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navigating through mental health services:

perspectives and priorities of family members and mental health services staff

LOIS BOYD AND LYNDA SIGGLEKOW

INNOVATIVE PRACTICE FUND NO 9/11
MAY 2011

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ISSN 1177-8172 (Print)
ISSN 1177-8180 (Online)

ISBN 978-0-478-34944-0 (Print)
ISBN 978-0-478-34945-0 (Online)

families commission
kōmihana ā whānau
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ACKNOWLEDGEMENTS

We would like to thank:

- the 23 family members and staff members who were interviewed for this study
- our reference group members: Vicky Pomeroy, Wendy Hamer, Susan O'Connell and Julie Scrimongeur
- the Supporting Families in Mental Illness Nelson committee and members, for their patience, contributions and encouragement
- Nelson Marlborough District Health Board (NMDHB) Mental Health Services staff, for passing on information they came across in practice
- Robyn Byers, District Manager Mental Health Services, for her ongoing support, encouragement and superior editing skills
- the late Michael Lynch, who generously shared his considerable local knowledge, expertise and passion for working with families
- Supporting Families in Mental Wellbeing Marlborough staff and families
- Suzie Dimmendal, for so generously sharing her research journey
- NMDHB Consumer Advisors Merrill Brunt and Barbara Georgesen
- Nicola Ehau, former NMDHB Director of Mäori Health
- NMDHB Iwi Health Board
- the Mental Health Commission, Ministry of Health (MOH) and Te Pou Mental Health Workforce Development, for allowing us to reproduce key documents
- and last, but definitely not least, our families.

All participants said they hoped that by contributing to this study they could improve family members' future experience of mental health services.

"It's really nice to be able to say your piece and, as part of contributing to a wider force, that it may [bring] change." Family member

"Sometimes, when I've looked at how to improve things, I've gone back to what was wrong the first time, what things can make me better here… [and it] prompted me to start thinking more about families." Staff member

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EXECUTIVE SUMMARY

> The importance of including family members in the care of people experiencing mental illness cannot be overstated. Whänau Ora, family good health and wellbeing, is a longstanding and ongoing key health target (Ministry of Health, 2002).

Navigating the Family Pathway through Mental Health Services is a project which aims to improve the way families supporting a family member, experience mental health services in New Zealand.

This research took place within Nelson Marlborough District Health Board (NMDHB), Mental Health Services. To maximise the participation of family members and mental health service staff members, the research used participatory action research methodology and mostly qualitative methods.

This document reports and compares the perspectives of family members and the staff members who work with them, and shows how these perspectives sit with policy documents that are focused on families.

We present the key components of a family pathway that is informed by the themes and knowledge derived from this research, other best practice research and policy direction.

Our research discovered learning opportunities and potential ways to improve the service, including:

- highlighting the importance of developing and maintaining respectful working relationships between mental health service staff members and family members
- emphasising the importance of respecting families' experiences, and taking the concerns of families seriously
- emphasising mental health services providing accessible, good-quality information to families
- recognising that family members can provide information that is useful in formulating a consumer's care plan
- recognising that for people experiencing a prolonged recovery from mental illness, family members may assume the main caregiver role and require additional support and advice
- supporting mental health services staff to improve their skills in working with family members by providing good-quality information systems, group facilitation training, family-focused supervision, mentoring by other staff members and feedback from families and family representative organisations
- awareness that family members are more likely to experience mental health issues themselves, and that mental health services are ideally placed to refer family members early for treatment and may prevent, or catch early, any illness- or stress-related health effects.

The key limitations of this study include its small scale and single region focus, which are later discussed.

1. INTRODUCTION

> People with serious mental illness are not ill in isolation. Their families, extended whänau and significant others, whatever they think about the illness, cannot escape being affected by it. The lives of people with serious mental illness are inextricably involved with the lives of those they love and care for, and the lives of those who love and care about them (Mental Health Commission, 1998, p.9).

Supporting the families of people accessing mental health services is an important part of modern mental health care. The expectation that mental health services are available to family members is very real in the practice environment (Ministry of Health, 2008). Meeting this expectation, while also providing the best possible treatment to people experiencing mental illness, is one of many challenging and rewarding aspects of mental health service delivery.

This research, conducted in the Nelson Marlborough region, builds on the work of Suzanne Dimmendal, who interviewed families in the region in 2003. In her study participants were asked to describe "what they wanted from the mental health services for their family member" (Dimmendal & Watson, 2005). The study's recommendations highlighted the needs that the family members felt were not met by mental health services.

The focus of this project is to learn more about what support and assistance these family members need.

Learning more about what families need when supporting someone through mental health services can improve services in the future (Stanbridge & Burbach, 2007). Understanding the experience of mental health services staff and the context in which they practise is also important (Beecher, 2008; Kim & Salyers, 2008).

In this study we interviewed both family members and mental health services staff members. Analysis of their perspectives then informed the development of a family pathway document (see p. 50).

1.1 Why focus on families?

There are many compelling reasons why actively involving families in mental health service delivery is considered best practice. It is well recognised that family involvement leads to better outcomes for both the consumer and family (Pharoah, Mari, Rathbone, & Wong, 2006; Pitschel-Walz, Leucht, Bauml, Kissling, & Engle, 2001). Also, family members caring for someone experiencing mental illness are at increased risk of physical and mental health issues themselves (Gallagher & Mechanic, 1996).

But we often forget to explore what families can offer mental health services: their unique perspective and knowledge of their family member (Lakeman, 2008). They often know the person in care best, and their knowledge of the person's mental ill health can be useful for informing recovery strategies.

Families, friends and relatives of people with mental health problems have often felt unheard and excluded from their relatives' care. This is in spite of the fact that they are often the first to become aware of difficulties (both onset and relapse), encourage the person to seek help and, in cases of enduring mental illness, provide much of the day-to-day support (Stanbridge & Burbach, 2007, p. 22).

Families often feel that mental health services do not consider the information they provide, and this contributes to less than optimal care (Lakeman, 2008).

1.2 Why a family pathway?

The idea of framing this study around the production of a family pathway for mental health services came out of a discussion regarding the NMDHB Client Pathway (Nelson Marlborough District Health Board, 2007, Appendix 12). The Client Pathway is a living document produced to guide each stage of the consumer's journey through mental health services. It integrates recognised mental health standards, policies, procedures and forms into one document.

NMDHB staff also use the Client Pathway as a reference for planning new quality initiatives, or when developing, auditing or reviewing the services they provide.

So why not develop a 'family pathway' too? This idea was supported by mental health services staff, family advisors and organisations supporting families.

This research focuses on gathering the perspectives of family members, staff members and information from literature to inform the development of a family pathway for mental health services.

The current practice environment emphasises family inclusion. This emphasis is legislated (Ministry of Health, 2006a), promoted as best practice (Medical Council of New Zealand, 2008, Ministry of Health, 2008; Nursing Council of New Zealand, 2007) and directed by policy (Ministry of Health, 2005, 2006b).

The shift from institutional care to community- and recovery-based models has changed the role of the family in mental health care, from visitors and supporters to main caregivers, particularly when recovery is prolonged. But mental health services have not always changed their relationship with families at the same pace (Dimmendal, 2005).

A number of useful guidelines (NZCHMP), family-focused research (Barnett & Barnes, 2010; Collings, 2009; Dimmendal & Watson, 2005) and training (Whiteside & Steinberg, 2003) are now available to mental health services staff and family representative organisations in New Zealand. Families now have increased access to assistance, support and information from Supporting Families[1] branches, and to district health board-appointed family advisors.

While these new developments have had a positive influence on practice and knowledge, less attention has been paid to integrating family-inclusive best practice into existing organisational structures, systems and processes. Providing staff with training, policy and guidelines is good, but if this is not supported by systems-based change it may be difficult to change their practices (Cleary, Freeman, & Walter, 2006).

Like the Client Pathway, a family pathway will provide staff and families with a systemic framework on which to promote best practice. The family pathway will be a document to refer to, guide practice and resolve issues.

1.3 Exploring the perspectives of mental health services staff and families

This research was carried out during 2008–09 in the Nelson Marlborough area. It took a participatory action research approach, as described in Chapter 3, to maximise participation and collaboration. A reference group comprising members of staff and representatives of family organisations in the area also informed the research process.

Family members of current NMDHB clients and current NMDHB staff members were interviewed on their experience of mental health services' response to families. They were also asked to explain their priorities for a family pathway. In Chapter 4 the perspectives of both groups are explored. A summary table outlining the key similarities and differences in staff and family perspectives is found on page 35.

1.4 Mental health services in Nelson Marlborough

The NMDHB catchment area covers the top of the South Island of New Zealand and spans the Nelson, Tasman and Marlborough regions. Its boundaries reach from Golden Bay across to Murchison, then to Ward on the East Coast, including Marlborough. The resident population of this area was 130,071 at 2006 census count. The resident Mäori population was 10,953 (Statistics New Zealand, 2006 Census Data). A more detailed population profile is provided in Appendix 9.

The Nelson Marlborough district is made up of eight Manawhenua iwi: Ngati Apa, Ngati Koata, Ngati Kuia, Ngati Rarua, Ngati Tama, Ngati Toarangatira, Rangitane and Te Atiawa. These iwi, via a Memorandum of Agreement with the NMDHB, work together to achieve the best possible health outcomes for Mäori, via the ongoing development of the *Nelson Marlborough Mäori Health and Wellness Strategic Framework 2008–2038.* "Kia korowaitia aku mokopuna ki te korowaitanga hauora" – healthy as! (Nelson Marlborough District Health Board 2008a).

