.



The paranoia started, it was terrifying sometimes, it was like you'd go into places and it was quite scary. You'd think people could hear what you were thinking about. I kept on drinking a lot, mostly drugs really that led to a lot of smoking, marijuana. That triggered it off. They put me into hospital and gave me some medication and then yeah (Awhi).

Awhi was involved in mental health services for most of her life. Her story continues as a partner, mother and grandmother.

Martina, Tania, Huia, Tamara, Rangimārie, Meri, Max and Pua described a range of experiences and dispositions that, in their view, were either not dealt with properly at the time or not dealt with at all.

I just missed not having a father around. I always felt like I wasn't good enough, that I was not lovable. My mother drank. My brother and sister looked after me. I don't think my sister bonded with me although she was my primary caregiver. My brother and sister had different fathers. They have a relationship with their father (Martina).

...it (anxiety) was all I knew so I didn't think anything was particularly wrong. I found it difficult to cope with life. I worried about things that weren't worth worrying about but I didn't know I was doing that. I suffered from excessive anxiety as a child (Huia).

I've been in and out of services since I was 13. I got teased pretty badly in high school, and I was on fluoxetine and when I was on that medication it made me quite schizophrenic and I was hearing voices and I thought people were coming to kill me. I wouldn't leave my bedroom most of the time and my parents thought I was just making it up to get out of school (Tamara).

At high school I would climb the stairs and I'd get out of breath. I started to keep away from people. Not really talking to anyone. I couldn't relate much to people (Rangimarie).

No-one knew how to relate to me. I played a role, pretending to be someone I wasn't. I moved from group to group and made friends easily. I wasn't secluded in the corner. Then I changed school. Then I got to play that new person in a new environment. I'd have anger moments. My personality would change for no reason at all (Meri).

At age 14 I had an incident involving sexual relations with people. At school, the counsellor picked up on it, and they took me up to the farm [term for psychiatric hospital], they said it was just normal teenage behaviour. I was a victim. That was



the first incident—if you deal with the first trigger you can deal with all incidents that came after and you can get well (Max).

I was 15 years old. I was home for Christmas holidays during the summer and one night, this man, um broke into our house, and um when everybody was asleep. My parents and brother were home and my older sister had gone out to a party. And I woke up, and there was this random guy ten times my size staring at me, I didn't know him from a bar of soap (Māpihi).

Ummm, so I was sexually violated, but the interesting thing about this bit of trauma is that I didn't scream, or cry out for help, even though I knew my parents were in the next room because I thought that he was going to hurt them. I didn't know what his intentions were. Ummm, so I let that happen (Māpihi).

Māpihi said the sexual assault impacted on her grades at school. She was eventually diagnosed with chronic depression and regularly engaged with health services and the crisis team. Māpihi felt that regardless of her traumatic experience, she was always going to be, in her words, "that way", implying that there was something in her character that was different to others. Although she received counselling from the Accident Compensation Corporation (ACC) she felt belittled and treated like a child by the counsellor.

...she wasn't really good because I think she just used standard ways of dealing with trauma, like by using toys to illustrate your pain. But for me, I felt like I was more intelligent than that. I could articulate pain without using animals and without using words like I FEEL SAD or I FEEL MAD and things like that. So the whole mental health system didn't give me enough credit (Māpihi).

Most of these whānau went on to develop chronic and acute psychological difficulties. As young wāhine Huia, Meri and Māpihi were diagnosed and treated for major depression, Tania was treated for post-natal depression and Tamara was treated for anorexia nervosa and borderline personality disorder. Martina, Tui and Rangimārie's first diagnosis was for bipolar disorder. Other whānau not named above had similar experiences.

Awhi was the only participant diagnosed with bipolar disorder as an adolescent. She said she was stressed because of relationship problems and she started hearing voices and becoming paranoid. She was also smoking marijuana and drinking heavily.

In my teen years; when I was about 16. The paranoia started, it was terrifying sometimes, it was like you'd go into places and it was quite scary. You'd think people could hear what you were thinking about (Awhi).

Awhi was working when she became unwell. Her boss took her to the mental health service where she was diagnosed with bipolar disorder. She said she did not have much support and her friends abandoned her. Awhi did not talk much about her childhood; however alcohol was a significant feature throughout her life and impacted on her ability to get well.



Four times I've slipped up in the last seven years on alcohol, because I used to drink and drink full on for ten years and hearing voices and getting paranoid, I was paranoid for years, it drove me crazy (Awhi).

Some whānau experienced such high levels of dysfunction in their upbringing they could not be overlooked as causal influences on later mental health issues.

#### **Vulnerable families**

Several whānau spoke of an unstable and dysfunctional family life during their childhood from parents, foster parents and step-parents, and a lack of support when life began to spiral out of control. Negative childhood experiences involved physical and emotional abuse, caregiver mental health issues, exposure to alcohol abuse, controlling parents, high Child, Youth and Family Services (CYFS) involvement (foster homes), and sexual assault.

Rangimārie's story highlights a situation similar to other whānau in which a stressful event occurs and the reaction is to consume alcohol over a period of days. Rangimārie described her father as a, "control freak" who had a, "mental attitude and torturing way of talking to mum". Rangimārie's first bipolar episode occurred after she had, in her words, "rumbled with him" and ran away from home. She spent three days drinking and not sleeping. She said she woke up in Tokanui Psychiatric Hospital and has since spent most of her life in and out of mental health services.

They told me I had manic-depressive bipolar disorder I had no idea what it was. '85, '87, '89, '91. '93 I was in there for three months. '96, '97. I was in there a lot longer (Rangimārie).

Two whānau (Tania and Niwareka) were removed from the parental home as children. Niwareka lived in more than 30 foster homes after being removed from her mother's care at age two as a result of her mother's mental illness.

I endured mostly sexual abuse, physical abuse, and emotional abuse in all of those homes. Because I moved around so much I came out feeling like I had no identity, no record of my life (Niwareka).

Niwareka's story shows a long history of mental health concerns, for herself and her mother, that were untreated and exacerbated by her personal circumstances.

My first suicide attempt was at age 14, my second attempt was at 23, and my third was somewhere into my 30s. Each time I was just put in hospital and then sent home. I was never ever sent to a psychologist for help (Niwareka).

Similarly, Tania described a history of abuse that went unchecked. She was also prescribed antidepressants but they had little or no effect on her which led to further investigation into her moods. Her presentation indicates the possibility that she was experiencing trauma as a result of repeated abuse and a lack of appropriate support systems.



So yeah, I was always different, and people knew I had mood swings and I had lots of nicknames like psycho, or dizzy, you name it, you know. A lot of the family didn't know, they just thought it was a hippy thing, always moving houses, they judged, they didn't want to know. They knew about a lot of other stuff, there was a lot of abuse in our family, always, but there was no support in the family (Tania).

Tania also had negative encounters with her foster families at a young age resulting in her running away on several occasions.

I ran away a lot after being sent to CYFS. The cops would find me but I'd just run away again. And I'd tell them too. I just got sick of all the abuse and all of the hidings. Anyway, I got put back into CYFS, the doctor put me on medication. I was sleepy, and I'd cry a lot. I was a mess. Our step father was a paedophile and a murderer, and he was a rapist (Tania).

Tina shared a similar story of early childhood abuse impacting on her developmental pathway. She said she was sexually abused and beaten as a child which contributed to what she says was severe trauma.

...My mother's response to things was to bash. My sisters couldn't stand up to it. My mother said I was a nutcase. I was going through counselling at the time. I chose to take the perpetrators (of the sexual abuse I experienced) to court. So mother used my mental health as an excuse saying, "she's mad, she's got a mental illness" (Tina).

The blame and abuse Tania, Tina and Niwareka were exposed to as children continued into adolescence and adulthood where they entered unstable and abusive intimate relationships. The effect of pre-existing stressors in whānau wellness across the life-span is evident. The effect on them and their families will be explored further under the themes Consequences of bipolar disorder from page 59 and Intimate relationships on page 42.

#### Significant events – contextual factors

Across each narrative the transition period between late teens to adulthood was noted as a critical point for many whānau as they sought independence, started work, studied, entered and left intimate relationships, engaged with their cultural identity and had children.

Several subthemes emerged within the context of precipitating factors and adulthood revealing high levels of unmet need. For some whanau those unmet needs meant they stayed in contact with mental health services as they grew to become young adults, mature adults and elderly adults. Some of these whānau were diagnosed with bipolar disorder following years of service use and multiple diagnoses, while others were diagnosed at their first admission and had no prior contact with mental health services. Of the latter group, while they could pinpoint issues in



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their childhood or adolescent years, those issues did not prevent them from living full lives until a catalyst propelled them into the mental health system.

Some whānau reached crisis point and were pushed beyond their ability to cope. Adult independence did not always mean freedom to make decisions. For some wāhine living in an abusive relationship was often the cause of mental illness and, unlike others, they had very little autonomy. In some cases coming to the attention of mental health services was pivotal to wellbeing, while others found their engagement with services placed them at further disadvantage.

#### Drug and alcohol use

Drug and alcohol use was a major coping strategy for many whānau. Zane, Meri, Martina, Pua and Tamara had already started using drugs and alcohol while still living at home. In each case drugs and alcohol were used to self-medicate or to 'fit in with peers'. Tamara's mental health issues started in her early teens. She was frequently in and out of services and became a heavy drinker. She was treated for an eating disorder and was constantly self-harming. Both Tamara's arms bore deep and superficial scars from her wrists to her elbows. Without surgery they will be permanent.

I think it wasn't until my mum started going to my bedroom, finding stashes of alcohol hidden everywhere and stashes of pills everywhere and razors and that kind of stuff. I think it was then that they kind of freaked out and they thought, "No wonder she can drink all the time"; and I was stealing my parents' alcohol (Tamara).

Meri described how she left school at 17 and started drinking and smoking cannabis,

I hung with older people. I started smoking weed. I felt happy. Through that feeling of being relaxed, I remained a drunk for a while (Meri).

Meri said she realised drugs and alcohol provided an escape from her self-hatred and negative thoughts. Her drug and alcohol consumption escalated to the point where she was regularly intoxicated at work, which culminated in a referral to a general practitioner. She was 19 years old and was self-harming (cutting herself). Meri said she became depressed because she could not escape her thoughts.

I couldn't even get out of bed. I grew really dark because I didn't have that relief from the drinking (Meri).

Zane, Rangimārie, Pua, Grayson, Max, Awhi and Martina all described heavy drug and alcohol use as a form of self-medication that eventually led to further illness and a diagnosis of bipolar disorder.

Tania's alcohol use was tied to the chronic stressors in her life.



[I'd] get drunk and get real messy real fast, and then break down in tears. That was the old me (Tania).

As a pathway to wellness however, most whānau described no longer using drugs or alcohol or at least having managed their consumption. Those who abstained had fewer relapses.

#### Adulthood

Early adulthood was a time when whānau were more independent, or were expected to be independent. For whānau who had not received help for existing concerns, adulthood was particularly stressful as they were not prepared for the pressure of leaving school, beginning work, studying or entering intimate relationships. Some whānau used alcohol and drugs extensively which exacerbated or precipitated mental health issues. Like the previous narratives, whānau talked about events and situations where they could have been helped earlier but faced barriers too difficult to overcome without support.

As adults, whānau who were raised with limited engagement with Māori culture found they struggled to cope with their dual identities. Philip said his pathway to illness began when he was exposed to Māori culture.

At that time I had just sort of met the mother of my first daughter, and yeah it sort of opened up things that I didn't really know about. Things like Māori and that sort of stuff. Because I was brought up in a Pākehā boarding school and another Pākehā boarding school after that, so when I was in standard one, I was in boarding school. And then yeah this sort of other world opened up and I was like errrr, and that stuff got a bit...you know. I didn't know how to deal with it. You start feeling things, and then the hairs on your back start standing up and you don't really know how to keep yourself safe (Philip).

### Leaving school

This theme was relevant because some whānau indicated that leaving school was a point of difference. Developmentally, whānau were ready to do different things and make their place in the world. For some, however, they were not prepared for the stress adulthood placed on them and they succumbed to mental unwellness. While employment issues were present for many whānau, there was a point of difference for school leavers entering the workforce compared to adults already engaged in work and experiencing work-related stress.

Zane and Martina described not being able to work because of anxiety and depression and drug and alcohol abuse. Rob said he became unwell after losing his job which, in his view, contributed to a spiral of low self-esteem and self-doubt. Rob was 17 years old when he left school to work at the local freezing works. His goal was to save his money and buy a car. He said he did not drink, smoke or take drugs, unlike many of his friends and family. Like other whānau he worried excessively about his self-worth and whether he was a valued member of the family. At age 18



Rob became unwell following an incident at work where he lost his confidence and eventually his job.

My job? Just trimming, just a C butcher in the beef house. Some of the jobs I was doing, I was actually doing my own job and giving the guys a break. I had a job setting up the conveyer belt and my mate helped me but the hose was in the road and it tipped over, and there was a ding-ding outside like they do when someone does something, oh no over! So yeh! I just got real under pressure in my job, and I thought I was no good after that. Then they said I had to leave (Rob).

After losing his job Rob's cousin manipulated him to spend his savings on travel, drugs and alcohol. With his savings gone Rob returned home; he described being unable to function. Within six months, Rob's uncle told him he was a burden on his parents and he needed to go to the doctor.

I'd just stay in my room all day and um don't eat just sorta sneak to the toilet and have a drink of water and go back; don't eat for a few days. I would cry. I just wanted to give up (Rob).

Rob's experiences reflect a pattern among whānau of vulnerability and low-self-worth. Despite his attempts to work after he left school he was not able to recover from being dismissed from his job. When he was 19 Rob's doctor prescribed him Haloperidol. Some months later, he attempted suicide and was admitted to the psychiatric hospital. He said he did not really understand why he was diagnosed with bipolar disorder.

They thought I had bipolar schizophrenia. Oh well I wouldn't know, um I think I got bipolar cause um when I'm around people I'm alright, it's just when I'm on my own, and uh, I didn't hear voices. I was just thinking you know, thinking thoughts, but no voices talking to me or anything just my own thoughts thinking I was no good (Rob).