In-patient mental health services are provided in Nelson only, on the Nelson Hospital campus, which has an admissions unit (26 beds) and a short- to medium-term rehabilitation unit (13 beds). Community mental health services are based in Nelson, Motueka, Blenheim and Golden Bay.

The Mental Health Service employs approximately 170 clinical staff across the region and in the 2007–08 financial year saw 4,600 individuals, approximately 3.53 percent of the region's population. Its services are geared towards people experiencing moderate to severe mental illness.

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[1] Supporting Families in Mental Illness New Zealand (formerly Schizophrenia Fellowship) has 22 branches and affiliated organisations across New Zealand. In the Nelson Marlborough region there are two groups affiliated with the national organisation: Supporting Families in Mental Illness Nelson and Supporting Families in Mental Wellbeing Marlborough. Both local organisations provide a range of advocacy and support services for family members in their communities. Fieldworkers in Nelson and Motueka provide support groups, telephone support, referral to other agencies, educational resources and workshops, and regular newsletters to members. Supporting Families Marlborough provides similar fieldwork services to families in the Marlborough region and some additional services to meet the needs of the Marlborough community.

The *NMDHB Mental Health and Addiction Action Plan, 2008–2015* (Nelson Marlborough District Health Board, 2008b) estimates that 27,000 people in the NMDHB catchment area experienced a mild to serious mental illness within the previous 12 months.

The Mental Health Service employs a full-time family advisor. The advisor's role is to:

> Effectively represent the interests of families/whänau/carers of people with serious mental illness within Nelson Marlborough, by providing a family perspective in the planning, development, delivery and monitoring of mental health services, together with advice on current issues affecting patient care and family involvement. (Nelson Marlborough District Health Board, 2005 p. 1)

The family advisor is available to mental health professionals and family members. The support she provides families is short term, usually regarding crisis situations, and she refers most families on to Supporting Families. The ideal pathway is that staff members make family aware of the DHB advisor and the services that Supporting Families provides.

1.5 The challenge of including families in care

Families present mental health services with diverse strengths, experiences and issues. Some families will know little about mental illness. Some will have limited financial resources. Some will have extensive support networks, and others no support at all. Some families will cope with mental illness as if it were any other illness, and for others it will be a traumatic and unexpected development in their lives.

The key challenge for mental health services is providing good information and support to a wide variety of families – all with unique needs, experiences and expectations – as well as providing the best possible treatment to the person in care.

This can be difficult, as balancing the needs and the wishes of the person in care with the concerns of family members is an ongoing tension for mental health services staff.

This project focuses on how we can work better with families, in order to achieve positive health outcomes for everyone involved.

2. LITERATURE REVIEW

There is a large amount of material written about families and mental health services. We reviewed literature for this project to:

> find information that will support the aim of the project: to improve responses to family members engaging with mental health services
> describe the key drivers to improve family involvement during the past two decades and the current mental health practice context
> describe the requirements for family involvement that are expected at legislative and policy level, in the New Zealand practice environment
> source national and international research that focuses on best practice and the relationship between family members and mental health services.

Details of the search strategy are on pages 15-16.

2.1 A word about language and definitions

The terms used to describe people who use mental health services and their family members are very diverse, and are usually the subject of debate among writers and researchers (Cleary et al, 2006). When drafting this report we started with consumer/tangata whaiora and family/whänau. After reading through drafts, responding to people who provided feedback and attempting to improve the clarity and flow of the document, we decided on the following terms:

2.1.1 Family – a set of relationships

Family is not limited to relationships based on blood ties and may include:

> relatives of the mental health consumer (including a spouse or partner)
> a mixture of relatives, friends and others, in a support network
> only non-relatives of the mental health consumer.

Within this definition, examples of 'family' include:

> whänau/hapü and/or iwi
> a nuclear or extended Päkehä family
> family from a Pacific people (eg, aiga, koputangata, magafaoa)
> family from any other cultural grouping
> family from a particular community (eg, gender-based, gay or lesbian, deaf communities).

This definition of 'family' is adapted from one in *Involving Families Guidance Notes,* Royal Australian and New Zealand College of Psychiatrists (RANZCP) (2000).

The original definition from the RANZCP included "family relationships as defined by the consumer". After discussion with the ethics committee and consumer advisors, we chose to remove this part of the definition as it would exclude an important family group: estranged family members (see p. 20).

The family members who volunteered for the study were all immediate relatives of mental health services consumers, either their parents or children. While we discussed limiting the definition to immediate relatives, we decided that a limited definition would not reflect the practice conditions of the mental health service, which encourage a broad definition of family.

2.1.2 Consumer

In this study the term 'consumer' is used to describe people who have or have had mental ill health, and who receive mental health care (adapted from Phillips, 2006). This term does not have widespread approval by those who access mental health services, and other terms such as 'service user' and 'tangata whaiora' are also commonly used to describe people accessing mental health services.

2.1.3 Main caregivers

Family members, most commonly mothers of adolescent/adult children and sometimes partners/spouses. When someone needs ongoing practical and emotional support to recover from mental illness, their family members often provide this. Main caregivers often live in the same household or nearby and, if not living together, see each other several times a week.

2.2 New Zealand mental health practice context

2.2.1 Recent history and policy

As in many other countries, mental illness is no longer treated mainly with long-term hospital care (Mental Health Commission, 1998). For most people requiring mental health care, early detection of mental illness and community-based care is seen as the best option (Ministry of Health, 2006b).

Along with the move away from care in tertiary services, mental health services are increasingly focused on encouraging the use of recovery models and practices (Mental Health Commission, 2001).

Another key influence on both mental health services and the wider community is the Like Minds campaign. Like Minds has established both national- and community-based initiatives to reduce the stigma and discrimination associated with mental illness (Ministry of Health, 2007). Funding for this public health approach to mental health issues was launched in 1997, following a recommendation from the Mason Inquiry:

> We are optimistic enough to believe that a well-informed New Zealand public will then realise that [people with a mental illness] are people whom we should nurture and value. (Ministry of Health, 1996, p. 164)

Following the success of the initial five-year project, the Government has continued to fund Like Minds as an essential public health activity (Wyllie, 2007). Annual reports on its effect on public attitudes towards people with mental illness continue to be positive (Wyllie, Cameron, & Howearth, 2008).

In the last two decades mental health policy and standards have said that family involvement could improve. For example, Standard 10: Family/Whänau Participation in the Ministry of Health Mental Health Sector Standards (2001) is one of 18 standards that mental health services are expected to meet. In 2001 the Mental Health Commission also released the *Recovery Competencies for New Zealand Mental Health Workers*, including a competency detailing how to work with families (Appendix 8).

These documents described the changes that mental health services should make to work better with families in practice (Mental Health Commission, 2001). When these documents were released, many mental health services trained their staff on working with families. The training was provided by Supporting Families branches and private providers (Whiteside & Steinberg, 2003).

What appears to be missing in these documents is an acknowledgement of the need for a corresponding change in systems, in order to support practice change. For example, most mental health policy, guidelines and training documents suggest that staff should provide family members with good-quality written information, as best practice. However, these suggestions have become frustrating to staff who cannot easily access the information they want to provide to families.

If robust, nationally mandated information is not available, staff who wish to provide this information must research and write it themselves. But, as much time is involved in producing well-researched, good-quality materials, staff members' initial enthusiasm for the task may wane.

Current policy and planning documents weave the importance of family involvement and whänau ora concepts through documents at a more strategic level (Ministry of Health, 2005, 2006a) (Appendix 6). These documents promote the idea that family/whänau involvement should be integrated into each stage of a consumer's journey through mental health services (Ministry of Health, 2005).

As current policy and planning documents position family/whänau involvement more strategically, there is potential for its operational importance and focus to be reduced. The only recent document that defines 'responsiveness to family/whänau' as a key competency is the *Let's Get Real: Real Skills* document, which provides workforce development modules for staff working in mental health and addiction services. In these self-learning packages, mental health workers must demonstrate their skill in responding to families/whänau, as well as six other core skills (Ministry of Health, 2008) (Appendix 7).

These self-learning packages can have some influence on wider mental health systems, as individuals set goals for their own practice and, with their manager, identify potential changes required in the workplace. While this is a step in the right direction, the document does not provide information on resources, skills or support available to implement the changes required (Ministry of Health, 2008).

2.2.2 Relevant legislation

There is a range of legislation that affects the relationship between mental health services and families. Families who are new to mental health services are not always aware that staff are required to operate within legislative boundaries at all times. Mental health services staff members must have a sound working knowledge of several Acts of Parliament and the guidelines prepared to assist interpretation of these acts (Ministry of Health, 2008, p. 18).

The Privacy Act (1993) has, since its inception, been a source of frustration to families attempting to obtain health information about their family member (Dimmendal & Watson 2005). The Health Information Privacy Code (1994) was published by the Privacy Commission to provide guidance to health professionals interpreting the Privacy Act in practice settings (Privacy Commission, 1994). Complying with the legislative boundaries and requirements of the Privacy Act has become part of core training for staff at many district health boards (Nelson Marlborough District Health Board, 2009, p. 24).