Rob's admission to hospital and confusion about his diagnosis is consistent with other whānau experiences and will be explored in more detail later. At this stage of the research the lack of understanding and information about mental illness was a significant finding in most whānau stories.

# Intimate relationships

This theme reflects the impact of intimate relationships on each participant. Some stories clearly show that abusive, controlling and manipulative partners were often the cause of mental unwellness; while others were not capable of being in a relationship because of their mental health issues. Other relationship effects were the end of a marriage or partnership.



Six wāhine described relationship difficulties most commonly involving abuse, rejection or a relationship break-up. Tina described her first bipolar episode as the, "longest" and "strangest". At the time she was in a violent relationship.

I was in an abusive, violent relationship. It affected my babies and me being pregnant. I was suicidal, I started cutting (Tina).

She felt this was a reaction to trauma rather than a mental illness.

If I was in a loving relationship (or not in an abusive one) would I be like that? I don't think so (Tina).

Hine was pregnant at 18 years old and married Walter when she was 19. She wondered whether getting pregnant at such a young age and having a husband who was physically and emotionally abusive to her contributed to her mental health issues.

I just felt this almighty whack...I'd never ever been hit by a man (Hine).

Walter continued to abuse her physically and emotionally.

I had a lot of negative stuff coming at me and it done nothing for my self-esteem. Only one year after we were married, we were in Hamilton and all I heard was, "I want a divorce you're effed in the head". All this negative stuff and I thought, this isn't love, it was so cruel! I was 19 at that time. I mean, perhaps it has a bearing, but that's just for me, it was so personal. But I kept on trying, you just don't give up, you always have hope that things will improve. So I stayed with him (Hine).

Hine and Walter were married for 26 years before he left her. They had eight children and two miscarriages. Hine said Walter, "did his own thing" and that at times she felt like a solo-mother. Walter also had multiple extra-marital affairs. Hine had three psychiatric admissions during her marriage. She recalled one episode where her sister and brother persuaded her to get admitted.

I was really tired, and the kids had gone to Jaylene; the other ones were at Uni; and it was my sister and my brother who said I was really stuffed and not getting any sleep, and I was staying up the road by myself. I don't know whether Walter was having his affair then or what, I can't remember, but they were the ones who persuaded me to go in again (Hine).

Hine was diagnosed with bipolar disorder when she was 38 years old. She described her 30s as being the most difficult years.

I had more kids to care for, and just the home environment, and relationship more than anything else and trying to cope with the kids (Hine).



Meri's abuse story exemplified her vulnerable position. She quickly entered a relationship with Peter within a month of recovering from an episode of major depression and alcohol and drug dependency. Her relationship lasted five years and featured emotional and physical abuse. She described her role in her relationship as that of a slave.

He had taken everything away from me. My drinking spiked again. I was stoned all day, every day. I was either in a stoned bliss or drunken state. We had people over all the time – growers. Everything was social. People would tell me how shit my relationship was. I became the slave for all of them. I cooked and cleaned for everyone and I paid the bills. All my money went on bills and groceries. Then I'd get in trouble for not having money for cigarettes (Meri).

Peter left Meri several times in their relationship causing her to feel abandoned and distressed. She eventually decided she had enough and left permanently. Meri's story highlights not only abuse concerns but also the effects of unstable relationships. Unfaithful partners had a particularly devastating effect on vulnerable wāhine who, as noted earlier, were struggling with mental health issues; some since childhood. While not considered abusive, the consequences of unfaithful partners for wāhine produced similar effects.

Tāne in this study who did not have a current intimate partner talked about the importance of finding the right woman. Grayson and Max said they did not have many opportunities to meet women and were concerned the ones they knew needed more support than they could provide. Grayson said although he wanted to be in a relationship, he often chose women whose lifestyle were triggers for him.

The girlfriends, they got kids, got a ready-made family you see... That was one girl, the girl over here, well; she was an alcoholic and drug addict (Grayson).

Grayson, Max, Rob, Antonio and Zane said it was important for men to feel loved, to be in a relationship and to provide for their partners and families. However, because of their illness they felt they deserved to be on their own. The comment, "I don't blame her for leaving me" was often heard.

Some whānau in the study presented with low self-esteem, self-harm, fear of abandonment, drug and alcohol abuse and severe dietary restrictions (which suggests an underlying eating disorder) that impacted on their ability to engage in healthy relationships. These factors also highlight issues of co-existing diagnoses particular to bipolar disorder that will be discussed later.

Tamara, Martina and Meri were young wāhine who became unwell when problems arose in the relationship such as infidelity (real or perceived) or when the relationship ended. Antonio said he reacted badly to his girlfriend leaving him after he told her he was too young to get married. He said he stowed away on a boat to get away because he, "couldn't handle it" and that, "no-one



had ever dumped me before". Impulsivity was a common feature among younger whānau, particularly when relationships and alcohol and drugs were involved.

Alcohol and drug use was also common. A particular feature for some whānau was a lifetime of difficulties with low self-esteem or feeling abandoned by their parents, and how those feelings played out in their intimate relationships. Meri said her difficult relationships eroded her sense of identity and self.

I met this guy who was nine years older. Charismatic, exciting. Within a month of leaving home I met him. I was excited and thought I wanted to be with him forever. That was the worst decision I could have made. I quickly moved in with his life, family and friends. He loved it that someone idolised him. He wasn't at all attractive (Meri).

Martina said she suspected her boyfriend of cheating on her which led to checking his phone when he was asleep. When she discovered text evidence on the phone, she confronted him.

We were out drinking and I looked at his cell phone. He was texting his exgirlfriend. We had a big fight and I ran out of the party and tried to jump in front of a car (Martina).

Martina commented that she often worried and was highly anxious; she eventually became extremely depressed. She added that, "he was bad for me because he drank and he wanted to keep texting his ex". Martina said that at the time she was working full-time and she felt the pressure to perform at a consistently high standard. The stress of her unfaithful boyfriend contributed to a break-down.

Her first entry into the mental health system occurred after she became severely depressed at work, which she attributed to increased pressure to perform and her struggle to cope with her boyfriend. She described a continuous internal dialogue that she could not control.

If I'm not happy at work, people are going to talk and if I'm not good I won't get the work done, then people will think I'm useless and I'll lose my job. Then I'll be a bum and my family will think I'm useless too. Then my boyfriend will leave me. You know, it's just snowballing (Martina).

Her ruminations and intrusive thoughts led to an episode of intense and relentless anxiety, and then depression and suicidal ideation. She thought she might drive into oncoming traffic. Ironically, the final trigger came when her car failed a warrant.

I started to lose myself. I decided I was going to kill myself. I would cry in the shower. It was the anxiety. It was hard to get out of bed. I'd be crying in bed, then I'd get in the shower and I'd be crying. I just wondered how I was going to get



through the day. I didn't want to hurt myself because I knew it would hurt my family (Martina).

Martina was taken to the mental health service, assessed by the crisis team and prescribed sleeping pills, anti-anxiety and anti-depressant medication, which she said helped her to settle over the following weeks. The bipolar diagnosis came after her second visit to the service six months later, again, following a period of intense worry, lack of sleep and a fight with her boyfriend. Martina stopped using substances, ended her relationship with her boyfriend and feels more in control of her life.

Martina felt that her life had been heading, in her words, "downhill" for a while, but she said was the, "bad breakup" with her boyfriend that affected her wellbeing,

I was really low, like not wanting to get up, not motivated, crying all day... starting to hear things and see things. I'm like, was that really there?! But I was having problems because he was too busy talking to his ex, so I was like, well if you're going to go back there then just go back, and just leave me alone (Martina).

Pua described multiple stressors leading to her first episode; however, she felt her relationship break-up and the passing of her friend had been large contributors.

I was diagnosed in 2010, and I was admitted into the intensive care unit in Wellington hospital, but before that I was studying full-time at uni, I was studying full-time at Te Wānanga o Aotearoa, I was working full-time, I was working on releasing my album, and then I had a relationship break up and my best friend passed away. I stopped eating and sleeping for like five days, and I was heavily self-medicating, smoking marijuana, and then that led to psychosis (Pua).

Each story shows the significant impact relationships can have on mental wellbeing and that when multiple stressors are present there is eventually a tipping point.

# Raising families

# Postnatal depression

This theme relates to childbirth as a significant life event that precipitated mental unwellness, in particular, post-natal depression. The theme relates specifically to wāhine although it is recognised that family members of wāhine with postnatal depression also experience considerable distress and disruption. In each story it appears that pre-existing mental health concerns were present and child birth precipitated a diagnosis of bipolar disorder or post-natal depression. Some wāhine experienced multiple stressors which caused the 'balance to tip'.

Tina, Awhi, Hine and Niwareka were diagnosed with post-natal depression following the birth of their children. Their experiences are almost mirror-copies.



I think I had post-natal depression way back in 1969 but I didn't understand what was happening and I couldn't talk to anybody. But through that not very nice experience and having a baby, and lack of sleep and stuff like that, I think it aggravated things. I was trying to tend to the baby, but for me it was that, trying to look after my baby, but not really looking after myself (Hine).

Hine struggled to understand what was happening to her emotionally. She sought help from her parents and together they went to see the family doctor who put her on medication for postnatal depression.

I didn't know anything about post-natal depression. Pania was my third child and I wasn't supposed to have any babies after her; the doctor said, but I went to him and said you going to send me to Tokanui are you? (Hine)

Hine, Tina and Niwareka lived in abusive relationships and had histories of child abuse and trauma. Their stories reflect a cycle of abuse that was not addressed for many years.

Despite Tina's abusive upbringing, mental health issues were not formally noticed until she was in her early 20s. She recalled dealing with trauma-related issues such as flashbacks of her childhood abuse, and she lived with a partner who was emotionally and physically abusive to her.

I was in an abusive, violent relationship. It affected my babies and me being pregnant. I was suicidal, I started cutting. Looking back; is that mental illness or is that trauma? If I was in a loving relationship, or not in an abusive one would I be like that? I don't think so (Tina).

Tina's relationship ended when her baby daughter was three days old. At that time, she had three other children under the age of five.

I couldn't hold the baby; just spent hours just staring into space. Panic attacks, flashbacks of stuff. That's what I saw as unwell. I felt detached, numb...I realised that I wasn't ok. I cried a lot. I went to a doctor after I had baby and was diagnosed with post-natal depression. I never experienced a period of wellness...wellness is the opposite of all that (Tina).

Tina went on to another relationship and became pregnant with her fourth child. She said she was aware of the risk of post-natal depression and told her GP. At that stage she was living alone with no other family around. She was supported by the rural mental health team.

I was hospitalised after baby was born and diagnosed with bipolar disorder. The children went with their dad. I couldn't understand the diagnosis. I moved back to Wellington. I was with the community mental health team (Tina).



While the responsibility of raising children was a protective factor for some wāhine, three whānau found childcare a major stressor that they associated with their tipping point. Hine said she found it difficult to cope with child-rearing alongside her relationship difficulties with her abusive husband, "I was trying to tend to the baby...but not really looking after myself".

Awhi's situation was similar to Tina and Tania. Awhi, who already had a diagnosis of bipolar disorder, was diagnosed with post-natal depression after her first child was born. As the years past Awhi was unable to care for her children and they were placed in care.

I brought her up here and I was in hospital and they said, "we can't have her here" so CYFS said, "we'll take her for three days" and I never got her back. For years, I just kept on drinking and the illness got worse. This was about 2001 when that happened. I was on medication at the time but I can't remember what it was...

But it is sad losing my daughter; I was screaming and went through all sorts (Awhi).

Awhi's daughter was placed in several foster homes until she eventually settled with one family. Her other two children lived with their father; a decision she was grateful for.

I had them up until three and four years old, then I passed them on to their dad, he brought them up, because I was kind of like manic and always hearing voices; in and out of hospital (Awhi).

Awhi was now happy with the way her daughter was treated.

When I looked after her down South, it was freezing cold, but she never ever caught a cold, but then I get up here and I find out she's been through seven homes and she's had glue ear, all these colds and you know it hurt really bad realising that she went through that. But she's good now. She's been with this family for about seven or eight years, and they're religious so that's good (Awhi).

Awhi said she gave her children to their father when she was in a 'manic phase'. Although she tried to get her daughter back, she was not successful. She did not say whether she had appropriate support to help her look after her children; however, she said she kept a clean home and her children were looked after until she became unwell.

Huia attributed being acutely depressed with having children. Huia's ability to parent was severely impacted by her depression which she lived with for many years until she received medication that suited her.



I got married and had children. As soon as I had children I turned grey. It was so hard raising kids. It was so hard being on medication. It wasn't good. I felt trapped because I couldn't go off medication (Huia).

The stories describe how much support is needed when women with mental health concerns have children. The stressors in the lives of women who have unmet needs are exacerbated when they are faced with childrearing responsibilities. The way women and their families were treated at critical times in their lives appear to have contributed to their on-going illness.

# **Everyday work stress**

As a precipitating factor, this theme relates to life events that become increasingly pressured. Life events refer to normal, expected routine situations that become too difficult to manage. The type of events or situations whānau described included employers setting unrealistic deadlines, study pressure being too great or more than expected, and employment being terminated. For some whānau the work environment was tied to their wellbeing and was seen as a place of safety and continuity.

The pressure of work or situations beyond whānau control, combined with relationship difficulties, was the catalyst for mental illness. Whānau often described maladaptive coping patterns that fuelled their problems, such as working longer hours, not sleeping, or drinking and taking drugs.

Niwareka said she was, "one of the best in her workplace" but as a result more pressure was put on her to achieve higher targets.

I had hit 100 per cent of the target for three years running. The downside, however, was that I was rewarded by having the goal post raised, and with MSD [sic] and bipolar, this was the worst thing to do...In the same period I was going through a relationship break up (Niwareka).

The culmination of a marriage break-up and increased workload proved unbearable for Niwareka. Not only had she worked hard to sustain her marriage despite the infidelities and abuse, in her view her workplace had, "moved the goalposts" on her.