The Health and Disability Commissioner Act (1994) and the subsequent development of the Health and Disability Commission, with its advocacy and investigative function, has markedly improved health consumers' awareness of their rights. The Commission has encouraged a culture where consumers and their families expect health services to provide good-quality information about their rights, health conditions and treatment options.

The Mental Health Compulsory Assessment and Treatment Act (1999) Amendment Act – Section 7a introduced a requirement for the medical practitioner or responsible clinician to consult with family members when considering whether someone be placed under the Mental Health Act, during treatment under the Act, and before discharge. However, there is one provision that the medical practitioner should not consult family if they do not believe it would be in the best interests of the consumer, or if it is not reasonable or practicable.

The Health Practitioners Competence Assurance Act (2003) has increased the legislative focus on the competency of a wide range of health professionals. Many professional groups' standards and guidelines feature competencies relating to family involvement (see following section).

The Mental Health Commission has recently had reviewed the legislation under which it operates. The Mental Health Commission Amendment Act (2007) revises the Commission's function to include:

> Service user and family advocacy – to act as an advocate for the interests of people with mental illness and/or addiction and their families/whānau generally (rather than for individuals or groups) while taking into account the interests of other stakeholders. (Mental Health Commission, 2007, p. 2)

2.2.3 New Zealand organisations supporting families

Many organisations support families who are involved with mental health services. Most of these organisations are not specifically focused on mental health, and support families across a wide range of health and social needs.

The three organisations that have a higher profile in supporting and advocating mental health and addiction issues are: Supporting Families in Mental Illness (New Zealand), Kina Families and Addictions Trust, and Carers New Zealand, which focuses on families who provide long-term care for a sick or disabled family member.

Supporting Families in Mental Illness New Zealand, formerly the Schizophrenia Fellowship (NZ) Inc, was established "by families for families" (Throll, 1997) in 1977. With 21 member branches across New Zealand, their mission is to provide the best possible information, advocacy and support for family members (SF website, 2008). Local branches provide families with advocacy and support services that are tailored to local needs.

Kina Families and Addictions Trust is another prominent organisation that supports family involvement in alcohol and drug services. To encourage its strong focus on family-inclusive practice, the trust has produced a range of resources for staff working in alcohol and drug services. It also provides training opportunities. The trust believes that families have the right to support, and that involving families in a client's recovery improves the chance of successful treatment and recovery (Kina website, 2009).

Carers New Zealand provides networks of support and information for people caring for a sick or disabled family member. They worked with the Ministry of Social Development and the New Zealand Carers Alliance to publish the *New Zealand Carers' Strategy and Five-Year Action Plan* (Ministry of Social Development, 2008). This document highlights the important role that some 750,000 carers play in New Zealand society, and some of the challenges they face. It also plots key areas of action for addressing the main issues of carers, which include: the provision of information; the health and wellbeing of carers; respite time for carers; financial support, training and employment for carers.

2.2.4 Professional organisations – standards, guidelines and competencies

All mental health professionals are required to engage with families and support people as part of delivering service to the consumer in care (Ministry of Health, 2008).

Different professions detail this in a variety of ways, in their particular standards or guidelines.

Te Ao Maramatanga – New Zealand College of Mental Health Nurses describes mental health nursing, in the preface to their practice standards, as:

> A specialised expression of nursing which focuses on meeting the mental health needs of the consumer, in partnership with family/whänau and the community, in any setting. (Te Ao Maramatanga – New Zealand College of Mental Health Nurses, 2004, p.1)

Under key areas of competency, some guidelines include working in partnership with families as an example. For example, the Medical Council links consulting with families to the 'communication' domain of competence.

2.2.5 Involving relatives, carers and partners

> 17. You must be considerate to relatives, carers, partners and others close to the patient. Make sure you are sensitive and responsive in providing information and support. (Medical Council of New Zealand, 2008, p.10)

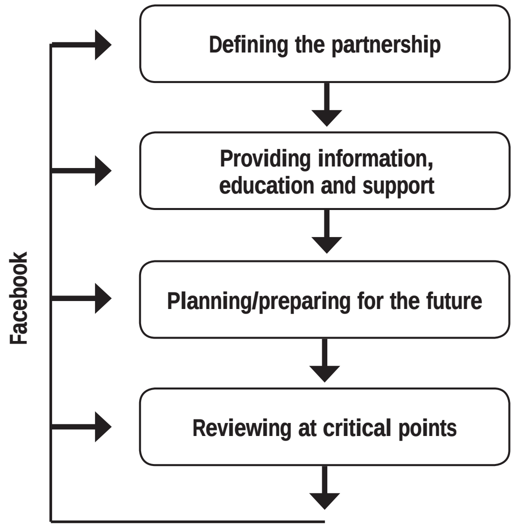
The Nursing Council of New Zealand lists this under Domain 3: Interpersonal relationships:

> Acknowledges family/whänau perspectives and supports their participation in services. (Nursing Council of New Zealand, 2007, p.26)

When searching for information about practically involving families, the *Involving Families Guidance Note* was one of the most useful documents we found. It was prepared by the Community Liaison Committee of the RANZCP. The Guidance Note provides a commonsense, practice-based framework to assist mental health staff become aware of what families need from services (Royal Australian and New Zealand College of Psychiatrists, 2000).

Within the document, the following diagram is broken down into its four parts, with both practitioner- and systems-based suggestions to ensure good practice at each stage.

Partnership of family, tangata whai ora and mental health staff a dynamic process with four main aspects:



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An extension of involving families in practice has been to actively seek out a family perspective to inform the development of mental health services. This is reinforced as a priority by a statement in the RANZCP 2005 practice guidelines for the treatment of schizophrenia and related disorders. These guidelines detail the treatment clients and families should expect from mental health services, and also state:

> Genuine involvement of consumers and relatives in service development should be standard. (Royal Australian and New Zealand College of Psychiatrists, 2005, p.1)

2.3 Research on families and mental health services responses

There is a large body of research and review that focuses on families and mental health services. The material we reviewed needed to inform the aim of this study: to improve responses to family members engaging with mental health services. We paid particular attention to finding research that combined the views of families, staff and consumers of mental health services, with research that explored systems-based responses to improving practice, as well as workforce strategies.

One study met all these criteria. Stanbridge and Burbach (2007) combine a systems approach with consumers, families and staff members in a mainstream mental health service. They describe how a Carers and Families Steering Group was established in a Somerset-based, mainstream mental health service. The group, comprising carers, service users, mental health service clinicians and managers, meets bi-monthly with a specific family or carer. It influences policy and integrates a family view into clinical practice and systems.

So far the group has focused on:

> improving information and support services for carers
> increasing the involvement of families/carers in the assessment and treatment process
> raising staff awareness and skills for working with families
> influencing Trust policies and guidelines. (Stanbridge & Burbach, 2007, pp. 21-43).

The idea of using a systems-based approach to clinical issues and scenarios is explored throughout the paper. One example is their approach to workforce development and skills. Rather than focusing on training, the group focused on raising awareness of family issues in staff groups. As well as clinical supervision and access to family therapy specialists, they introduced ‘interactional cycles’ to explore the relationships between staff and families (Stanbridge & Burbach, 2007).

These interactional cycles analyse common practice scenarios and assist staff and the organisation to develop systems-based approaches to common communication-based practice issues. It provides the following example, from an admission ward, to demonstrate the approach:

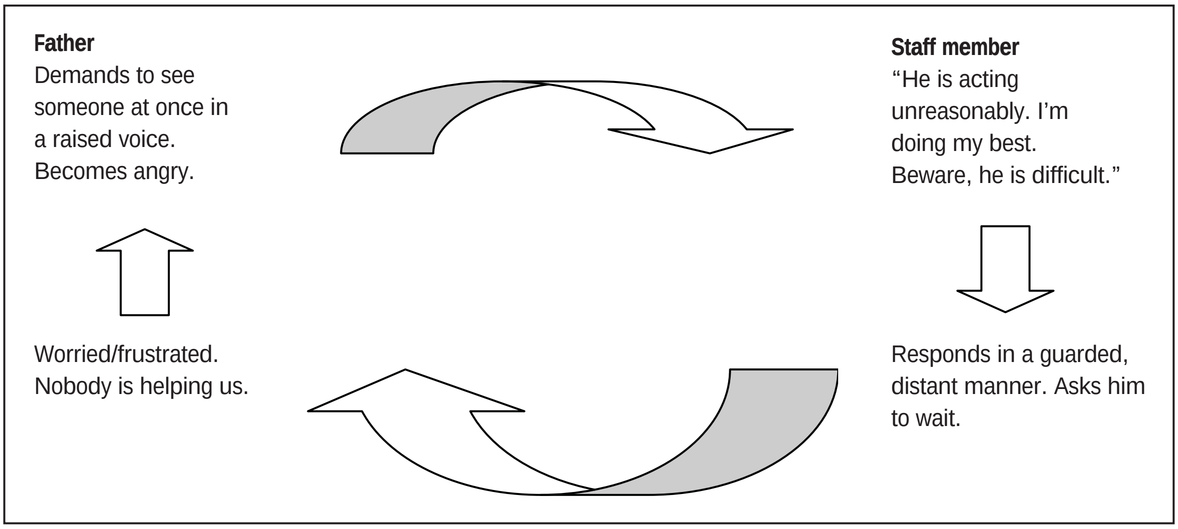
> In subsequent staff discussion about this common scenario, staff were encouraged to think about systems-based and practice-based solutions for breaking the cycle. Stanbridge & Burbach observed that this type of discussion enabled staff to consider that what they were observing in this particular scenario was a ‘stressed relative needing support’ rather than a ‘problem relative from which to distance themselves’. (Stanbridge & Burbach, 2007 p.39).