Tina said that she had been working as a consultant for five years without taking any breaks. When she finally did take a break her contract ended without any notice. Shortly after she became depressed she sought help from her GP who prescribed a new antidepressant. Tina had a, 'manic reaction' to the medication lasting three days before she was stopped while driving for a routine breath test. She said she was just over the legal limit and was charged with a driving offence. A few days later, she said, "I crashed; suicidal, self-harm".



The psychiatrist said that I had reacted to the drug, called it citalopram, that created a spike. They saw that I had epilim, zopiclone. That's when they said that I had bipolar (Tina).

Tina's 'manic reaction' features in other whānau stories and will be detailed later. A work-related stressor occurred when Huia went on an overseas exchange for 16 months. Early into the exchange, Huia's anxiety escalated to the point that she did could not function. At the time mental illness was not openly discussed as it is now.

It was so important to do the exchange. I had to keep going. All I needed to do was stop for a little while and say...but at that time they didn't know anything about mental illness. They talk about it naturally now. People didn't know. It was very frightening, because I was getting sick. My vision was blurred. I was so miserable and I knew I shouldn't feel that way. I was usually so happy (Huia).

Huia said she became depressed and could not be left on her own; she was eventually sent home, "I didn't know what was happening and I didn't know how to manage it; I used to cry all the time. I was frightened, I was absolutely frightened". A feature of Huia's illness related to the amount of pressure she was under. As a married woman with two children she decided to try studying, however, the workload became unmanageable.

I had been struggling all my life but I was determined to try and get somewhere. I studied part-time then I went full-time. At that point I started to break down. I was losing it. I was stressed trying to meet deadlines. I was very, very, stressed and I couldn't function (Huia).

Huia became acutely unwell and sought help from the mental health service. In her view, the team did not believe she was unwell and refused to help her. It was several weeks before she received help and that was only after her husband rang the service and after she went to the service and refused to leave the reception area. Her experience is similar to other whānau and will be described later.

Tui had spent more than a year living overseas. When she came home she struggled to resettle and was overly concerned about her weight and what she was going to do with her life.

I didn't know what I wanted to do with my present [sic]. I was always thinking about the past when I was overseas doing this and that. So I think the reality of it all made me get a bit unwell I think. I was now back in NZ, had to get a job, didn't know what I wanted to do, all sorts of things...I had also put on a lot of weight too (Tui).

Her family noticed she was acting strangely and worried that she might hurt herself. Tui said she was taken to a mental health service for assessment and remained there for one week. Tui did not think she was managed well and should have stayed longer.



They noticed straight away, strange behaviour from about a month before leading up to when I was admitted, I was also psychotic, thinking people were persecuting me, I was getting paranoid. Just thinking people were out to get me (Tui).

Like other whānau, Tui was discharged before she was ready and she refused to take her medication (Tina also refused for many months) believing she was capable of managing on her own. A common finding among whānau was that they enjoyed the feeling of being elevated, particularly after periods of deep depression. Tui said that, "the doctor was spoiling my buzz. I was hearing all these good voices. Everything was wonderful and a lot more exciting than it normally was".

Within a few months of being discharged her illness exacerbated to the extent that she committed a violent crime and was hospitalised for several years. She said she does not remember the event but believes it to be true. Her diagnosis was changed to paranoid schizophrenia.

Others mentioned study as a major stressor which triggered their illness. Māpihi's first episode was brought on by a heavy workload at university. She described having little support during her time there. It was in her third year at University when Māpihi began to experience changes in her mental state.

It seemed so huge that it was a mountain I couldn't climb. I couldn't see how I could climb it, and I didn't have a strategy for how I would do that. But the more I thought about it, the more unwell I started to get...I realised I hadn't slept for a week, because if I slept, or if I ate anything then I'd feel guilty that none of this work was getting done (Māpihi).

#### **Summary**

Each whānau described how they came to be involved in the mental health system. Some of them received a bipolar disorder diagnosis at their first admission while others spent years, even decades, in and out of services before they were diagnosed. Whānau described, in detail, the context for their episodes of mental illness and psychiatric admissions. The evidence for bipolar disorder was unclear as the stories showed considerable premorbid (pre-existing) mental health concerns and situational stressors that contributed to ongoing difficulties. These stories show that pathways to mental illness must be understood so that the appropriate care can be provided. The trauma-informed model of care provides a more comprehensive understanding of the presence and consequences of prior traumatic experiences on mental health.



# Onset of bipolar disorder

This theme outlines the period when whānau were first diagnosed with bipolar disorder. There were mixed reactions to the diagnosis. Some whānau felt the diagnosis was incorrect, too early, or that it came too late.

Whānau were asked to describe events leading up to a diagnosis of bipolar disorder and their reactions. The events are described as they occurred including what was conveyed to them by health professionals or family members. Their experiences show a range of characteristic highs and lows in behaviours and thought patterns that affected their wellbeing or the wellbeing of others. Most whānau knew their warning signs and when to seek help; while others had no idea they were unwell.

Whānau most commonly described increasingly stressful circumstances that precipitated their mental health crisis immediately before their bipolar diagnosis. Some experienced multiple stressors which caused them to behave uncharacteristically and were, more often than not, a cry for help. Accounts of stressors most frequently involved destructive relationship break-ups and abuse, stressful work situations, paranoia and hearing voices.

A predominant theme across the stories was the potential and actual risk to self or others. Several whānau spoke of suicidal and self-harm behaviours during times of pressure and struggle, and their inability to cope with the demands of work, relationships, study or childcare. Others told stories about their 'bizarre' behaviour that was concerning and out of character.

Some whānau described their first visit to a mental health service, while for others the visit was one of many. Niwareka, Tania, Awhi, Tina and Hine's stories are similar, in which multiple admissions were a feature of their lives and living with mental illness had taken its toll on them and their families.

#### Risk - to self and others

Risk refers to the impact of unmet needs. Whānau risk involved suicidal ideation and behaviour, drug and alcohol abuse, gambling addictions, physical and emotional abuse and the ability of whānau to care for their children. In many cases whānau responded to the stressors in their lives with little or no support and, often, with extreme consequences. Huia's comments reflected the views of other whānau who sought relief from the effects of chronic and acute depression and distress.

I understood why people wanted to die. Now I understand why people want to commit suicide. Inside your body there's no comfort. There's just emptiness, total complete emptiness, a fear of being on your own, and just frightened (Huia).

Zane, Rangimārie, Māpihi, Max, Grayson, Awhi, Tamara, Martina, Meri and Pua responded to the stressors in their lives by self-harming, drinking or smoking cannabis. Martina threw herself in



front of oncoming traffic following an argument with her boyfriend, Tamara cut herself to relieve intense emotional distress and Awhi drank alcohol and smoked cannabis for many years.

Four times I've slipped up in the last seven years on alcohol, because I used to drink and drink full on for ten years and hearing voices and getting paranoid, I was paranoid for years, it drove me crazy (Awhi).

A pattern emerged in the stories that showed the chronicity of whānau unmet need. Niwareka had made three serious suicide attempts at age 14, 23 and, again, in her 30s, but she recalled there was no follow up after each attempt, "each time I was just put in hospital and then sent home. I was never ever sent to a psychologist for help…my stomach was pumped, and I was discharged with no follow up" (Niwareka).

The third attempt occurred after she found out she had to run a new course at work. She described feeling, "as though someone had me by the throat and up against the wall, and I kept hoping that not enough whānau would show up so that I didn't have to run the course". She contacted a psychologist and asked for an urgent meeting. Following a brief consultation she felt well enough to continue working. After a few days she became increasingly agitated. She called her partner and he told her he was leaving her. In her view it was, "something that just broke the camel's back which led me to make my last serious attempt to commit suicide. I just couldn't take it anymore". Niwareka was committed to the inpatient unit in Rotorua and a psychiatrist diagnosed her with bipolar disorder.

I was disappointed that I was still alive. It was as if all of those years of anger had just come out. I was determined that if I was released that I would go home and "finish the job". The pills hadn't worked and I was so angry, but I was determined to either shoot myself or drink weed killer. I was asked to volunteer to go into the ward but I wouldn't because I thought that there was nothing wrong with me, so I was committed (Niwareka).

Niwareka's story is typical of whānau, particularly women who had a long-history of service involvement. There appeared to be multiple entry points where their needs could have been addressed earlier. A few whānau said that although they wanted the pain to end, they knew their families would be devastated. Similarly Huia said she wanted to end her life, but because of her religious beliefs she thought she might be depressed in the afterlife, which horrified her.

Tania started seeing a psychologist when her children were taken from her by CYFS. Her mother and sister notified CYFS after they learned she was living in a bus in a motor camp.

So it was about, the year 2000 or something, I was finally diagnosed with bipolar and by that time CYFS had taken my children. We were left at home by ourselves as children; all six of us. Yet my mother was quick to judge me and call CYFS to report me. My family all knew that I had been diagnosed with bipolar but they never told my sister. She [Tania's mother] told CYFS that the



whole family had tried to support me and help me with my living situation, but that wasn't true at all (Tania).

As noted earlier, childbirth and childcare were major triggers to unwellness for most female whānau. After her second child Hine was diagnosed with post-natal depression and really struggled, "...through that not very nice experience and having a baby and lack of sleep and stuff like that, I think it aggravated things". Hine's second child was born with a cleft-pallet and required, in her words, around-the-clock spoon-feeding. It was not until her mid-30s that Hine was diagnosed with bipolar disorder; by then she had five children.

I had more kids to care for, and just the home environment, and relationship more than anything else and trying to cope with the kids (Hine).

Tina also struggled to care for her new born baby and was diagnosed with postnatal depression. She explained that she was hospitalised after her child was born and was diagnosed with bipolar disorder, "the children went with their dad. I couldn't understand the diagnosis". She said she struggled to understand what this meant and what a diagnosis of bipolar II might lead to.

When they gave me the diagnosis I asked what it is and they told me that it has highs and lows...I remember thinking, I don't believe you guys? Yes lows, but I'd never had a high. Then they told me I was bipolar 2. They didn't explain. I asked, well is there a 3, 4, or 5 that goes after that? (Tina)

Tina described herself as 'rebellious' for the first year of her diagnosis. She refused to take her medication. She felt that each time she experienced a 'manic' phase it was directly after her anti-depressant medication was changed. Her experience was similar to Huia and Martina. Several stories highlight the risk of a spike in whānau behaviour when they took medication for the first time, or when the dosage changed.

Generally, whānau felt they were unable to control any given situation and that even simple daily tasks became difficult to comprehend. One quote in particular that stood out was from Niwareka.

My whole life is like surfing. I can never guarantee whether I am going to be on a high or a low. Some days I'd be driving to work and would have a real euphoric feeling, like something really exciting is about to happen, but then the next day driving to work I would have that sort of feeling that someone close to me has died, and there's no reason to it, that's just the way my life goes.

I may even be at happy occasions or social events, yet I can't shake the feeling of being so down, and likewise at funerals or sad occasions, I may all of a sudden feel euphoric, and am unable to truly connect or feel sad emotions... These states are totally unrelated to what's going on in reality (Niwareka).



Niwareka described a range of reactions that were out of sync with what was happening around her. Her story also reflects the experiences of other whānau who described experiences of paranoia, hearing voices and seeing things before the illness was identified.

Pua took the initiative to go and see a counsellor because she felt she was not coping following her friend's death and a relationship break-up. She said she was admitted to hospital after five days of not eating and sleeping and self-medicating with cannabis. She was sectioned under the Mental Health Compulsory Assessment and Treatment Act and diagnosed with bipolar disorder. Due to a previous episode of depression, she was referred to a psychologist. Pua said she was told by an elder that she was a matakite (someone with the ability to foresee events).

I thought I was hearing my ancestors, I thought I was Papatuanuku, I thought I was the Māori Moses too, I thought I was seeing demons and angels. It was like erratic thinking, one hour I'd be here, and another hour I'd be there and I'd just chop and change...It was scary, it was probably the worst experience of my life actually, being in the ward. It was like I felt like I had encounters with spirits (Pua).

A negative reaction to medication resulted in Tamara hearing voices, "it made me quite schizophrenic and I was hearing voices and I thought people were coming to kill me". For Awhi, paranoia started after heavy alcohol and drug use, and for Tina, she explained that the voices were, "driving her mad".

Other less frequently mentioned stressors included child-rearing, study, bereavement and fatigue. Most whānau were able to recall the critical incident which triggered their first episode; however, some wāhine only referred to incidents that triggered later episodes.

Tina had become unwell after her work contract was abruptly cancelled while she was on leave. She recognised she was becoming unwell and contacted her GP who, at the time, was on holiday. The attending GP gave her an incorrect dose of medication which produced a 'medication spike'. Tina said she was diagnosed with bipolar disorder after she, in her words, "crashed again".

I was a nutter. I was doing some amazing things. I was moving bricks, all these man-things...It wasn't enough, I cleaned the house, gardening, non-stop. It's hilarious. I wasn't sleeping, eating – it was mad. I was in such a great space. I drank on top of it – a couple of gin and tonics while I was gardening. I needed something from my house so I jumped in my car and I got pulled over by a police officer. I was over the limit. I went to court. It wasn't until a few days later that I crashed – suicidal, self-harm (Tina).

Tina self-referred to the Crisis Assessment Team within a service she had helped to establish (Tina worked as a consultant for mental health services). The psychiatrist said she had reacted to the drug citalogram which created a spike. The effect of incorrect medication, incorrect



combination and dosage was a consistent experience of whānau and, more often than not, seemed to make matters worse.

Antonio (married with three children) was working as a social worker when he came to the attention of a work colleague who was a psychiatrist. He recounted that his colleague asked to speak to him citing some of his behaviour as a reason.

I'd hop on a bicycle and disappear for two days. I was just going for a ride, just cycling around. I didn't think it was anything strange. But then my colleague was the one who said I was bipolar. They used bipolar and manic depression. I asked him to explain it (Antonio).

Antonio said he agreed with his colleague and that other family members had similar experiences. Antonio was hospitalised several times throughout his life, adding that stress was his main trigger. He said eventually his wife left him as he was difficult to live with. Antonio moved to Auckland, taking his older sons with him while his daughter stayed with his wife.

Max said he was sexually assaulted when he was 14 and was admitted to a psychiatric home when he was 16. In his view, the assault was the reason he was unwell.

At that time, confusion, different moods going up and down and up and down again, you know crying and then next thing happy, and aggressive and then happy (Max).

Max said he was officially diagnosed with bipolar when he was 16 years old.

I've had every single chemical known to man for bipolar, trying to find the right dose. I've been on epilim now for nine or so years (Max).

Max said it was easy to notice when he was becoming unwell as his mood changed and he gave away his property.

Things like giving away smokes, giving things away, early warning signs, signs of aggression, and fluctuations of mood. For me giving smokes away but going overboard like giving whole packets away, overindulgence in things, isolation is another one, sitting in your room, in your house, paranoid whether you're on drugs or not. Going to drugs and going to addictions is another sign, alcohol, marijuana, dairy dack, gambling; giving yourself happiness through things like that (Max).

Some whānau described their experiences as exciting and amazing and others as scary and terrifying. They were most commonly characterised by racing thoughts, high creativity, hearing voices, grandiose thinking, irrational choices, over spending and overworking within their work place. Tania experienced rapid shifts in her moods in which she was constantly switching from highs to lows, racing around doing the gardens, going on shopping sprees, binge drinking and then feeling regretful about it.



I suppose you go into manic episodes of having delusions of danger, or you think you're God and all this sort of stuff. Yeah, you can go there; it sort of escalates over time, you feel you get more powerful (Philip).

The euphoric feelings are exciting for me, it's just like geez something GREAT is about to happen. It's as if you've won lotto and you're just waiting for someone to tell you. It's not very frequent though there are more lows than highs (Niwareka).

I thought I had to do these certain things. I have these visions of things that you have to do, they say its grandiose ideas...your mind is just racing and its unrealistic...you just can't believe it, it's just impossible for you to comprehend, you don't have logic, you don't have reasoning skills, you have nothing, because everything that you're experiencing is against the normal human feelings and everything I had felt in the past (Huia).

Paranoia started, it was terrifying. Sometimes, it was like you'd go into places and it was quite scary. You'd think people could hear what you were thinking about...The voices were pretty scary, and then there are other voices that just talk and talk and they don't stop, it's like whoa. Everywhere you go. You have sleepless nights and just want to run away from your house and have a break away from there. You hear voices coming from the walls. It's just so scary (Awhi).

There's no real warning for the manic phase, I guess not sleeping and talking a lot, just not really like me, I'm usually quite reserved, but at the same time with the manic phase you feel quite euphoric, you tend to ignore those signs because you feel alright, and with the depressive phase, it can last for ages, for months (Zane).

There appears to a consistent story from whānau about how they became manic after taking a course of antidepressants which is then documented by health professionals or family members and, at times, provided as evidence of bipolar disorder. Huia described shifting from a depressed state into a high after her psychiatrist prescribed her, "an enormous amount of pills".

I woke up in the morning and it was like going from dark to light. It had an instant impact on me. I could feel again. I could taste. I was so excited. But then I went straight into this mania. I didn't know. I thought I was ok. You can imagine the elation that I felt. I thought I had lost my life, then straight into being really happy. But I was really aggressive (Huia).

The majority of whānau said they were unable to comprehend how they could have done the things they did. As Hine said, "I just took the risk and did it". Huia also said, "I didn't even know I was doing it". Niwareka went on to explain that when she was out of her manic phase she was able to, "sit there and have time to reflect" which she found helped her recovery. A theme



described later highlights the necessity for whānau to reflect on their experiences and develop insight into the progression of their illness and its effects.

Typically, when the highs subsided, whānau described slipping into deep depression. For many, these periods involved a lack of motivation, excessive sleep, drug and alcohol abuse, feelings of hopelessness, sadness, emptiness and, in some cases, thoughts of suicide.

I just kept being told depression until I got admitted the first time they said we want to look at personality disorders... It's always just been, "you show traits of this" but they've always said, "you show traits of quite a few but we don't know which one it is" (Tamara).

Huia said being depressed robbed her of her life. For most whānau, depression impacted on their everyday functioning and relationships with others.

When you plummet back down to earth you go into depression. For years after that my medication made me feel heavy. I could see everyone else functioning well. But I couldn't do the same thing because it felt so laborious and I'd get really tired. The drugs made you sleepy anyway. They numb you (Huia).

Pua and other whānau felt their depressed states were associated with their prescribed medication.

I didn't really get into the depression until I started taking medication...I don't know if it was coming down from the mania or if it was the medication itself but it was like I had no feelings. I felt like a zombie. I didn't go anywhere, and I'm a very social person (Pua).

Most of the time I was in a depressed state, the medication was so heavy, I felt like I had bricks in my head, I couldn't think, I couldn't function, but I just thought that was my lot, this is my life you know, and it was horrible (Huia).

Tina's depression occurred within a context of childhood sexual abuse and an abusive partner who had left her with three children while she was pregnant with the fourth child. Although she knew her partner was abusive she was still deeply distressed at the separation.

Dealing with trauma related issues, flashbacks of my childhood. I realised that I wasn't ok. I cried a lot, just spent hours just staring into space. Panic attacks, flashbacks of stuff. That's what I saw as unwell. I felt detached, numb. Those feelings I've had forever, since childhood. Numb. I was worried about how I was feeling and my girlfriend suggested that I go to therapy (Tina).



Tamara said that she felt, "really low, not wanting to get up, not motivated; crying all day". Pua described how she was under a compulsory treatment order which years later, she felt warranted a complaint.

I hated it, it was depressing. I fell into depression. I watched TV for two years, didn't laugh for two years, and I was heavily, heavily medicated (Pua).

Tina, like other whānau, was deeply affected by the hopelessness associated with depression.

I hated myself, I walked with my head down and shoulders hunched. I didn't look at anyone in the eye. All I saw was illness and ended up with me self-harming. I stopped ringing friends. I didn't want them looking at me in disgust (Tina).

Depression appeared to place the highest burden on whānau and their families. Whānau talked about how their thoughts and ruminations about poor self-esteem, lack of motivation, wanting to belong and hopelessness affected their moods. Importantly, whānau often did not know what they could do to alleviate their distress.

# Consequences of a bipolar disorder diagnosis

# Experiences of mental health services

Whānau were asked to talk about their experiences of mental health services. It has been established that for some whānau engagement with health services was a lifelong experience that was largely unsuccessful in meeting their complex needs. Others talked about service involvement over a relatively short period of two to five years. Tina's account of her experience of mental health services contributed to her low self-esteem and self-worth.

I experienced a lot of discrimination. My experiences, from their perspective, anything I displayed emotionally, it was mental health, it wasn't human. They took the human out of me. If I was sad, I was seen as depressed, take a pill, if I was excited about something, I was manic, take a pill. Everything was seen through mental health and so I started discriminating against myself – theory of internal stigma – beyond shadows (Tina).

This section describes how whānau sought help from services and details what worked and did not work for them. The stories show a variety of experiences that were seen as either supportive and empowering, or disempowering and negative.

Sub-themes included not receiving help, being treated as non-person, being discharged too early, a reliance on medication and diagnostic issues. In particular whānau spoke about how heavy medication affected how they engaged with the service and whether they participated in the treatment plans offered.



Whānau saw a range of health professionals which included GPs, crisis assessment teams, counsellors, psychiatrists, nurses, tohunga, care workers, psychologists, social workers, health advocates and teachers. Overall, they were more likely to be seen by a GP or a psychiatrist.

Whānau described feeling like they were, "just a number" when they engaged with mainstream mental health services. They expressed concerns that staff spoke to them as if they were children and treated them as if they were not normal.

Sometimes staff out there would treat you as if you're not like them, like you don't need a husband or you don't need a partner; you know, you're not well for this, you're not well enough for that (Tui).

Tui's comments are reflected across several whānau who felt that they were not acknowledged as real people; rather, they were just another patient who required their services. Niwareka's comments highlight a concern that there were other contributing factors that needed addressing, "maybe some more personal questions so that they could make me feel as if I was a person, they didn't know me, I was a stranger...nobody asked what my home life was like or what I had been through".

Whānau experiences show they had to convince service staff they were unwell. At times, family members or work colleagues had to advocate for them so that service staff would take them seriously. Whānau said they became distressed, suicidal or anxious when they were ignored.

When Huia began to feel unwell she sought help from a mental health service and found it difficult to convince the service to organise an appointment with a specialist. She spoke with the crisis team for an hour, was prescribed another brand of antidepressants and sent home.

I knew that I was getting unwell. I went to a service and they were good to me and told me that I needed counselling. They didn't think I was that bad. They thought I needed more confidence. That was a Māori service (Huia).

Huia said within a week she nearly had an accident which prompted her husband to take her to a mainstream mental health service. Although she said the psychiatric nurse, "was brilliant" and she felt, "he really heard me", she was sent home. A few days later, and still without an appointment, Huia went back to the service.

I went into the service and blew them up. That was Tuesday. I went in on Friday. I asked to speak to them. They knew I was angry. I was all dressed up. I had my make-up on.

I said, "I want to speak to this person. I'm leaving in ten minutes". There were two of them. I said, "you are bloody useless. I told you I was unwell. You can get stuffed. I'm going up north".



They asked me what medication I was on—what dosage. They said, "can you wait?" I said "no, get stuffed". I said that I've been unwell for so long and you haven't helped me, so get stuffed (Huia).

Huia's medication was adjusted and she went to her mother's home for one week. On her return she saw a psychiatrist who confirmed she had bipolar disorder and she had not been given the correct combination of medication. She welcomed the diagnosis and changes to her medication.

Huia's actions indicated the lengths she went through to get help. That she narrowly escaped a car accident is telling. Māpihi, Tamara, Martina and Tina explained that their suicidal and self-harm behaviours were calls for help because they were not able to communicate what they were going through. Tamara said that her cutting behaviours were cries for help, "well now people know I'm sad, like someone acknowledge this please, someone acknowledge that it's real. It's all saying that something's wrong".

Tina recalled suicidal behaviour and cutting herself while in an abusive and violent relationship but said, "looking back, is that mental illness or is that trauma? If I was in a loving relationship, or not in an abusive one, would I be like that? I don't think so". Tamara and Tina's questions reflect a prevalent finding among whānau that the lack of information and not having a tailored approach impacted on their recovery.

Awhi found she did not have a voice in the mental health system. Although she wanted to tell others what was happening for her, she did not understand what was happening.

People in the mental health system, the clients, they don't know how to communicate, their voices are just going around and around, they don't know how to talk to the doctors about what's actually going on (Awhi).

Māpihi explained that within mainstream services they did not acknowledge the importance of, "our Māoritanga" and dimensions such as, "taha wairua, taha whānau, taha tinana, taha hinengaro". Several participants also spoke of this disconnection in their encounters.

Max and Grayson lived in a kaupapa Māori residential facility with 24-hour supervision. Both whānau said they enjoyed being at the facility because it stabilised their situation and reconnected them with whānau, often because they had, "burned a few bridges" (Grayson).

Through my gambling addiction, that's the only reason, you go to your addictions, mine is gambling, then I'll end up on the street because I haven't paid my board, then I run to a service like this to save my ass because I fucked up (Grayson).

You never really left aye, I've known him since he was 19, we've both been here since 1999, so we've been here a long time now, we always come running back here when we need help, it's always a good stable place to live kai, house, the needs are met (Max).



Most of the time, I live here, but the thing is you're in your own environment, you're [sic] with the boys, mates, sharing cigarettes, it takes you away from the world aye. Bills are sorted, kai is sorted, medication is sorted, it's all done for you so it's easy to get up and do the other things. Your told do your dishes! Clean your room! So you got to listen, or you get the consequences (Grayson).

You get put into routine, and that's what you need in life aye because at the end of the day, once you've got a routine, everything seems to slot into place. When you have an appointment, you get to your appointment you don't miss it, because they're onto you, the staff (Grayson).

Residential, supported accommodation provided stability, food, social connection and routine to whānau. Whānau said a particular benefit of kaupapa Māori services was that their cultural identity was visible and valued and there were opportunities for them to reconnect with their families.

Not everyone had positive things to say about mental health residential services. Tania felt that residential care only offered medication as a treatment option.

The difference between people who don't live well with bipolar and those who do is that they're in residential care and they're over-medicated and under-talked... Without the talking there's no healing, and medication only numbs it (Tania).

# Disconnect from family and friends

During the initial stages of bipolar disorder whānau experienced disconnection and often spoke of feeling isolated or wanting to isolate themselves from others. Some whānau felt shame, guilt, embarrassment, self-doubt and very low self-esteem during periods of unwellness. These feelings were associated with the stigma attached to mental illness, as well as the manic and depressive episodes that had occurred in their past and the consequences of those episodes. During periods of wellness, reconnecting with family was a significant concern for many whānau.

Tania experienced a lot of derogatory remarks and lack of support from people who found out she had bipolar. She said that, "everyone was too busy pointing the finger at me instead of understanding my mental illness". Other whānau felt having bipolar disorder impacted on their ability to read certain situations and to act appropriately to their surroundings and social interactions. Many described intense paranoia which left them frightened and unsure of what to do because they did not have an understanding of what was going on for them. Pua described feeling "flat a lot of the time" and "feeling like a zombie".

For most whānau, the symptoms they described were the result of inadequate information about mental illness for them and their friends and families. Many whānau described difficulties in maintaining friendships and relationships, mostly after they had been diagnosed with bipolar disorder. Tina, Awhi and Tania became more and more distanced from their friends as a result of the shame, guilt and stigma attached to bipolar disorder.



Tania described feeling, "socially inadequate"; while Tina stopped ringing friends because of embarrassment she felt after she had done something, "out of the norm". Both Huia and Hera felt unable to connect and relate to people, and Pua, who described herself as once being a, "social butterfly" became very withdrawn and kept to herself as a result of being bound to her home for two years.

Niwareka said she began to feel "socially-phobic" which influenced her decisions to attend any social occasions that involved a lot of people.

I would always decline any kind of invitation to socialise. However, it was important for me to ensure I had some contact with people and stay connected even though it was difficult for me (Niwareka).