In this study, raising awareness among staff resulted in a policy that all visitors be greeted on arrival, and that families be included in the admission process. This kind of systems-based change makes sense to health professionals, who are trained to work within a system.

This approach is gaining popularity in other aspects of clinical practice, such as sentinel event reporting (NQIP, 2009). After a serious or adverse event, the mental health service investigates ways to improve their systems while also exploring individual practice issues (NQIP, 2009).

The researchers found that the mental health system failed to respond to families in a number of ways. Cleary, Freeman, Hunt, and Walter (2005), in a study involving 407 consumers and carers, found that both groups thought that the written information provided to them

FIGURE 1: Pursuit cycle



was inadequate. The other prominent systems issue highlighted by families was easy access to the mental health service (Rethink, 2003).

Another strong theme was a lack of family participation and consultation in service development, and the systemic barriers to such involvement (Lakeman, 2008).

Murray-Swank et al (2007) asked mental health consumers about their views on their family's participation in their care. Sixty-seven percent of consumers interviewed wanted family participating in their care. Those with weekly contact with family members were more likely to want family participation.

Research focusing on the relationship between family members and professionals reinforced the importance of orientating families to mental health services and providing clear communication (Clarke, 2006). Some studies outlined the importance of involving families in care (Dimmendal & Watson, 2005) and conveying respect in communication with family members (Ewertzon, Lutzen, Svensson, & Andershed, 2008).

The wider social and financial impact of mental illness on the family is extensively outlined in a report commissioned by Supporting Families in Mental Illness (M-Tag, 2006). This report raises issues of family isolation, stigma, discrimination and financial impact on families. Recent New Zealand-based research (Barnett & Barnes, 2010) explores in some depth the issue of discrimination, both within and towards families and whänau of people diagnosed with mental illness.

There are also significant studies that show family members have a higher risk of developing a mental illness themselves (Collings, 2009; Martens & Addington, 2001; Perlick et al, 2007) and the benefits of interventions that reduce the stress associated with providing care (Reinhard, 2007; Zauszniewski, Bekhet, & Suresky, 2009).

Evidence shows that standard medical treatment for mental illness is more likely to result in a sustained, successful recovery if families are actively engaged with mental health services (Sherman et al, 2009) and are involved in treatment planning and providing ongoing support (Pitschel-Walz et al, 2001).The evidence for involving families in care is particularly strong in the psychotic disorder spectrum (Pharoah, 2007). From an extensive systematic review, Pharoah et al (2007) concluded that involving families in relapse prevention strategies reduced relapse rates, and that educating families about medication improved consumers' adherence to medication regimes.

2.4 Summary

After investigating system-related barriers to enabling carers to participate in mental health services, Cleary et al (2006) found that there was "an absence of information about the challenges of translating carer policy and directives into practice" (p.189).

This literature review clearly shows that mental health services staff are expected to work in partnership with the family of mental health consumers, where possible. However, to do this staff need to be supported by changes in the New Zealand mental health care system, and this support was less evident in the review. While it is useful to train staff on including families, how much of their renewed enthusiasm for working with families will be retained if the system around them does not support a change in practice?

2.5 The place of this research

This research contributes to existing knowledge about family inclusion in mental health services, comparing the perspectives of staff and family members to inform future service development and systemic change.

Mental health services have clear service pathways for consumers but families, who are not always viewed as an essential part of service delivery, can be marginalised.

Combining mental health services staff and family members with a service development focus was only found in one other study (Stanbridge & Burbach, 2007). Opening a conversation between these two groups will provide key information to help mental health services respond better to family members.

3. THE RESEARCH DESIGN AND PROCESS

The participatory action research process translates knowledge into action. Central to this process is a cycle of critical reflection and learning. Reflection is about learning to understand our human situation and ourselves as we try to construe meaning out of the experiences and situations of which we are a part (Koch & Kralik, 2006, p. 30).

3.1 Introduction

A key feature of this study is the comparison between the views of families and staff members. In this chapter we describe the research design, methodology and aims of the study. We discuss how we resolved some early ethical issues and how we applied the participatory action research model.

3.2 Research questions

The questions for investigation are:

1. What are family members' issues and experiences of the support and assistance THEY receive/have received from NMDHB?
2. What would family members and mental health services staff prioritise as essential components of a 'family pathway' for mental health services?
3. How do the above 'essential components' compare with nationally recognised standards such as the Code of Family Rights, the National Mental Health Standards and the Blueprint for Mental Health Services?

3.3 Aims

To improve the way mental health services respond to families of mental health consumers.

3.4 Objectives

> To hear participants' perspectives on their experiences and issues.

> To record their ideas in order to improve services and guide a family pathway document.

> To compare participants' ideas and experiences with nationally recognised standards.

3.5 Participatory action research

Participatory Action Research (PAR) is a process in which 'we', researchers and participants, systematically work together in cycles to explore concerns, claims or issues that impact upon or disrupt people's lives. Collaboratively we reflect on ways to change situations or build capacity (Koch & Kralik, 2006, p. 27).

PAR methods require key stakeholders to be both research participants and members of the research team.This collaborative approach and a practical outcome to the research attracts researchers focused on improving services.

3.6 Why use it for this project?

This project required collaboration between mental health services staff and family members, and between NMDHB and many groups interested in becoming involved. As some action on service improvement was also expected from this project, PAR was a good choice.

The Mental Health Commission has used PAR to facilitate several projects and encourages other mental health organisations to consider using it to develop and improve their services.

The Commission urges people providing mental health services to think seriously about using action research to improve aspects of their service. We believe that it can produce ongoing and out-flowing benefits for people using mental health services and satisfaction and empowerment for people working in services (Mental Health Commission, 2000, pp. 1-4).

3.7 How was PAR applied in this project?

A wide range of interest groups and potential participant groups were involved in all stages of this project. We convened a reference group comprised of a DHB family advisor, two representatives each from Supporting Families (SF) Nelson and Marlborough, a family advisor from Gateway Housing Trust, three NMDHB staff with an interest in working with families, and Mäori Mental Health staff. The late Michael Lynch, a fieldworker from SF Nelson, was also very involved in the design process.

The lead researchers envisioned that this group would exceed the usual expectations of a reference group. A key feature of the PAR approach is that those involved in the area of research can be involved as co-researchers, and can influence all aspects of the research process, based on their experience (Heron & Reason, 2006, p. 144).

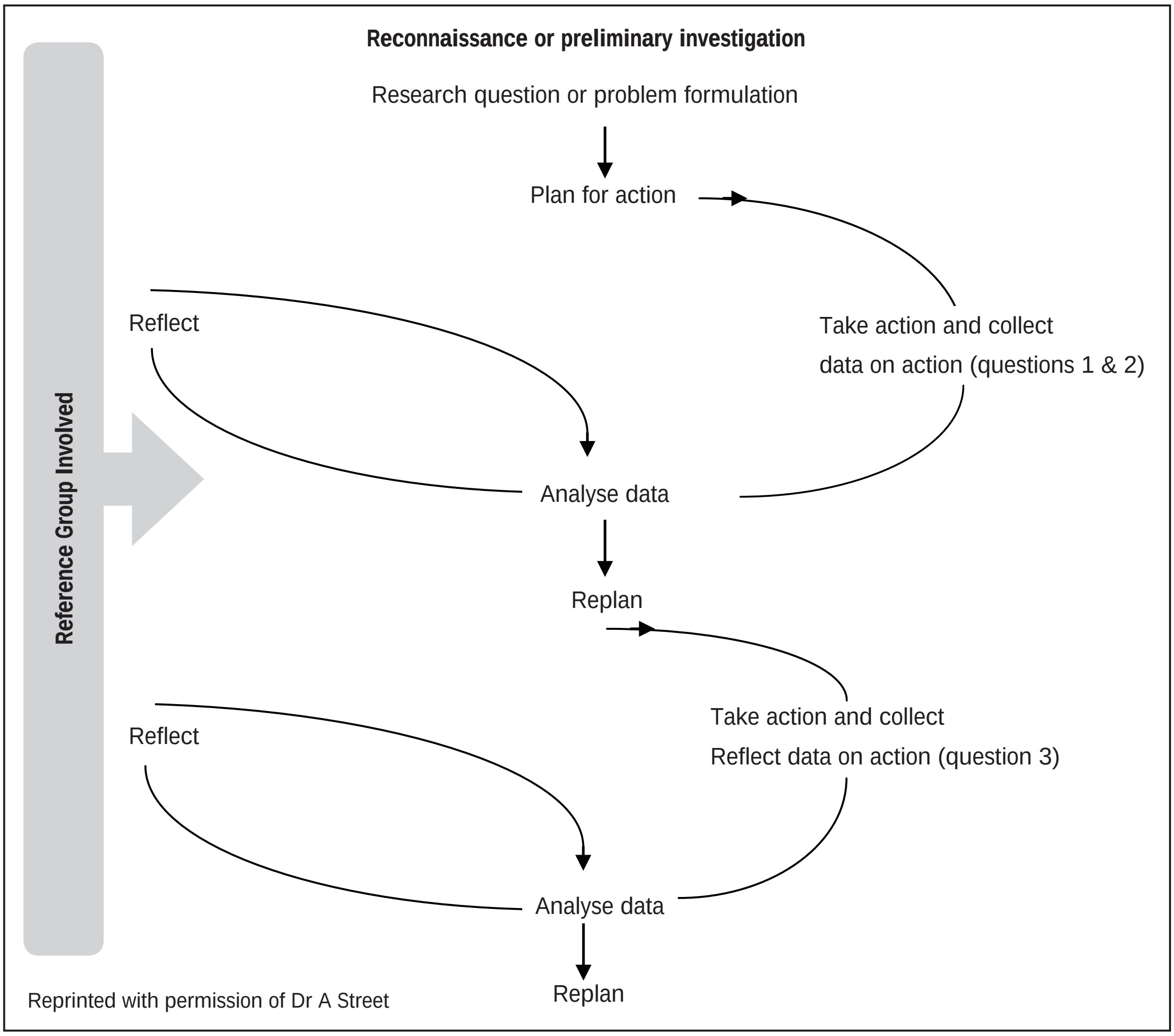
However, this aim was not easily achieved because the members of the reference group were also busy with many other commitments. At most meetings, just two to four people attended. Although the lead researcher followed up with those unable to attend, as the entire group never managed to meet together it could not function at the depth originally expected.