She also felt she was unable to maintain close relationships as she found them, in her words, "suffocating", in particular when she was in a romantic relationship she explained that she would fall in and out of love very fast. She said, "it doesn't last long".

The personal impacts of having bipolar disorder were significant for whānau and hindered their ability to live positive, healthy and well lives. The process of learning about and understanding the illness and also themselves helped them to push through barriers of self-doubt and low self-esteem to pursue their goals and their aspirations to live well.

The following section outlines the impact of bipolar disorder on relationships with whānau and children, child-rearing, and study and/or employment.

Because bipolar disorder had been put on my file, it had affected my professional life where I was unable to get income protection insurance, yet I never missed a day of work. The week I had in hospital was the longest time I had been off work. Insurance of any kind became more difficult for me to attain (Niwareka).

One of the questions to whānau was about their perception of the impact of mental illness on their ability to parent their tamariki. Two major themes emerged from their responses: the need for support to raise their tamariki and tamariki as a source of strength and wellbeing.

Whānau expressed that their children were a pivotal aspect to their wellness and recovery. Hine and Hera loved to watch their children and mokopuna learn, grow and achieve, "it took away the loneliness" (Hera). Tania's bond with her grandson made her happy, despite her son's disapproval of her. Niwareka said looking out for the wellbeing of her son was, "part of the healing process", and Tui, although she was told that she should not have children, loved to spend time with her nephews.

Zane also talked about his love for his son and the motivation he drew from him. Zane was a sole-parent for a time but his son eventually decided that he wanted to live with his mother. As a



retiree, Antonio lived in a residential home for the elderly which was situated next to his grandchildren's school. He said he enjoyed looking for his grandchildren during their breaks and, although they could not see him through the window, they still waved in his direction. It is important to consider the role of fathers, as often men are portrayed in unhelpful, stereotypical ways (Hokowhitu, 2004). Zane and Antonio linked their wellness to their children and, in Antonio's case, his grandchildren. The importance of supporting parents with mental health issues to continue to be parents was a significant finding in this study.

The effect of parental mental illness was significant for many whānau. Some described how they struggled to be parents, while others were resigned to not seeing their children again. Max said he had a daughter (now 42 years old), but he only met her on one occasion. "I only seen her just the once when she was about three years old, all I did was bought her a milk and took her shopping for some clothes, that was about it, haven't seen her ever since". Whānau acknowledged the difficulties their children experienced as they were growing up. A significant finding was the lack of support for whānau to be parents and the constant risk that they would lose their children.

A few of the whānau described heavy involvement from CYFS. Tina and Hera had at least one of their children removed from their care by whānau because they were unable to cope and had no support at home. Tui did not have children of her own but recalled high CYFS involvement among the wāhine in the mental health service. She said, "all of them had kids and 99 per cent of them had the kid taken away. And the lucky ones, they were given to an aunty or their grandmother or something, but it can be very sad".

Not all whānau were lucky. Awhi said she tried to get her daughter back, but she was not successful, "I've tried a lot of things to get her back. I went to all the appointments...but it never happened". Experiences of being watched over by CYFS and discrimination from CYFS, family and other health professionals provided challenges to whānau. Tina described a long history of CYFS involvement.

CYFS was around me a lot when I was unwell in the early days... The father was really abusive and it kept making me unwell and I was making bad judgments. CYFS were constantly threatening to take the baby away. I fought that, I didn't want to lose my baby. I dug deep within myself. They weren't supportive. They policed me and my whānau. They didn't say which organisations could help (Tina).

She explained that having a mental illness did not make her a bad mother it just meant she required extra support from others to raise her children. She said, "if I had lost a limb I would have got more support. Would they have taken my babies if I couldn't catch up with them when they crossed the road?" Although this made an impact on Tina's wellbeing, she was determined to keep her children.



A particular difficulty for some whānau was that having children contributed to their illness. However, they also understood that they sought to be well for their children, or grandchildren. Huia explained that she had a "short fuse" when it came to raising her children, "especially while on medication". She said her husband was the main caregiver and because of some of the poor decisions she made about taking medication she, "made life hell for my children and my husband".

Huia had been on heavy doses of medication since she was 19 years old. With the benefit of hindsight, Huia said that although she was quick to react and take her frustrations out on her children, she also realised, "that this was a normal part of parenting whether I had a mental illness or not".

The relationship between unmet parental need and the effects on children was apparent throughout whānau stories. In some cases, younger whānau in this study replayed the lives of older whānau. Tina said while she was in hospital, her daughter was admitted into the youth and adolescent mental health service.

Her going into the ward really just knocked me and pushed me to fight the illness to awhi her. We both got discharged on the same day. We had a cake to celebrate (Tina).

Rangimārie's parents raised her children from a young age. She said she wished she could have been a parent but she was too unwell.

My mother pretty much brought up my daughter. She is a bit of a mess too. She has bipolar disorder as well. She blames me for her life. I don't accept that, we make our own choices (Rangimārie).

A similar pattern was seen with Rangimārie in which her son and daughter became heavy drug and alcohol users. Like many whānau, Rangimārie credits her recovery journey to making a decision to care for her grandchildren.

Then my granddaughter came along. She was two when I had her. I told my daughter that when she is well she should come back and get her. My daughter wanted her back. She attacked me, she stabbed her partner, and kicked my mother. I went for custody after that. There were lots of fights. She had her children for Christmas and she rang me that day as there had been drinking and fighting. My daughter went to jail for six months (Rangimārie).

Rangimārie was the primary caregiver for her grandchildren for two years until she became unwell. Her mother and sister started caring for her grandchildren when she moved into supported accommodation. Rangimārie's mother did not like her living arrangements.



Mum doesn't like this place. She asked if I was lonely. I had just moved in and I was standing outside crying and crying. I felt so lonely.... Because I was lonely, I had my mokos for such a long time; the loss. My mum went home and she cried. She went home and cried for me. I closed myself in my closet and cried (Rangimārie).

A year after that event, Rangimārie said she visits her elderly parents daily to see how they are doing and to clean their house. Her father has Parkinson's disease which has impacted his mobility. Like other whānau, Rangimārie's wellness is intricately tied to her ability to look after her parents and grandchildren. Her story highlights the importance of providing support for parents and grandparents to raise children.

There appears to be evidence for a cycle of unmet need that potentially influenced each generation. In Tina's case her daughter attempted suicide when Tina was in hospital, while Rangimārie became the primary caregiver for her grandchildren because her daughter was addicted to drugs and alcohol. From a strengths-based perspective, it was apparent that whānau who lived with mental illness wanted to reconnect with their children to make amends or to provide support so that their children did not make the same mistakes they made.

Tina felt her children's wellbeing was important and decided that to care for them she had to firstly address her own issues. Tina's other children also had an understanding of her illness and her triggers and were quick to support and encourage her to seek help when they could see her becoming unwell. Through this support, her relationships with her children became stronger.

Hine said her children helped her to maintain focus on wellbeing and also provided practical help. She explained that she put all her attention on caring for her children and neglected her own health and wellbeing. When Hine's health deteriorated, it put a strain on her older children.

It's been very trying for my kids I think. Sometimes I felt like a big hōhā; like a burden. When I've been sick or in hospital, they've taken our responsibility to look after the rest of the kids while he's off doing his own thing in Wellington, his fling. I just think that that's just so unselfish, it's just their love (Hine).

Although Hine found it difficult to raise her children, she appreciated that her older children helped her when she was unable to. She attributed her recovery to children and said their actions strengthened her relationship with her family.

For Tui the impact of having bipolar disorder impacted on her decision to have children. Tui's doctors discouraged her from having children. She explained that not having children really upset her. To compensate, Tui spends time with her nephews, "I don't see it as such a big issue now, I've got nephews". She explained that parenting was a difficult role and when someone is mentally unwell, appropriate support was critical, "the support base when you have children...if you don't have support it's the hardest job out".



Zane, Antonio and Max were the only fathers in the study. Zane said his son is a great source of encouragement and motivation for him to stay well. Zane's son lived with him for a period until he moved home with his mother, a decision Zane accepted because he felt his son needed his mother.

In many of the stories, caring and looking out for the wellbeing of children was a significant aspect of whānau wellness. Regardless of whether whānau struggled to care for their children, it was evident that whenever possible they put their children's wellbeing first and, with support from family members, they were able to develop and maintain positive parent-child relationships. Without support some whānau lost the bond with their children and either did not re-establish contact or were engaged in a process of reconciliation.

The role of mothers and fathers was integral to whānau/family wellbeing. While raising children placed additional strain on whānau, particularly single parents and wāhine in dysfunctional relationships, having their children removed compounded their emotional vulnerabilities. An important finding is that with family and social support, whānau overcame the challenges associated with parenting, particularly once they came to know themselves and what was possible for their families.

Māpihi had a close relationship with all her whānau; however, she explained that the "sympathy" was too overwhelming for her. As a result, she began to hide things from her whānau and did not tell them about the stress and pressure she was experiencing.

They'd look at me like I was just damaged, but I already felt those feelings for myself, I didn't really need anybody else to feel that for me. I couldn't even be strong for myself at the time so it was very hard for me (Māpihi).

Several whānau recalled making bad judgments and getting into trouble with the law and with family when they were in a manic phase. They explained that they had no control over what they were doing and when they came out of the phase they were left feeling, in their words, "confused", "embarrassed" and, for some, "worthless".

For example Tui had been hearing voices telling her that people were out to get her which led her to commit a violent crime. She said, "when I got well I couldn't understand how I could have done such a thing". As a result of her actions her whānau had distanced themselves from her, although her mother tried to be supportive.

It's been pretty hard even for my mother and father because after doing such a thing they must have been nervous at first, even though I am their daughter (Tui).

### Impact on Work and Study

[I'm] more well than not well, which can be hard; functioning normally, working and having a social life and having a relationship and then you know out of the



blue you'll have an episode and then you lose all of that. It's been hard and then there's the getting well afterwards. It becomes hard to find jobs and you end up living with family, I'm lucky I had that family support. But it's really hard to get back to normal life after you've had an episode. (Zane)

The majority of whānau described wanting to work or study so they could contribute to their family, buy a home, a nice car, and pay for their food and everyday living costs. Some whānau said they could not secure a stable job, or felt their workplace environment made them unwell by placing unrealistic demands on them. The effects of unemployment and instability meant that whānau could not hold onto their rental accommodation or pay their mortgage. Obtaining insurance was also a difficult for many whānau.

Awhi spoke of the difficulties in trying to attain employment, explaining that it became, "quite limiting" to get a job and, "hold it down". She explained that, "you can't do normal things in life, because you have to have medication just to keep you stable". Awhi continues to struggle to find employment but she remains determined.

After Niwareka was diagnosed with bipolar disorder, she continued to work within the mental health profession supporting whānau who were living with mental illness. While working she explained that most days she would be fine, but some days she could not take the pressure, "I just have to push through those times and fake it", which left her feeling "extremely drained" and impacted on her health. She also described difficulties in being able to receive insurance.

Because bipolar disorder had been put on my file, it had affected my professional life where I was unable to get income protection insurance...Insurance of any kind became more difficult for me to attain (Niwareka).

Study for many whānau tended to be more about their own determination and perseverance to achieve a goal or an aspiration. Some spoke of study after their diagnosis in a positive light. It was about personal development and showing they had the skill and ability to achieve their goals.

Before Pua became unwell she was studying full-time at University, studying full-time at the wānanga, working full-time at a Kohanga Reo (child-care) and also working on releasing her own music album. Pua was diagnosed with bipolar disorder after her relationship broke-up and her friend passed away. She was not allowed to re-enter Victoria University although she continued at the wānanga, with a smaller workload.

They were very supportive. The tutors even came to my house to help me when I needed help. I got one-on-one time and I finished my degree in the four years (Māpihi).

Although she was not allowed back into University, she managed to complete her degree in weaving with sufficient support from the wānanga.



I really think that weaving was a big part of me getting better again...The support and actually having to sit there and use my brains through pulling things together (Pua).

Study for Pua was a positive experience in her recovery, and although she was unable to continue studying at University during that time, she is now re-enrolled and working towards completing her degree.



# Pathways to recovery

Much of the recovery process required whānau to come to terms with the impact of bipolar disorder on their lives and find a way to move on, even if it meant starting over again. At this point in their journey many whānau discussed the process of learning as they made mistakes and, accepting those mistakes, finding ways forward through self-determination to live well. This section discusses aspects of wellness and the tools whānau discovered throughout their journey which helped them to manage their illness.

Intellectually, wellness for me is having my mental faculties about myself, clear and sound decisions for myself. Wellness is also being able to reflect. Physically, it's about being present in my body, being able to listen and feel my body, feel the sun being connected with Papatuānuku, being open to messages from my tupuna and recognising it. From a whānau level, we are happy, engaged, planning together, and sitting together. Un-wellness is the opposite of all of that (Tina).

### Recovery and wellness

Whānau were asked to describe what they thought wellness meant to them. Consistent with the recovery literature, wellness was not just the absence of mental illness, but being able to live a normal life and managing the difficult times. Recovery and wellness for whānau meant being able to enjoy life and what it offered. Also, whānau wanted to have trusting and nurturing relationships with family and intimate partners, to be meaningful employed, to keep busy, to live in stable accommodation, to have support from employers and to reconnect with friends and family. Māpihi credited her friends with helping her to recover as they kept her from being isolated and alone.

The things that have made the most difference to me were when friends would say, "come and do something with us" and I would usually say no. But they never gave me the chance to say no and that's probably a really good thing; because I would just isolate myself and make excuses for why I couldn't do something because I just didn't want to (Māpihi).

For some whānau reconnecting with family and friends meant fixing the damage done during times of illness. Tui's journey of reconnecting with family is ongoing and she recognised that wellness for her included family support, "family, they might come and give you a hug or something". Grayson and Max said while they lived in supported accommodation they were able to reconnect and rebuild their relationships.

Yeah his [Max] whānau has been good for a while because he's being looked after here. Same with my parents because I'm getting looked after and I'm doing well for myself (Grayson).