This group provided feedback and advice to the lead researcher at key stages throughout the project, and this had a significant impact on the study design and recommendations. Had the group been able to meet regularly, with more members present, it could have achieved the full extent of a PAR process. An important aspect of PAR is group discussion, sharing of stories from practice and strategising about how to improve the issues being researched. While aspects of this still occurred, we could not completely adhere to the PAR model.

Two NMDHB consumer advisors also generously contributed their time and expertise to the project, when requested.

We achieved two action research cycles. The first concentrated on collecting data from families and staff members, and developing themes. The second compared these themes with nationally significant documents that set standards for family involvement in mental health services.

FIGURE 2: The participatory action research process (Street, 1995, p. xxv)



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3.8 Should PAR be recommended?

To quote a previous study the lead researcher was involved in: "Yes and no!" (Walsh et al, 2001).

Where researchers are required to work collaboratively and focus on practice, PAR is ideal. However, maintaining a commitment to ongoing collaboration and consultation can become a challenge when there is competition for time and resources, as noted earlier in this section.

Walsh et al, in their 2001 PAR study on discharge planning in an acute mental health setting, found that competing commitments, time and varying levels of commitment to a project made implementing the PAR model difficult.

However, in this study there was a consistently strong, ongoing level of commitment from research participants, reference group members and DHB- and NGO-based organisations. The interest in this project and its potential outcomes was very high and therefore so was a commitment to support the work of the researchers.

The participants were disappointed at times when timeframes and deadlines for completing work were extended. Some delays were due to other work commitments, but many were due to the requirement to consult widely, which the researchers viewed as an essential principle.

3.9 General characteristics of the two groups

Twenty-three people volunteered to be interviewed for the project. Of these, 13 were family members and 10 were current mental health services staff members. All participants said they were of New Zealand European or European ethnicity.

3.9.1 Family members

Thirteen family members, from 12 different families, were interviewed in Motueka, Nelson and Blenheim. The participants were mostly parents with children, ranging from young children to adults, who are currently using mental health services. A daughter and two partners were also interviewed.

Most participants said the family member receiving mental health services had experienced moderate levels of illness, with two rating their family member's illness as severe.

Eight participants lived in the same house as their family member. The remaining five, who did not live with their relative, made contact with them on average one to two times per week.

Family members' contact with mental health services varied from very frequent, between daily and weekly, to monthly, which was the most common time interval. Most family members said they would like to be contacted more frequently.

The family participants engaged with a range of mental health services, including inpatient; adult community mental health; adult outpatients; Child and Adolescent Mental Health Service; and Addiction Services.

The combined number of years that family participants had interacted with mental health services totalled 58, with the range being three to 15 years.

Most family members wished to be involved in the study to provide feedback on their experience and contribute to future improvements in service.

3.9.2 Staff members

Ten staff members from inpatient, outpatient and adult community mental health services, in Nelson only, participated in this study. The study was advertised service- and district-wide.

The staff members' experience in mental health services ranged from two to 30 years, with a combined total of 140 years. Their contact with families varied between daily contact, for staff working in inpatient services, through to monthly or less frequent contact for community case managers.

Staff expressed various levels of confidence in working with family members, from 'low' among newer, less experienced staff, through to 'very high' for staff members with extensive family therapy training and many years in practice. However, their confidence in working with families did not always equate to the number of years they had spent in practice; some experienced staff expressed a low-moderate level of confidence, despite a real willingness to work with families.

All staff interviewed rated working with families as 'important' to 'very important'. Most people said they were volunteering for the study because they were interested in working with families and believed that mental health services could improve in this area.

Several staff members interviewed had another motivation: they had family members who were currently or previously treated by mental health services. These staff felt that their dual perspective, while often difficult personally, added to their professional attributes and assisted them in working with families.

3.10 Interviews

Interviews were conducted in person, at a time and place of participants' choosing. Most family members chose their own home, with a few coming in to Te Whare Omahu, the family and consumer advisors' office and meeting space at NMDHB.

Participants could choose to be interviewed by the principal researcher and/or the NMDHB family advisor, Lynda Sigglekow. Two participants, one family member and one staff member, requested that the family advisor attend their interview.

Three participants requested copies of their typed transcripts and all were interested in receiving a copy of the final report and verbal feedback from the principal researcher after the project was completed.

3.10.1 Ethics approval

Ethics approval was granted for this project on 22 April 2008 by the Upper South A Regional Ethics Committee. See page 20-21 for further discussion regarding the ethics approval process.

3.10.2 Characteristics of participants

The study was open to interested people who said they had a family member receiving NMDHB-funded mental health services, and to all clinically based, current NMDHB mental health services staff members.

3.10.3 How participants were informed about the proposed study

Participants were recruited using flyers and posters on noticeboards in mental health services and participating NGOs. This method conveyed the information to families and staff without the principal investigator being aware of who they were, and without them having any obligation to take part. SF Nelson also published information in its newsletter to families.

The principal investigator also made a total of eight presentations, to staff and family groups, about the project and its aims.

Participants were invited to take part in a one-to-one semi-structured interview and to express their interest by providing their contact details on a slip found at the end of the project information sheet (Appendices 4 and 5).

3.10.4 What happened when people expressed their interest?

Participants were contacted by phone one week after their expression of interest was received. If they were still interested, we negotiated a day and time for the interview, and they decided where it would take place. Immediately after this conversation they were mailed a consent form and interview schedule (Appendices 1, 2 and 3). Participants were encouraged to bring a support person if they wished.

3.11 The interview

Before beginning the interview, participants were talked through the consent form and interview schedule, and were offered an off-tape debriefing interview afterwards. This offer recognised the potential for the interview to raise upsetting past issues for the participant.

The interviews focused on the experiences and issues of family members of current clients and what they believed to be the priorities for service delivery to families in the future. The staff members were asked their priorities for service delivery to families and talked about the experiences and issues they had encountered while working with families in mental health services (Interview Schedules, Appendices 2 and 3).

3.11.1 Data collection

The interviews were all face-to-face and with individuals or couples. Twice the principal investigator was accompanied by the NMDHB's family advisor, at the request of research participants. We initially proposed focus groups, but decided against them after correspondence with the ethics committee (see page 20 for further details). Interviews were audiotaped and transcribed, with transcripts returned to participants for checking and comment, if requested.

3.11.2 Data analysis

Thematic analysis was used to summarise and distil themes from the interview conversations. Each interview transcript was read, re-read and then sorted for themes. The themes were chosen from sentences and paragraphs within the transcripts, by content analysis. Tables were used to record the frequency of themes and to manage the development of themes and subthemes.

3.11.3 Data validation

Each transcript was read several times before it was analysed for data. For each research participant we prepared a one-page profile, summarising their experience and issues. Each profile was then compared with the interview themes and subthemes to establish if these were consistent with the experiences of individual participants.

At this stage each participant was contacted, usually by telephone, and the themes and subthemes were discussed. We also contacted the reference group members to feed back the themes and subthemes, as well as ideas regarding the conclusions of the study and recommendations for the DHB.

After receiving comments from participants and reference group members, we made some minor adjustments, but generally the data were validated by participants and reference group members.

We then considered the themes and subthemes in relation to recognised mental health standards for providing service to family members, as per question 3.

3.11.4 Feedback to participants

Research participants were individually given feedback about the findings of the study, and discussion about its application, either in person or by telephone. All participants will receive a copy of the final report when it is published.

3.11.5 The role of the reference group

Engaging a group of interested mental health services staff, family members and people representing the interests of family members has been essential to the relevance and credibility of this project.

Most meetings have been small, with varying membership. We have done a lot of ‘catching up’ with reference group members individually, often due to their other work commitments.

Working with a reference group during the early design phase of this project was very useful. The group drew on the knowledge of members who had past involvement in family research and had firm ideas about what they did not want to occur.

By relating issues from their experiences, group members have sometimes challenged the assumptions of the researchers, and have informed all stages of the project. The project and its researchers have greatly benefited from access to staff and family members with invaluable local, contextual knowledge.

3.11.6 Consultation with Mäori

Mäori mental health staff made themselves available in the early phase of the project. They also offered assistance if Mäori whänau came forward to be interviewed.