Recovery was an on-going journey of healing and transformation. Whānau talked about the need to reclaim their identity and positive sense-of-self despite the presence of mental illness and the



clear psycho-social influences that impacted on their wellbeing. Whānau wanted to live a life that went beyond being a consumer in the mental health system, where they could make significant contributions to their family and the wider community. However to do this, whānau relied on appropriate management strategies and support from mental health services, friends, family and employers.

The importance of support to aid recovery was evident across all whānau. Support came from family, friends and workmates, and involved small gestures to intensive intervention. In many cases there was at least one family member or friend who acted as a key support during periods of illness. Family members were grandparents, parents, extended whānau, children and partners.

In some cases, whānau spoke of relying on their tupuna (ancestors) to help them get through difficult times, particularly when they felt unsupported. Tina's comment is relevant as she felt that she had to be careful what she said to the doctor because she knew it could be used against her. She was adamant that her cultural beliefs should not be used as a symptom of mental illness.

It was weird and thinking about my tupuna, thinking that they would look after me and that they would help me because I wasn't getting help from anywhere else (Hine).

The doctor asked me if I spoke to my ancestors, "damn straight I do" I said, but that's not being ill (Tina).

The characteristics of family and friends who aided whānau in their recovery were acceptance and normalisation. It was important that whānau were treated as 'normal', valued members of whānau and society. Values such as aroha (love), manaakitanga (caring) and trust were noted across whānau stories. Support and aroha was also mentioned:

Whānau and big aroha aye; we need whānau to back you up, without whānau there's nowhere to go when you get out, and if you don't have the whānau you got to go to a place like this [a supported residential service] (Grayson).

All whānau said it was important to have at least one key person who they could trust and who cared for them. Max's comments showed the importance of being loved.

Yeah when you're loved in the family, it helps, and the aroha from the staff. The real love, you need that love to keep your wellbeing, your soul, spiritual things (Max).

Hine commented that she found strength in the support she received from her family, "knowing that I'm loved, by my whānau, children and friends...I just feel so blessed and rich in their love and in their presence". Zane too recognised his family's contribution to his wellness.



I have a brother as well who just wants me to be well, and he's never really judged me for being in hospital, and just cares about what I'm doing, my welfare. So yeah, I'm lucky to have family that will support me and take me in. Yeah they just want me to be well I guess (Zane).

Family support also included the provision of a safe haven when whānau felt they were becoming unwell. Comments reflected a need to be safe, secure and protected, "just being there physically so I would feel safe". Huia said when she first became unwell her mother, "washed me like I was a baby even though I was 19 years old". Years later, Huia knows she can return to her mother's home whenever she needs to. Meri's parents also provided immediate support, stability and comfort when she was unwell.

Mum and dad came and took me home. They supported me. They took turns checking up on me to make sure I wasn't alone. Every hour they took turns (Meri).

It was apparent that many whānau were debilitated by their illness, requiring ongoing supervision and care for basic needs such as providing shelter, taking care of children, keeping safe, eating, sleeping, washing and keeping mobile. Antonio said his mother and sister looked after his sons for long periods when he was in hospital. Tania credits her wellbeing to the way her sister encouraged her to take small steps towards achieving larger goals. The tailored approach worked well for Tania as she initially thought the smallest tasks were insurmountable.

Other little things that helped me were things like having [my sister] over to help me do my house work and chores. Especially when I was real low, just little things like encouraging me to do even one little chore, and saying that that's one less thing on my to-do list, and she'd do another chore for me, and it really helped. Chores got easier for me especially having her here to talk to me as we were cleaning, because after a short while the job would be done and it didn't even feel like a task because I had her there to talk to and she was cleaning with me. But yeah, I learnt to break it in to smaller steps (Tania).

Other whānau talked about how they were supported at work, or while studying which they attributed to their recovery.

There was this one day that I hit rock-bottom fully. I was at work. I had an annoying client ring in for an appointment. So I booked her in although I knew that I wasn't going to come in the next day. I was outside having a smoke and my friend who helped me earlier asked me if I was ok; I said I was losing it. The manager came out and asked me if I was ok. It was good to have someone notice (Martina).

The level of support required extended beyond the home as whānau needed help dealing with government agencies, housing agents, health services, schools and employers. A relevant point



across the stories is that the provision of information explaining bipolar disorder is critical to recovery, in particular how bipolar disorder is assessed and treated and whether whānau can expect to live well lives.

Some whānau worked in a mental health service or had family who worked in a mental health setting and knew when to intervene. Zane said his family was supportive because they had a good understanding of bipolar disorder and knew what to expect.

Family was good, I had the support. My mum had been through hospital and stuff like that with my sister so she kind of knew a little bit more about how the system worked and how bipolar worked, so she was really supportive and gave me a place to stay and made sure I was taking care of myself (Zane).

# Reconnecting with family

Some whānau described weakened relationships with at least one of their children as a result of their mental illness episodes. Some children were more inclined to direct anger, hate and blame toward their mothers. For example Tania's daughter blamed her for what went wrong during her upbringing and does not allow Tania to see her grandson, with whom Tania has a strong bond. Tania was afraid for her daughter's health and was worried that her daughter was showing symptoms of bipolar disorder. Tania said, "I'm just hoping that she sees a doctor who might be able to help her I just really don't want her to follow my path and end her life early".

And that's what happens. I was happy my family did want to stick by me, but trying to work by it themselves, I was affecting them; you know they started going errr. But yeah, my family, my brother, even my brother said, "I know alcohol, I know drugs". And I thought, "that's right, I taught you all" (Phillip).

Awhi acknowledged that she had made several mistakes while raising her children, and to this day has minimal contact with them. She recalled missing an important phone call to her mokopuna on her second birthday. Since then her son has denied Awhi all contact with him and his children, something that has caused her significant distress. Awhi expressed her desire to, reconnect and she said to, "find that bond" again with her son. She said, "his daughter is my first grandchild and I'd like to keep in contact with her". Her journey of recovery is fuelled by her determination to mend what has been broken and move forward positively and well.

The influence of family was the predominant theme in this study. The pathway to wellness and the motivation to stay there, involved family; especially tamariki and mokopuna.

Oh, when my grandson was born when I was 37. My pathway started when he was born; watching him grow, watching them learn. Seeing my parents enjoy them. Taking them to kindy. My mum tells me how good they are. I've got three moko (Rangimārie).



Functioning normally, working, having a relationship, casually seeing friends and stuff like that, eating well, sleeping well, and just living a normal life I guess (Zane).

Keeping well for me was to not be in a relationship. Avoiding alcohol, avoiding relationships and looking at a healthier lifestyle became my main focus (Niwareka).

Bearing and raising a child was a positive new experience providing a fresh start for some wāhine. Tamara was experiencing a lot of negative thoughts about her current life situation and was persistent in trying to take her own life. It wasn't until she found out she was pregnant that she decided to focus on recovery for herself and wellbeing for her child. The thought of bringing a new life into this world had a huge impact on Tamara's determination to get well and be there for her child. She said, "I'm pretty much still only alive because I'm having a baby". Although Tamara was optimistic, she requires a high level of support to help her connect with her family and to continue with treatment.

The importance of intimate, caring relationships was expressed in many whānau stories. Some whānau felt they did not want to be in a relationship because they had been physically or psychologically abused or they did not want to lose their partners when they became unwell. Niwareka was happy to not be in a relationship. She said, "It wasn't loss or emptiness, but it [being single] made me happy". Zane, who has a young son, said although he had good relationships, after a time it became too difficult for his partners, particularly during the depressive episodes. Zane's wish is to be in a relationship again, however, he still has reservations.

Yup, also had relationships where they've been supportive and stuck with me through the admissions and stuff, but unfortunately after the manic phase, the depressive phase comes as well, and I think that's really hard on the relationship and yeah. So I've lost relationships through being absolutely depressed and feeling like I'm unworthy of anyone loving me or have pushed people away because of it. I suppose it just depends on the person (Zane).

Some whānau wanted to ensure they were well before they entered another relationship. Meri said she wanted to focus on wellness as she knew relationships had not gone well for her in the past because she tended to, as she said, "give everything too fast".

I love having someone near someone to ask how you are, like someone who cares about you. I do want that. But I'm so scared. I don't trust my thinking about it. My friends and family think I should wait until I'm ready (Meri).

Rob and Pua's stories offer hope to those who are worried about being hurt, or hurting others. Pua experienced a destructive relationship prior to being diagnosed with bipolar but has since found a partner who loves and supports her. She said, "he's supported me through my illness it's



actually made our relationship stronger, which I never thought I'd find someone like that". Rob was the only male in this study with a partner whom he met at Te Māpihiwai, a kaupapa Māori service. Rob's recovery strategy and aspirations were to find a good job, to provide a home for his partner and to have children.

Being in a supportive relationship provides stability and reliability which can be protective for many whānau. Huia said although she married her much-older husband to have someone to take care of her, over the years she has come to love and care for him as he was pivotal to her recovery. Features of supportive partners highlight the importance of normalising and accepting their partner's mental illness. Tania said her husband was her "rock" because he understood her and her illness, "My husband doesn't have a problem with it. I say I've got bipolar, he says he's got a bad heart, so what?"

### **Building trust**

Trusting others to seek help and support on their behalf was an important factor in whānau stories because they were unable to reach out and seek help for themselves. The majority of whānau appreciated the strong friendships they had, and those 'persistent friends' who did not allow them to slip through the cracks; as Māpihi said, "the friends who would visit even if it was only every so often". Whānau also recognised they needed to trust family to monitor medication and stress levels, and allow family to offer helpful advice. Some whānau said at times they got annoyed when their family asked them if they had taken their medication as though it was the cure for everything.

Whānau also said it was important for family and friends to continue providing encouragement despite receiving negative feedback which often came from a variety of sources and, more often than not, from the person who most needed help.

To me, when you're like that, you sort of hurt the ones that are closest to you, and then not many people can go with that journey. And that's how a lot of people get disconnected from their families, because tragic things happen and they just don't want to know them anymore (Grayson).

Hine said that although she did not want her family to help her, she was grateful for the support. This comment reflects the propensity for whānau to be ambivalent about their needs.

My sister told them I didn't want to see anybody, and that's what I had said, but really, I did. You say the opposite and hope that they'd get the hint, but Pania just ignored Marama and she just came in; she and Peter (Hine).

Hine's story reflects what other whānau said; they did not want to be a burden to anyone. Awhi's advice for people who are supporting whānau highlighted the need to persist and to provide encouragement.



You need to advise them and encourage them, and to be there when they're really stressed out going through a hard time. Most of all just to help them, give them hope, and to let them know that life is worth living for...it's kind of sad (Awhi).

Zane went on to say he did not fully agree with the diagnosis and would like to have had more information, "Yep, at the time there was a lot of confusion, and I didn't think that the doctors had got it right with bipolar, but at the same time, all of the manic behaviours were there".

Whānau spoke of their strengths and the positive interrelationships of their self-determination, supports, therapies and personal resources. Reflecting ideals of self-determination, whānau often described a point at which they realised that in order to be well, some things would need to change and that it was up to them to make those changes.

I stopped blaming other people for my illness and started realising what I can do to make things better by observing other people's behaviour. It just made me realise there are things that you can do that will make it worse, and there are things that will make it better, and it's up to you. You can't fix me. I'm the only one that can fix myself. I can reach out for your support, but you can't fix me (Niwareka).

A focus on healthier living and eating featured in several stories, however some wāhine had to focus on rebuilding their self-esteem and confidence in order to progress forward.

I worked very hard at my health...that made me work very, very, hard at it, so I was very conscientious to eat the right foods and stuff to try and make up for that difference (Huia).

### Creativity, art and being productive

Wellness for whānau was also about having a sense of self and knowing exactly what they enjoy and what makes them happy. Accounts of wellness often involved creative works and hobbies such as painting, jewellery-making, weaving, singing and song writing, and baking. Huia's wellbeing was enhanced by having her own home and creating a Māori atmosphere full of Māori designs. Other whānau found listening to or creating music helped them to stay balanced and enjoy the creativity of other artists. Wellbeing for Huia, like other whānau, incorporated eating healthy meals, exercising daily and part-time study.

The availability of digital media and digital music enabled Grayson to consider becoming a musician, "I'm actually a recording artist, I'm just waiting for my acceptance into a studio, and then I'm going to be recording my album. I've got about 60-odd beats". Grayson also said, "Aroha, wairua and technology" helped him to get well. Max enjoyed listening to music and creating art using mixed media, "I'm artistic, I'm not good at making music but I like listening to it. I do my art you see, glass paintings and wood carvings".



Antonio's creativity led him into a life-long career as an actor. In the interview he produced his portfolio detailing the acting roles he had in the past 40 years. Antonio said being on stage or on a movie set gave him the opportunity to reduce his stress levels, focus his thoughts and assume a role outside himself.

# Helping others

Whānau who were productive said that as their stress levels decreased, they could manage intrusive, unwanted thoughts and they enjoyed their relationships with others. Rangimārie spent each day helping her elderly parents and, when she could, she would help her friends with little jobs. She grew vegetables in pots outside her flat. She was also an avid reader and looked forward to reading to her grandchildren when they visited.

A number of whānau have helped others by choosing to work in the mental health system. Roles include caregivers, consumer advocates, social workers or policy analysts. Pua said she wanted to work in mental health to prevent others experiencing what she went through.

From that trauma I wanted to use it to help girls...To me it's like a whole new world opening up where I finally understood what it was like to hurt and that there were heaps of people around me that were broken the way that I was (Pua).

For whānau to really engage in these creative works required focus and dedication. Taking time out to focus on something they enjoyed was pivotal to their recovery, "you just focus...as simple as it may sound, it's really effective...those little achievements can lead to way bigger things" (Hine).

Pua felt that weaving played a significant role in getting well again.

In the year I was diagnosed I made a hieke, like a rain cape out of corn husk, and I dyed them all black, called one te pango o te pō because I was in that kind of state. And then the year after that I made a contemporary korowai out of rainbow emu feathers all different colours, and I called that te uenuku harikoa. Quite a bit of a transition, through that process I did heal, creating things (Pua).