Two meetings with Mäori mental health staff were held and a recommendation to meet with the NMDHB Director of Mäori Health was followed up on. The endorsement of the Iwi Health Board was requested and granted.

During the research, reports were made to Mäori staff and the Iwi Health Board. This was an important part of the research process.

While two Mäori whänau expressed interest in the study and were supported by Mäori mental health staff members, they later decided not to be involved. Mäori mental health service staff said that one case was due to personal circumstances and the other to involvement in other health-related research.

Not managing to recruit Mäori staff or family members has significantly limited this study. However, the Mäori staff members in the reference group, the Director of Mäori Health and the Iwi Health Board have made a valuable contribution to the research.

3.11.7 Literature search strategy

We searched electronic databases using terms focused on the relationship between families and mental health services: Ovid Online, Medline and Nursing, PsychINFO, British Nursing Index, Cochrane Library, Index New Zealand. Searches were restricted to English language, post-1995. The following search terms were used:

> Family and mental health services: inclusion, participation, involvement, engagement,

communication, support, information, advocacy, rights, standards.

The above phrases were then searched for again, using the term ‘whänau’ instead of ‘family’ and ‘carer’ instead of ‘family’.

Key government policy documents from the Ministry of Health, the Mental Health Commission, the Health and Disability Commission, Standards New Zealand and Te Pou – Mental Health Workforce Development were also searched for any reference to family involvement in mental health services.

Another source of information was the NMDHB family advisor and her contacts nationally. These contacts provided copies of the information available to families in different areas of New Zealand.

Google and Google Scholar were searched to see the type of information more commonly available to the public.

3.11.8 Ethical considerations and approval

Some interesting ethical issues arise when interviewing family members about their experiences of mental health services. While the study focuses on family members’ experiences, we must consider the rights of mental health consumers and whether seeking information from their family compromises their rights.

In our initial application to the Ministry of Health Upper South A Ethics Committee we did not feel this was the case; we highlighted the family focus of our questions and the aspects of study design that reduced the risk to family members participating. The initial application to the ethics committee was deferred and the committee’s response highlighted two main concerns about consumers’ rights.

Their first, very valid concern was about families being given the option of being interviewed in multi-family focus groups. In our initial planning, fieldworkers at Supporting Families said that families meet together regularly for their meetings, and may like to be interviewed as a group. The ethics committee pointed out the following:

> The committee is concerned that a focus group may not be an appropriate platform for this type of discussion regarding a third party. Please consider the feasibility of one-on-one family interviews in place of the focus groups. (Letter from ethics committee, 26 Feb 2008)

After discussion with the family and consumer advisors and reference group members, we agreed that this was a valid point and decided to hold single-family interviews instead. Members of the same family could be interviewed together if they wanted to, but not members of different families, as privacy issues could arise.

3.11.9 The second major concern of the committee was not as straightforward

> The committee is concerned about the rights of patients who may not wish their family members to divulge information about them and/or their situation, and may not want such a discussion to take place at all. It is felt that it is appropriate to involve the patient themselves in the consent process. Please further clarify what information will be gathered. Please also consider including a statement regarding the disclosure of information on the consent form, to be signed by the patient… It is felt that it may be appropriate for the patients themselves to be involved in the study. (Letter from ethics committee, 28 Feb 2008)

Again, this was discussed with the consumer advisors and family advisor. They all clearly believed that the study focused on the experience of families and to more explicitly involve consumers would change the whole focus of the study. After much discussion we decided to add a statement to the interview schedule asking family and staff members not to provide details about their family member and reiterating that we were focusing on their experience of mental health services.

A consumer advisor commented that requiring consent from consumers would also exclude a group of family members who could add valuable information to the study: estranged family members:

> One [consumer] advisor commented that she would be concerned that requiring consumer consent would exclude a number of family members from being able to contribute to this project because their family member would not agree to their participation because of estranged family relationships. Families trying to support their family member in a context of strained and difficult family relationships have particular support needs that would be useful to record and discuss in this study and highlight with mental health services. (Letter of reply to ethics committee, 28 Feb 2008)

As a third and final response to this issue, before the report was released to the Families Commission the consumer and family advisors would read the findings chapter to double check that nobody involved could be identified from the interview excerpts used.

This information was accepted by the Upper South A Ethics Committee and the project was then able to proceed.

The points raised by the committee certainly made us consider the research's implications for mental health consumers. We were concerned that the family focus of the study was not clear to the committee, and being able to check this with the consumer and family advisors and the reference group was very valuable.

When interviews did occur, there was only one occasion where the tape had to be stopped and rewound over inappropriate information provided by a family member. After discussion with this family member, they adjusted their response. They commented that they realised the need for privacy but were feeling so comfortable talking that they had 'slipped' into discussing their family member in more detail.

All participants, staff and family members were very respectful of consumers' privacy and were clearly aware that the focus was on them, as staff or family members, not on their family member.

4. FINDINGS

4.1 Introduction

The following chapter sets out the main themes and subthemes from interviews with family members and staff members.

The first question was only asked of family members as part of a semi-structured interview.

Question 1: What are family members' issues and experiences of the support and assistance THEY receive/have received from NMDHB?

The themes from this summarise their experiences, both positive and negative, of their interactions with mental health services.

The second question was asked of both family and staff members, and the similarities and differences between both groups were recorded.

Question 2: What would family members and mental health services staff prioritise as essential components of a 'family pathway' for mental health services?

The third question is an audit of the themes generated from the first two questions. This was undertaken to see if the themes generated from family and staff are present in key policy, planning and training documents.

Question 3: How do the above 'essential components' compare with nationally recognised standards such as the Code of Family Rights, the National Mental Health Standards and the Blueprint for Mental Health Services?

A table summarising the themes from question one is on page 25. The table for question two is on page 35. The third question analysis is presented in the table on pages 36 and 37.

4.1.1 Question 1: What are family members' issues and experiences of the support and assistance THEY receive/have received from NMDHB?

Theme 1: Communication and quality of relationships with mental health staff

Building and maintaining good relationships with mental health staff is very important to family member participants. A demonstrated commitment to good communication and rapport with family members by mental health services staff builds trust and confidence in the services being provided.

a. Being believed by mental health services staff

The project's most prominent subtheme centred on family members feeling believed by mental health professionals. This was particularly important when family members felt they 'went out on a limb' by talking to mental health professionals, risking their own integrity by 'betraying' their family member.

When family members described particularly helpful mental health services staff, their most important attribute was that they believed them:

> There's that sense that they believed what I told them and they took note of it; they remembered it and they used it. (Family member)
>
> She did home visits and she supported us, believed us when nobody else would. She believed us and held us. (Family member)

Conversely, family members became disappointed with mental health services when they felt they were not believed:

> The thing about [my family member] is that she's really good at disguising, no matter how bad things are, the depth of her illness. As a family member, once again you feel like you're stepping in again trying to convince the professionals that there really is a problem here. (Family member)
>
> Why does the care worker question what a family is saying, why do they not believe it? (Family member)

b. Being acknowledged for their unique perspective

When families felt acknowledged, this often increased their confidence in mental health care and service. This is a typical example:

> They made you feel like a person and that [your family member] was important and that they did care for her. (Family member)

Family members often felt that mental health professionals did not acknowledge or make enough use of the unique perspective they could provide:

> That has been a huge frustration to me [as he] presents really well, [he's] quite casual, 'Everything's fine; yep, taking my meds; I'm doing well'… I know that there are packets of pills unopened, that there are big issues going on or that he's about to be kicked out of his flat. (Family member)

c. Effective communication and confidence in treatment

Family members often felt less anxious and more confident about the care received when they could relate to the mental health professional caring for them:

> This is really important, probably even more important in mental health than in physical health areas, that there is communication, understanding and some sort of rapport or connection between the person who is dispensing the advice or the treatment and the people around the one suffering. (Family member)

Several family members commented that they felt they were able to be more supportive of the treatment if they felt comfortable with the staff involved. This was a typical comment:

> She's in her 30s but she's still our daughter and so … it makes us more comfortable if we have met her carers because then you can say 'Yes we are comfortable with [staff member] and we think she's the best person for you at this time.' (Family member)

At times, they were also concerned for the wellbeing of staff and how this affected the quality of service they were able to offer:

> I s'pose there's a danger with that kind of work that you get toughened up to it and you have to put up your barriers but you've got to remember to take them down sometimes too. (Family member)

Access to case managers was very highly valued by families:

> I could ring him and I had many questions in the beginning because our world fell apart, and I was impatient as well and I wanted things moving and so I had great chats with him … so he was really an important tree for us to hold on to and we felt he was really being honest … he managed to say, 'This is what we have to work with, this is what we can do' and that was majorly important to us at that point. (Family member)

Theme 2: Information – asking questions and searching for answers

Most of those interviewed mentioned searching for mental health information on the internet, going to the library at Supporting Families (SF) or buying books on mental health-related subjects.

The amount of previous exposure to people with mental illness varied across the group. Some had other family members with mental health difficulties and so had some prior knowledge and experience. Some had no prior experience in mental health. All said that learning more from mental health professionals and other resources would help them support their family member.

There was a strong connection between family members being able to access information and feeling acknowledged by and confident of the mental health service provided:

> The first contact we had with the unit … the nurses were really great and I just cannot fail that system because I had to reach out which was fair enough but when I had questions they were answered and I felt very taken as a real person and my questions were valid. (Family member)

a. Access to good-quality information about mental illness and treatment options

Access to good-quality information, when and where families need it, is highly valued by family members. Providing the right amount of information, at the right time and in a format that the family will understand and appreciate is often a challenge for services and staff. Information that helps one family may confuse another. Some families interviewed had read the DHB family pack of information and then gone searching for more, while others had found the information in the family pack overwhelming and confusing.

Some family members thought that access to good information sources would improve if staff introduced them to resources earlier or in a more practical way:

> The pamphlets are all there but you still have to go out and do things for yourself … perhaps they could be taken to [Supporting Families] and introduced to all the information that's there… I got out three very good books from the library there and they've been really really helpful to me. (Family member)

b. Guidance on how to best interact with mental health services

Many family members were unsure how to best access information about their family member, and how to best provide important information and observations to mental health services. They were often reluctant to 'bother' busy health professionals but wanted to ensure their family member had the best possible care. During interviews they often said they might have been dissatisfied with the service as they didn't know the best way to engage with it. The following were typical comments:

> I don't know whether I didn't ask enough questions. (Family member)

> You don't know where to go to find out what's happening … who do I talk to and, if I've got a concern, who do I go to? When you're a few days into it, you read through your brochures and you find Supporting Families and you think 'Oh good, there's someone to talk to.' (Family member)

c. Families as the main caregiver

Some family members we interviewed provide the main support for a person receiving ongoing mental health services. These family members appreciate having their important role acknowledged by health professionals, and realise they need advice, support and guidance from mental health professionals to be effective as caregivers:

> You were able to sit and ask her questions and I felt this time through it was such a big improvement. (Family member)

> He gave us a lot of guidance… We're not the professionals, we're not psychiatric nurses, we don't know what we should be doing, we don't know what we should be looking for and [Supporting Families] gave us lots of help in that area. (Family member)

Families often wanted mental health staff to help them support and participate in treatment plans:

> If you have more of a chance to interact with [case manager] you might be able to say, 'Well is this the best approach, is it supporting what you are doing by organising her with a bit of a list, should I be doing that or not?' (Family member)

> Particularly where you have a child who has left home, been independent, got on with life and then all of a sudden they're back and needing your support and assistance… How much do you do, how little do you do, what do you let them do for themselves? You want someone to ask about those sort of things. (Family member)

They also discussed some of the hidden costs of being the main caregiver, including having to give up work, and having to travel significant distances to visit family members in hospital. Information on the social and financial aspects of caregiving was not readily provided by mental health services:

> Even if it's just, 'Look, are you aware that you're eligible for financial assistance?' Nobody told me I could have my petrol reimbursed. I found out two years too late that one of my children was eligible for a disability allowance. So I think the mental health services, even though they're not directly providing the money, need to make that information available and encourage people … it might never have occurred to you that you'd be eligible for any extra help. (Family member)

Another aspect highlighted was the stress on themselves and other family members:

> You can juggle an awful lot in terms of family dynamics and, as the main caregiver, your time, your energy, your money, your emotions … there might be other children, or a spouse or other jobs, or other people in your life that are also expecting things from you… I think the toll it takes is not acknowledged enough, especially when it's an ongoing thing. (Family member)

d. Facing fears, stigma and uncertainty

Most family members remembered their fears and anxieties about entering the mental health system, and said these feelings made them less effective at communicating:

> I was blocked by fear, by fear of the unknown. I had no reference points to work on; it was all new and what do you do when it's all new because you don't know so you don't know what to ask really… Acknowledging where that person is sitting at the moment with all the worries, with all the not knowing stuff. (Family member)

Some people talked about the effects of stigma on their family:

> These issues are quite isolating; they actually put up a bit of a separation between you and the average family and I've really only begun to become very aware of the impact of that. I've been very fortunate in that I have really good and caring friends. (Family member)

Families also often become frustrated when mental health professionals cannot give a definitive answer or diagnosis immediately, unlike other health services. When mental health professionals cannot definitively answer questions from families, this can be misinterpreted by family members as reflecting a practitioner's lack of skill. This adds to families' mistrust of the professional, and of the mental health system:

> If you change a diagnosis like that, families aren't expecting that, that can dent your faith in the system … in the rest of the health service you would expect that you come in, you give your information, they make a diagnosis, they give you a timeframe for when it will be fixed, or they tell you it will never be fixed and you go on your merry way.
> But with mental health it's not like that.
> (Family member)

Summary

The following table provides a summary of the main points of Question 1. Communication, quality relationships with mental health staff and information are key themes from this first stage of interviews with families. These are discussed further in Chapter 5.

Question 1: What are family members' issues and experiences of the support and assistance THEY receive/have received from NMDHB Mental Health Services?

↓

Main theme 1: Communication and quality of relationships with mental health staff

The subthemes in their experiences were:

a. Being believed by mental health services staff
b. Acknowledged for their unique perspective
c. Effective communication, confidence in and support of treatment

↓

Main theme 2: Information – asking questions and searching for answers

The subthemes in their experiences were:

a. Access to good-quality information about mental illness and treatment options
b. Guidance and information on how to best interact with mental health services
c. Families as the main caregiver
d. Facing fears, stigma and uncertainty

Introduction: Question 2

In this part of the project we asked families and staff the same question: What would they say were the essential components of a 'family pathway' for mental health services? Family members who were not familiar with the DHB's Client Pathway were given a copy to look over (Appendix 12) and the concept was explained in more detail before moving on to the family pathway question (Appendices 2 and 3 for interview schedules).

A summary table of the following themes and subthemes is found at the end of this section. We start this section with the themes from families and then move on to staff members.

4.1.2 Question 2: What would family members and mental health services staff prioritise as essential components of a 'family pathway' for mental health services?

Families' priorities

Theme 1: Information – gaining knowledge

a. Simple information on initial contact, outlining more detailed resources available

Most family members felt overwhelmed by information when they first entered a mental health service. Many said they read some of the information "when things had settled down" but much later along their journey they were disappointed to find information that would have been helpful earlier. This was a typical comment:

> It can be quite overwhelming… Some understanding, in layman's terms, of what the condition is and then maybe something like an A4 to say we can give you help with … a, b, c, d, just on one page … if you wish to connect with any of these, please contact … so you don't have 30 pamphlets there in one pack. (Family member)

b. Access to a variety of resources

Family members appreciated the good-quality resources they had found, but wanted easy access to a larger, wider variety of information, both for their own interest and to help them aid their family member's recovery. Several people commented about the use of different media, specifically the internet and DVDs, that other members of the family could watch:

> We were given a video this time. The Unit produced this video and it was very good and everyone in the family watched it. The big thing is understanding it. (Family member)

Many families stressed the importance of being told about SF, which provides an important advocacy and support role. Having someone to talk to, external to the DHB services, was highly valued by families. Several expressed concern that they heard about this service either by accident or very late into their time with mental health services:

> I think it's important that some of this is provided outside of the mental health service… I know a number of people that I've talked to have been very reticent in what they've wanted to say because they were worried that would affect his care. (Family member)

c. Orientation to the mental health services

During interviews, family members reflected on their first experience of mental health services and how little they knew about the system. Being unsure how to approach mental health professionals and what to expect of them and the service contributed to an already stressful situation. This comment, as part of a conversation about families receiving a more comprehensive orientation to mental health services, was typical:

> I can tell you I had no idea. You come in real cold turkey; you don't know what you're allowed to ask, you don't know who to speak to, you don't know the right questions to ask. (Family member)

Families commented that an orientation to mental health services and advice on what to expect would be very helpful:

> Just having a bit more knowledge about the structure and what the expectations are. You are under so much stress anyway… All those things, they might be little, but they do add up. (Family member)

d. A place to go to access further information

Family members suggested that a welcoming place away from the admissions unit could provide them with good-quality information when they needed it:

> I think it would be really good to have somewhere away from the Unit because quite often families didn't want to be seen [by their family member] that they were talking to staff about them. (Family member)
>
> Somewhere that can be a bit of a haven, removed from everything, where you know you can go to increase your knowledge and ask questions. (Family member)

Theme 2: Proactive approach and relationships

a. Named contact person

Access to a named contact person was high on a family's wish list. Often family members felt that they were imposing on or bothering a range of different mental health staff and that it would be a great relief to have the name of a person they could contact regarding their concerns, or to find information.