Whānau spoke of their experiences and determination to further their education in the hope of being able to contribute to the field of mental health one day. A number of whānau work in mental health services and have been able to share their journeys with whānau coming through the system. Pua has already begun her pathway by setting up a mental health support group for university students:

Me going through the system, I saw things that weren't quite right and I thought in order to change that I'd need an education, and I love psychology, I love going to lectures. I plan to go as far as I can take it, like hopefully maybe a PhD one day Pua).



A significant aspect of whānau recovery was about setting goals and striving to achieve them. Most whānau had at least one goal or aspiration they were able to focus on which they were determined to achieve. For most whānau those goals involved being with family or significant others.



# **Discussion**

Within the health system, Māori, in particular, experience significant and unnecessary disparities in outcomes related to mental health issues (Oakley Browne et al., 2006). With these disparities in mind, finding optimal solutions to improving the health system required deep knowledge of the lived experiences of those who have used health services (Torrey et al., 2005). In order to do that, a narrative of the life-span of Māori who live with bipolar disorder was needed.

The available evidence reinforces the importance of understanding Māori mental health needs from a broad systemic perspective, with a greater understanding of potential barriers such as timely and appropriate access to services that provide good outcomes for Māori (Baxter, 2008). The findings of this research show social, physical, environmental and political issues impacted on whānau throughout their lives. Māori are exposed to a range of government, social and education systems that could, and often do, operate as a starting point where mental health issues can be identified and remedied early. However, this study found multiple missed opportunities when whānau did not receive help, resulting in their situations escalating to acute levels.

Baxter (2008) argued that levels of significant unmet mental health needs among Māori may reflect differences in patterns of access to services at a primary care level, diagnostic practices, and/or referral practices to secondary care. The narratives show clearly that some whānau did not seek help until they were in serious need or that some sought help early and were treated for other conditions.

Gaining an understanding of how Māori came to be diagnosed and recover from bipolar disorder requires a life-span analysis. Such an analysis is necessary to identify the priorities, issues and information gaps in Māori experiences. This discussion is framed within two contextual themes:

- Whānau connection: supporting intergenerational wellness
- Supporting whānau connection: pathways to recovery

A Whānau Ora approach is used because it takes into account the importance of family and the need to address disparities that exist for Māori across the social, political, education and health sectors (Ministry of Health, 2005; Robson, 2007).

# Whānau connection: Supporting intergenerational wellness

Consistent with the recovery literature, wellness was not just the absence of mental illness, but being able to live normal, fulfilling and productive lives (Lapsley et al., 2002). Whānau connection relates to having stable, supportive and loving relationships with parents, siblings, intimate partners, children and grandchildren. Whānau connection also includes being meaningfully employed, keeping busy, living in stable accommodation, having support from employers and reconnecting with friends and family.



Durie (1999) emphasised the importance of considering a Māori patient's entire sense of wairua and wellbeing, and enabling them to re-connect with whānau without assuming that medication and symptom-only focus treatments are the best approaches (Jones et al., 2013). During the illness phase of bipolar disorder, whānau often experienced disconnection and feelings of isolation, or wanting to isolate, themselves from others. It was noticeable that some whānau required intensive support and ongoing supervision and care for basic needs such as providing shelter, taking care of children, keeping safe, eating, sleeping, washing and keeping mobile.

The need for shelter, safety and family support is critical to recovery. Previous research identified that during periods of illness and instability, psychiatric survivors live in fear and lose control of basic human rights (Forchuk, Ward-Griffin, Csiernik, & Turner, 2006). The ability of whānau to hold onto and create relationships, identify supports and seek services while maintaining personal space and place is significantly reduced when everyday responsibilities become overwhelming (Brown & Anderson, 1991; Burt & Rasgon, 2004; Peace & Kell, 2001).

Antonio said his mother and sister looked after his sons for long periods when he was in hospital. Tania credits her wellbeing to the way her sister encouraged her to take small steps to achieving larger goals. Some whānau felt shame, guilt, embarrassment, self-doubt and very low self-esteem. These feelings were associated with the stigma attached to mental illness, as well as the need to fix damaged relationships. Having a strong family connection was associated with faster recovery and longer periods between relapse (Miklowitz et al., 1988). When whānau were unwell, their family or social supports took them to primary and secondary care services, their children were looked after, they had homes to come back to, they were encouraged to be hopeful, they had choices about how they wanted to live and they were encouraged to adhere to treatment.

Hine's sister Awhi was adamant that persistence and encouragement were needed to help whānau live well.

You need to advise them and encourage them and to be there when they're really stressed out going through a hard time. Most of all just to help them, give them hope, and to let them know that life is worth living for...it's kind of sad (Awhi).

Being in a supportive relationship provides stability and reliability which can be protective for many whānau. Some described how they struggled to be parents, while others were resigned to not seeing their children again. Max said he had a daughter (who is now 42 years old), but he only met her on one occasion, "I only seen her just the once when she was about three years old. All I did was bought her a milk and took her shopping for some clothes, that was about it, haven't seen her ever since". A significant finding was that whānau lacked support to be fathers and mothers and faced a constant risk that they would lose their children.



# Support to be a parent

Parenthood is a major developmental task and plays a significant role in social cohesion, self-esteem and family wellbeing (Judd et al., 2003). Whānau were asked to relate their perception of the impact of mental illness on their ability to parent their children. Two areas for discussion emerged: the need for support to raise children and children as a source of strength and wellbeing. Whānau unanimously said their children were pivotal to their wellness and recovery. However, when whānau were unwell they needed support to keep their children safe and secure, and to ensure they continued with school. They also needed to receive appropriate information about parental mental illness.

The importance of keeping families together is evident. While there were times when children and family were seen as stressors, they were also seen as protective factors as whānau tried to improve their personal wellbeing to benefit their family.

When whānau were well, they needed to have their children returned to them and appropriate supports put in place to enable them to be parents. These findings are consistent with research that shows the majority of women with mental health issues find great meaning and purpose in their relationship with their children (Johnson et al., 1999; Judd, Armstrong, & Kulkarni, 2009). Support to be a parent involved being in loving relationships, children eating well, having access to education, being free from neglect and abuse, and having access to appropriate and caring social and health services.

Some whānau talked about their experiences of being the child of a parent who had mental health concerns, while others talked about having their children taken from them. Hine said she turned to drugs and alcohol to manage the stress of having her child taken away and not returned. Tina's description of her history of CYFS involvement highlighted times when she could have been helped. It showed a lack of collaboration between services and a lack of caring support.

CYFS was around me a lot when I was unwell in the early days... The father was really abusive and it kept making me unwell and I was making bad judgments. CYFS were constantly threatening to take the baby away. I fought that, I didn't want to lose my baby. I dug deep within myself. They weren't supportive. They policed me and my whānau. They didn't say which organisations could help (Hine).

Several whānau who are now grandparents have turned to their grandchildren in the hope they can shelter them from the effects of their parents' psychological issues, which whānau feel they caused. Following more than 45 years of institutionalisation Rangimārie talked about how important her grandchildren and parents are to her wellbeing. After losing her children, Rangimārie is determined not to let her grandchildren grow up exposed to their parent's substance use or family violence. Like other whānau, her journey of recovery is fuelled by her determination to mend what has been broken and move forward positively and well.



There is an urgency to reconnect whānau with their families. The results from the PRIMHD analysis show the rate of bipolar disorder among older Māori is less than that for non-Māori. A simplistic explanation is offered; while Māori, like Rangimārie and Antonio, live well in their senior years and do not require DHB services, Māori also have high mortality rates compared to non-Māori (Oakley Browne et al., 2006). The PRIMHD result identifies a potential risk where whānau who are now parenting their grandchildren may not live long enough to enjoy life in the recovery stage or their status as kaumātua (Durie, 2003).

# Addressing unmet need

The life-span approach to this study highlights how unmet need impacted to the extent that psychological issues were perpetuated from childhood into adulthood and on into the next generation. Consistent with research, addressing the social determinants of mental health is particularly relevant as poverty, inadequate housing, low levels of education and unemployment placed whānau at greater risk of developing mental health and addiction issues (Marmot, 2007; Mental Health Commission, 2012; Ministry of Social Development, 2012).

The association between a history of child sexual abuse and adverse psychological and social outcomes is well-documented (Ministry of Social Development, 2012; Spataro et al., 2004). Whānau who experienced physical, sexual and psychological abuse within their early life and in their relationships described episodes of depression, anxiety, acute stress, substance abuse and suicidality.

Some whānau, now in their late 40s, 50s and 60s, continue to experience the effect of unmet needs. Max felt that his illness and subsequent depression, substance abuse, gambling and homelessness began after he was sexually abused. Niwareka described a life of foster care, neglect and sexual and physical abuse which was not addressed by child protection services when she was three years old, or adolescent and adult mental health services. She experienced hardship and stress for almost her entire life until she was able to leave an abusive marriage. The intergenerational effects of unmet need have transferred to her children as they witnessed family violence and were left to support the family when she was in hospital.

Martina's account of being abandoned by her father and her mother's drinking problems predisposed her to anxiety, substance abuse, depression and difficulty selecting positive intimate relationships. The literature is extensive in describing the effects of childhood adversity on healthy developmental pathways (Blehar et al., 1998; Freeman et al., 2002; Gluckman et al., 2011; Spataro et al., 2004); however, more research is needed to show how capable children are at managing their parents' mental health issues (Mordoch & Hall, 2008).

This section has described the mediating relationship between positive and supportive family connections and addressing unmet need to recovery. Barriers to recovery were the absence of familial and social connections and the absence of opportunities, due to illness, to engage in meaningful, productive, creative and restful pursuits. In the following section, maintaining wellness is described in the context of healthy and stable relationships. While it is recognised



that systemic, external, institutional issues are significant influencing factors on Māori mental health (Baxter, 2008; Cram, 2011a; Dore & Romans, 2001; Dyall et al., 1999; Hayward, Wong, Bright, & Lam, 2002; Ihimaera, 2007), the focus here is on the importance of whānau.

# Supporting pathways to recovery

Opportunities to live balanced lives, to engage in leisurely pursuits and to enjoy social connections are protective elements in pathways to recovery. When whānau were in healthy relationships they were better equipped to incorporate wellness strategies into their lives. Conversely, unhealthy relationships contributed to illness, exacerbated stress levels and prevented whānau from seeking wellness.

When external and internal factors to achieving wellness were optimal, whānau were able to reconnect and enjoy their family and personal relationships. External factors that contributed to and maintained wellness for whānau were being productive and creative, and having access to:

- stable and appropriate medication
- prevention and early intervention sources
- information
- talking therapies
- treatment for co-existing mental illness
- kaupapa Māori services.

### Access to stable and appropriate medication

Wellness for some whānau was related to appropriate and stable medication. Huia described a sudden shift from a depressed state into an extreme high after her psychiatrist prescribed her what she said was, "an enormous amount of pills".

I woke up in the morning and it was like going from dark to light. It had an instant impact on me. I could feel again. I could taste. I was so excited. But then I went straight into this mania. I didn't know. I thought I was ok. You can imagine the elation that I felt. I thought I had lost my life, then straight into being really happy. But I was really aggressive (Huia).

Whānau benefited most when they were given detailed information about appropriate dosage and combinations and medication side-effects. In particular whānau felt they should be treated as valued and autonomous members of society. This point was made several times by whānau who believed that the stigma attached to mental health prevented them from living well.

### Access to prevention and early intervention services

Several whānau described how difficult it was for them and their family to access services when they were in the early stages of becoming unwell. The stress and anxiety associated with not accessing services placed whānau, members of the public and the family at risk. In terms of early



intervention, whānau benefitted from services that respected their self-autonomy, confidentiality and provided information about bipolar disorder assessment and treatment.

Some whānau understood that interactions between social, economic and political disparities influence health for Māori. Those whānau felt that health services lacked an appreciation of Māori models of mental health. Tina described being cautious about her cultural beliefs because she knew they would be used against her. She said, "The doctor asked me if I spoke to my ancestors, "damn straight I do" I said, but that's not being ill." Whānau benefitted when they felt safe talking about their cultural worldviews and perspectives on illness.

### Access to information

A resounding gap for whānau was the lack of information on the bio-psycho-social theories of bipolar disorder. Information that is accessible conveys hope and optimism, is realistic and promotes autonomy is vital to ensuring recovery (Suto, Murray, Hale, Amari, & Michalak, 2010). Basic information about the development, course, co-existing disorders, consequences, assessment and treatment of bipolar disorder would have enabled whānau and their families to understand the nature of their thoughts and behaviour. Information was also needed as whānau believed they were a burden to others and were not valued members of the family or society.

The issue of stigma was prevalent, influencing the way whānau viewed themselves and how whānau were viewed by others. The effects of stigma in society towards bipolar disorder is considered insidious involving reduced social support and occupational success, reduced functioning, higher symptom levels and lower quality of life (Hawke, Parikh, & Michalak, 2013). The importance of increased awareness about mental illness for whānau and the wider community was evident throughout this study.

### Access to talking therapies

The Royal Australian and New Zealand College of Psychiatrists (2004) explored treatment and assessment recommendations for people with bipolar disorder. The review identified that medical and psychological treatments should be offered to restore patients to full health with the ability to lead a meaningful life.

Only three whānau members were offered psychological therapy for bipolar disorder. Other whānau saw either a psychiatrist, nurse or counsellor and Tamara was in the Dialectical Behaviour Therapy (DBT) programme. After following up with Tamara a year later, she commented that she benefited a great deal from the programme and thought that it should be offered to other whanau.

In general medication was the primary treatment offered. A difficulty with medication as the sole treatment option is that this approach privileges the bio-medical model of mental health and excludes alternative therapies. Although bipolar is considered to be a biological disorder, it is also known that the course and expression of bipolar disorder is affected by a range of bio-



psycho-social and environmental variables (Johnson, 2005; Kessing, Agerbo, & Mortensen, 2004).

Co-existing mental health issues such as substance abuse, anxiety, depression, relationship difficulties, parent training, suicidality, trauma and post-traumatic stress disorder were prevalent across whānau and required ongoing support. Given the extent to which co-existing disorders occur with bipolar disorders whānau should have been offered adjunctive or alternative treatment options such as cognitive-behavioural therapies (Szentagotai & David, 2010) and family and occupational therapies (Miklowitz, 2006; Miklowitz & Scott, 2009; Suto et al., 2010). Utilising emerging approaches such as positive psychology, self-determination and motivation, and providing integrated care driven by whānau's needs is in line with recommended practice (Todd, 2010).

### Access to kaupapa Māori services

Recommendations by researchers and the Mental Health Commission (2000) have emphasised the need for kaupapa Māori approaches and services to enable Māori to return to states of wellness and achieve their best life potential (Mental Health Commission, 2000; Wharewera-Mika, 2012). Furthermore, these services must have Māori staff who feel confident and able to practise from a kaupapa Māori standpoint, and who are supported within their work environment to do so (Mental Health Commission, 2000; Wharewera-Mika, 2012).

For unknown reasons, whānau did not access mainstream community mental health services, preferring instead to go to their GPs. Whānau perceptions of mainstream psychiatric services ranged from good, ok and beneficial to unsafe, dehumanising and lacking an understanding of Māori worldviews. Inpatient, community and community-residential kaupapa Māori services were used by whānau at several stages. The unique features across kaupapa Māori services for whānau was that they felt they could be Māori, that their worldview and culture was understood without the need for explanation, that they felt valued as Māori and that the service was accessible.

This last point relates to how some whānau were able to call into the kaupapa Māori service in their community for a visit or help out with odd-jobs. The social and occupational benefits of being able to associate with community service providers reflects every day, normal socialisation practices that are beneficial to whānau recovery and help to reduce stigma around mental illness (Lapsley et al., 2002).

### Unmet need: substance abuse/self-medication and risk

A developmental progression was evident in whānau stories about substance use. Substance abuse began in late childhood or early adolescence and continued throughout adulthood. Awhi drank alcohol and smoked cannabis for many years to escape from her thoughts.



Four times I've slipped up in the last seven years on alcohol, because I used to drink and drink full on for ten years and hearing voices and getting paranoid, I was paranoid for years, it drove me crazy (Awhi).

Most whānau gravitated to substances to escape the psychological effects of anxiety, trauma, stress, depression, sexual and physical abuse, dysfunctional relationships and cognitive distortions (eg shame, guilt and hopelessness), or to fit in with peers. Only two whānau said they did not use substances at any time in their lives.

A pattern emerged in the stories showing the chronicity of whānau unmet need. Niwareka had made three serious suicide attempts at age 14, 23 and, again, in her 30s, but she recalled there was no follow up after each attempt, "each time I was just put in hospital and then sent home. I was never ever sent to a psychologist for help...my stomach was pumped, and I was discharged with no follow up". As a young man, Zane moved into a world of drugs and alcohol to combat his anxiety and what he said was the, "excessive worry" that plagued his outlook on life. Previous research shows that single fathers have high rates of depression and are likely to misuse drugs and alcohol (Cooper et al., 2007). Zane's experiences highlight a significant gap in our understanding of how to help men who have mental health issues and who are also single-parents.

Risk refers to the impact of unresolved needs for whānau or their families. Many women in the study not only had significant childhood difficulties, they also lived with abusive partners. All of the women who were diagnosed with post-natal depression, except Huia, experienced emotional, physical and psychological abuse from their partners. Some also had unfaithful partners who openly flaunted their infidelities.

Some of the wāhine experienced multiple stressors which caused the 'balance to tip'. Consequently, whānau were incarcerated, hospitalised, had their children removed, or diagnosed with additional disorders. In hindsight, whānau recognised that substance use only provided limited relief or made the problem worse.

The findings highlight the importance of addressing unmet psychological need at earlier points in life. The indicators for psychological risk are well known however, these whānau fell through the system and were not helped early enough to prevent further damage. The effect of drugs and alcohol was extensive and intergenerational, preventing whānau from engaging with mental health services, exiting abusive relationships, building lasting relationships, maintaining employment and paying bills and expenses.

# Diagnostic issues

Early in the study, an issue of diagnostic reliability arose as it appeared that, for some whānau, the features or indicators of bipolar disorder were more often related to intense reactions to social and psychological stressors and substance use. For example, Martina threw herself in front of a car following an argument with her boyfriend, Tamara cut herself to relieve intense



emotional distress, and Phillip recalled some form of bullying or isolation while in school which he believed had an impact on his identity and wellbeing.

We used to get the bash at boarding school just for being Māori too. At a Pākehā boarding school, they'd say you black  $c^{**}$ ts! and you're all poor. So we went through that shit, and that's why I thought it was normal (Phillip).

The trend throughout the narratives was that women who were in dysfunctional relationships were diagnosed with depression, personality disorder, anxiety disorder and eventually bipolar disorder. Men were diagnosed with substance abuse disorders, depression, anxiety and schizophrenia.

Diagnostic issues were common for women in this study during their reproductive years. Regardless of prior or existing trauma, women who were pregnant, postnatal or who had children were most often diagnosed with post-natal depression or bipolar disorder. These findings show gendered patterns of diagnosis (Baxter, 2008) and misperceptions about the effects of puberty, menstruation, pregnancy, postnatal and menopause on symptoms for women (Rasgon et al., 2003).

In addition, women with mental illness often parent without adequate support from partners or health services, despite having children at the same rate as women without mental health issues (David, Styron, & Davidson, 2011). Other gender-specific concerns are that women are more likely to live in abusive relationships and in poverty, and have little support raising their children. Like other women in this study, Tina had a long history of hospitalisation, however she also had unresolved sexual abuse trauma and was living in an abusive relationship.

I was in an abusive, violent relationship. It affected my babies and me being pregnant. I was suicidal. I started cutting. Looking back, is that mental illness or is that trauma? If I was in a loving relationship, or not in an abusive one would I be like that? I don't think so (Tina).

The findings suggest that mental health service provision and treatments need to understand and respond to gender differences from childhood to adulthood, including day-to-day social, cultural and family realities (Judd et al., 2009).

### Genetics or unmet need?

More than half of the whānau described a history of mental illness within their whānau and associated their experiences of bipolar disorder with psychosocial stressors or a genetic predisposition. Comments such as, "my cousin is bipolar, my uncle and my father too; at least that's what my mother said" (Antonio) were often heard. Māori experiences of bipolar disorder is intergenerational; so too are the effects of Māori indigenous status, such as the effects of racism, colonisation, oppression and political and socio-economic disparities (Department of Economic and Social Affairs, 2004).



The presence of family members with mental health and substance abuse issues could be viewed as widespread unmet need. However, it appeared that for some whānau, family history may have been used as evidence of bipolar disorder rather than examining further whānau experiences. Tania's comments highlight the potential socio-cultural pitfalls in diagnostic reliability. She said the women in her family were the most affected by depression and bipolar disorder and it was negative childhood experiences and environmental stressors that set her on a path of mental illness.

I would say I had the potential for bipolar disorder as a result of my past experiences as well as the environmental stressors that surrounded me. My grandmother had bipolar, my aunty had it, my brother had depression; two other females in the family had bipolar. It seems to be much worse with the females in our family. I think my daughter has bipolar too (Tania).

The effect of intergenerational family violence, family mental illness and environmental stressors is clearly implicated in Tania's story and others like her. Whānau narratives clearly show a lifespan trajectory where Māori experiences of bipolar disorder are deeply underpinned by intergenerational experiences of unmet need.

The Mental Health Commission (2012) identifies that sustained efforts are required to develop the pathways of care and environments and workforces that will meet the current unmet need of Māori mental health service users and their whānau. These pathways will be located within the broader context and aspirations of Whānau Ora. These pathways will: meet the broader health and mental health needs of the service user in the context of their whānau; recognise a Māori worldview in service delivery; be culturally appropriate; address barriers to Māori accessing mental health and addiction services (Mental Health Commission, 2012).

### Management

Self-management plans are a significant part of bipolar management. These plans are designed to ensure people respond appropriately when warning signs are present and seek early intervention or support thereby reducing the length of an episode and the number of relapses (Perry, Tarrier, Morriss, McCarthy, & Limb, 1999). Some of the key features of management plans are acceptance of diagnosis, sleep hygiene, stress management, lifestyle changes, strengthening relationships, accessing support services, adherence to medication regime (the medication must be suitable), insight into warning signs and triggers, consistent professional involvement, compassionate care and mindfulness (eg begin aware of the physical, emotional, social and mental environment) (Russell & Browne, 2005).



# Conclusion

This research explored the experiences and life pathways of Māori who were diagnosed with bipolar disorder. Using a narrative inquiry approach that privileged kaupapa Māori perspectives, whānau shared their experiences of mental illness and their stories of recovery. The stories of their lived realities highlighted the need to co-ordinate primary and secondary health services for Māori across the life-span. The fragmented approach to service provision seen throughout this study appeared to result in a shift away from broader issues such as unemployment, inadequate housing, and disparities in access to services, family violence, childhood adversity, sexual abuse, drug and alcohol abuse and disconnected families. Across all whānau it was apparent that they needed help earlier, some as young as three years old, if they were to live to their actual potential.

Key to recovery for whānau was the importance of supporting them to reconnect and stay connected with whānau and friends. Strong whānau connections and ongoing support provided stability and conveyed to whānau that they were valued and loved family members. Furthermore, family support facilitated faster recovery and allowed for longer periods between relapse. Māori mental health policy within the context of aspirations for Whānau Ora requires a life-span approach from the health sector and broader social, justice and education sectors (Mental Health Commission, 2004). The need for a Whānau Ora approach as a framework for health services is evident in this study as whānau consistently talked about the importance of family.

Understanding Māori experiences of bipolar disorder requires knowledge and awareness of unmet need across generations. That Māori are diagnosed with bipolar disorder rather than depression as a result of unresolved trauma, or a diagnosis of anxiety or substance abuse, obscures the existence of disparities in broader social, education and health sectors.

A broad, systems approach that recognises and supports the role of children, parents, grandparents and extended family is fundamental to recovery for whānau. However, the strong link between recovery and culture and the wellness of whānau and tāngata whaiora depends on, and is affected by, the wellness of whānau. The circular nature of that relationship is often overlooked by health providers in favour of a linear, individual approach. By strengthening family and community connections in recovery strategies, whānau and their children will have a greater chance of living well.



# **Appendix**

# **Guiding documents**

The Health Practitioners Competence Assurance Act 2003

Addiction intervention competency framework (Addiction Practitioners Association Aotearoa, 2011)

Let's get real: Real skills for people working in mental health and addiction, particularly the Let's get real module: Working with Māori (Ministry of Health, 2008)

*Real Skills Plus CAMHS* (The Werry Centre, 2008)

The Aotearoa New Zealand addiction specialty nursing competency framework 2012 (Drug and Alcohol Nurses of Australasia, 2012)

*Te Puāwaiwhero: The second Māori mental health and addiction national strategic framework 2008–2015* (Ministry of Health, 2008a)

Bipolar disorders involve the presence (or history) of manic episodes, mixed episodes, or hypomanic episodes, usually accompanied by the presence (or history) of major depressive episodes (DSM IV-TR, American Psychiatric Association, 2000).

These four types of episodes, which characterise bipolar disorder are described below. The DSM-IV, TR describes mania as:

- A. A distinct period of abnormally and persistently elevated, expansive, and/or irritable mood, lasting at least one week.
- B. During the period of mood disturbance, three (or more) of the following symptoms have persisted (four if the mood is only irritable) and are present to a significant degree:
  - 1. grandiosity (elevated self-esteem)
  - 2. decreased need for sleep
  - 3. increased talking (pressured speech)
  - 4. flights of ideas (racing thoughts)
  - 5. distractibility
  - 6. overactivity (increase in goal-directed activity)
  - 7. psychomotor agitation and excessive involvement in reckless activities.

Hypomania differs from the above described manic episode in that criteria are only required to have been met for a period of four days (American Psychiatric Society, 2000).

A depressive episode as described by the DSM-IV-TR is as follows.

- A. Five or more of the below symptoms for a two-week period; representing a change from previous functioning with at least one symptom being either depressed mood or loss of interest or pleasure:
  - 1. depressed mood
  - 2. markedly diminished interest or pleasure
  - 3. significant weight loss or decrease/increase in appetite nearly every day
  - 4. insomnia or hypersomnia
  - 5. psychomotor agitation or retardation
  - 6. fatigue or loss of energy
  - 7. feelings of worthlessness or excessive inappropriate guilt
  - 8. difficulty with concentration or indecisiveness
  - 9. recurrent thoughts of death.



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# Information for whanau

#### Websites

http://www.mifellowship.org/content/understanding-mental-illness-fact-sheets?gclid=CPbm9eD317UCFQxepQodLWcA7g

http://www.headspace.org.nz/young-people/bipolar-disorder.htm

http://www.balance.org.nz/research/bipolar-disorder-research

http://besthealth.bmj.com/x/topic/392829/essentials.html

# Bipolar support:

http://www.balance.org.nz/support/regional-support-groups

#### **Movies**

#### **Dark Horse**

Written and directed by James Napier Robertson, *The Dark Horse* is an inspiring true story based on the life of a charismatic, little-known New Zealand hero, Genesis Potini, played by Cliff Curtis (*Once Were Warriors, Whale Rider, Boy*). The film also stars James Rolleston (*Boy*), Kirk Torrance (*Stickmen, Sione's 2 – Unfinished Business*), Xavier Horan (*Dean Spanley*), Miriama McDowell (*Dean Spanley*) and newcomer Wayne Hapi.

#### The Devil and Daniel Johnston

Daniel Johnston, manic-depressive genius singer/songwriter/artist is revealed in this portrait of madness, creativity and love.

#### Self-test:

http://www.blackdoginstitute.org.au/public/bipolardisorder/self-test.cfm

#### **Articles:**

http://www.balance.org.nz/information/depression/depression-in-nz-nz-listener-article

http://www.depression.org.nz/

http://www.depression.org.nz/waythrough/self+help

http://www.depression.org.nz/waythrough/talking+therapies

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# Māori and Psychology Research Unit

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