A number of participants prefer the guidance of a trained mental health professional, rather than an advocate or support person, when seeking information. Some people felt it was important that this was the treating doctor, while others didn't:

> I think each family should have a dedicated [person] to explain what's happening to their family member, what the diagnosis is, what the treatment plan is, what the family should expect. (Family member)
>
> Have the doctor's name and the nurse's name written down because people aren't very good at remembering names. So on the family pack that comes out have two or three names and phone numbers. (Family member)

b. Proactive communication

Families discussed how a more proactive approach to providing them with information would have sometimes been helpful. At an often confusing and vulnerable time for them, families felt that they were imposing on mental health professionals by asking questions. Families wanted these professionals to engage more proactively with them and invite them to be involved in the care of their family member:

> You just feel like you have to put up your hand all the time and you get sick of doing it, you just want people to be proactive and respond without you having to ask for it. (Family member)
>
> That communication, we're here to help, feel free to ask and we will contact you or we will give you access to these things or show you how to go about it. (Family member)

c. Family advice roles

Families who had contact with the family advisor really appreciated her input:

> I found her services invaluable; any time I talked to her about any issue something was done behind the scenes and something would happen and that was just fantastic. (Family member)

A number of people expressed confusion about the nature of her role versus the services provided by SF and were concerned that at times they may have accessed the wrong person. Both the NMDHB family advisor and SF fieldworker roles, as described in the introduction, involve support and education. Families find this confusing at times and this can affect their willingness to engage with either service:

> The thing about the [family advisor] role is you don't really know what her limitations are and I've said to her before, what her role is as such, and she tries to explain it but I get it wrong and I say to her, 'Should I be talking to you about this?' It's maybe partly my fault. (Family member)

Theme 3: Resilience and personal coping

Family members recognised that their relative's mental illness had also put their own mental health at risk. This personal toll affected their ability to support their ill family member:

> You keep yourself together as a family member; in a crisis you can't fall apart, you're actively engaged in trying to get that person through that patch but afterwards or when you've got a bit of respite, sometimes you can just feel absolutely shot and you can be shaky or depressed or anxious… You actually need help for yourself or some reassurance or something. (Family member)

a. Proactive checking on how the family are coping

Family members felt much more acknowledged and cared for by the service when mental health staff asked them how they were coping:

> There are individuals who have stood out along the way, who picked up on the strain that you might be feeling and acknowledged that or made some effort to just check that you're alright. (Family member)

b. Information and advice on looking after self

For some family members it was only on reflection that they realised the impact that the situation had had on them:

> Mental illnesses have a big impact beyond the sufferer, which is not to say the sufferer shouldn't have prime spot, but… I've been faced with these issues for many years now; I think it's really affected my mental health – or emotional health anyway – and perhaps I've minimised that... I've put myself second every time. (Family member)

In hindsight, many family members would have appreciated knowing earlier how important it is that they also look after themselves:

> I think I personally would have needed some personal help, psychotherapy I think, which I didn't ask for and there was nothing there really and I thought, 'I can cope.' (Family member)

c. Linking with support services

Families really appreciated the support services provided by SF and other agencies, such as being able to meet people with similar experiences of mental illness and mental health services:

> The support group was a real lifesaver to me. I was feeling lost and lonely on my own… That support group was really good, it opened my eyes to what could happen. (Family member)

d. Referral for own treatment/counselling

Some family members interviewed were coping with their own mental illness, as well as supporting the person in care:

> In my family's case, unfortunately this does seem to be genetic… It's hard for us to be in contact because it's really personal and we all know – but for the grace of God… It's hard to be a carer, a supporter, when you are under pressure yourself with the same illness. (Family member)

Those without mental illness themselves still felt they could have benefited from assistance to cope with the events and changes in their lives. At the time, they focused on assisting the person in care, but an enquiry about their own health would have helped:

> I'd really appreciate that because there were times that I felt like, 'Oh my God, I need counselling now', just to get some perspective. It's such a minefield. (Family member)

Theme 4: Acknowledging the main caregiver role

Some family members, often mothers, have ongoing responsibilities for the person accessing mental health services. As main caregivers, they actively support the person's recovery. Motivated by wanting to do the best for their child, partner or parent, they seek information to decide on the best approach to supporting them.

Most commonly these caregivers are parents supporting their adolescent or adult children. These families discussed the importance of being included as part of the treatment team, and being provided with guidance on how to best support their family member:

> Giving people messages of: you've got a big role within this. There are a lot of things that you can do that will be really helpful and we can help you with that. (Family member)

a. Extra coaching and support for main caregivers

> I think … families cannot be expected to be carers without a kind of coaching. (Family member)

As highlighted earlier, access to a contact person that family members could question was rated as important. When the family member was the main caregiver, they wanted access to someone who could guide them in this role.

Some family members felt that the case manager of their family member was an appropriate person:

> I think the best […] would be the case manager, because they have the knowledge of the person; they have the knowledge of the family. (Family member)

Some felt that it would be better if the person providing guidance was someone else:

> Sometimes the case manager needs to be there just for the client. Sometimes talking to the family is not what the person wants and if they do [talk to the family] the trust between [the case manager and the client] is reduced. (Family member)

b. Involvement in treatment plan and communications around main aspects of care

Families felt that they had a lot of knowledge to help assist staff in assessment and treatment planning. They could also offer support and practical assistance to their family member, and that should be considered when planning treatment and recovery:

> We see things that specialists don't necessarily see. We see [the family member] in a relaxed environment. (Family member)

When families felt included as part of the treatment team they were very satisfied with the service they received:

> We all know what's happening and I'm totally in the loop and they are doing a fantastic job. (Family member)

c. Information on financial and other practical support

Many families felt that they had missed out on information about financial support that they or their family member were entitled to. While they recognised that this money was often not provided directly by mental health services, they felt that the service could have advised them of grants and benefits available:

> I only recently found out about needs assessments. It was a really good process, where my opinion and input seemed valued and I learn about other services and that there were grants and respite that we could look into. (Family member)

Staff priorities

As with family members, staff members rated providing information as the most essential component of a family pathway. Staff members were focused on giving information to families and assisting them to understand mental illness:

> Essential components of a family pathway are information; they may need support, they may need and should be involved in the decision-making around treatment, around the plans… It's really important that the family is part of plans around the client. (Staff member)

Theme 1: Information – providing knowledge

a. Providing specific information about the family member in care

> Sometimes it's a bit of a balancing act, maintaining a client's privacy and giving useful, relevant information to family members. It's really important families are kept informed though, especially if they are the main caregiver. (Staff member)

b. Providing a range of good-quality generic information

The staff members interviewed realise that families cannot process too much information during a crisis, so they must follow up with the family later on, and not assume that all family members are literate. A staff member who is also a family member said:

> Sometimes when you're in that highly stressed stage… They give you the information and they think, 'Right that's that covered, I don't have to do that now.' And sometimes they can even tell you something and you don't hear it or you hear half of it because you're stressed… I think you're not in the space to be hearing a whole lot of stuff. (Staff member)

The staff members had a variety of ideas about how to provide families with relevant and accessible information:

> Maybe that's something that we could ask family members. We could say to people, 'How do you like to receive information? Would you like to sit down and have a chat to me about it, would you rather take away a

> pamphlet, a list of some good websites to be looking at, or can I give you a video to watch?' (Staff member)

> You really need to have someone who is a clinician because often the questions and answers are around the illness, medication and that kind of thing. (Staff member)

c. Orientation to the service

During interviews staff members did not place the same amount of emphasis on orientating families to the mental health service as family members did. However, some did discuss the idea of orientating families and were quite interested in progressing and developing this further:

> I like that idea of orientating a family to the service. We don't really orientate the family. They want to know how things work and when they can come in and out and what the living conditions are for their relatives […] and contact phone numbers. (Staff member)

> An information booklet about how things work here, something friendly and open and not too formal, but obviously inviting their participation. In terms of layout, something that looks bright and airy, and positive and hopeful. You don't want to bring the whole thing down; you want to keep it with a sense of hope. (Staff member)

d. Managing the expectations of families

Staff members talked about the challenge of communicating with families where families expected information, support or treatment that was not available, appropriate or best practice:

> I've had family say to me, 'Why can't you just give him an injection and knock him out so he will be compliant?' It's not always easy to explain to families who are very worried and can see their family member suffering that sometimes our treatments take time and sometimes they don't work as well as we would like them to. (Staff member)

Staff recognised the importance of educating families about how uncertain the journey to recovery can be:

> This is the start of a journey and yes we know what we're talking about but we can't tell you how this journey will pan out. Yes we have experience and we know what we're doing but mental health care can feel like trial and error… It's an uncertain journey. (Staff member)

When communication didn't go well, often under stressful conditions, some staff members reflected on their part in these situations and tried to learn from them, to improve things in the future:

> I've got a case like that at the moment and it's a really big issue: being clear about what you can and can't do. We can listen, we can provide advice, but this person wants someone to make it all better and fix it. I'm thinking, 'At what point was I not clear in my interaction, or wasn't clear enough?' (Staff member)

Theme 2: Family inclusion in treatment

> We need to look at this a bit wider, particularly now that people are in inpatient treatment for much less time than they used to be, so they come in, generally more unwell and they go out and they still have a reasonable level of unwellness … so we're expecting that families are going to pick that up and manage and I think that's a really big ask. (Staff member)

A number of staff members felt that more could be done, when consumers agreed, to include families in treatment planning, decision-making and support of consumers:

> We may trip over a bit along the way, but we need to work as a team. We need you to be involved. (Staff member)

Some felt that the professional hierarchy and culture of the services – not an unwillingness to involve families on behalf of consumers – were the most significant barriers to family members being involved in treatment planning:

> It's very much about a professional dictating to the individual. Often that's not in their best interests and ideally maybe we want to make the family more part of the decision-making and plans. (Staff member)

Others warned against assuming that all family members would want to be engaged and involved with mental health services:

> That's also assuming that they want to be involved, the odd one doesn't… They will bring them for help

> and never come near or just back off slowly. (Staff member)

a. Earlier proactive engagement with families

Staff members thought that earlier, proactive engagement with families could reduce the misunderstandings that can occur when situations are left to get more acute before services intervene:

> If services came into play sooner, you would see a family that was saying, ‘Hey, come in’; instead, they’re just about saying ‘Yes, we need help, but are you going to do it?’ It’s like a tug-of-war. (Staff member)

One project recently scoped for service development by the DHB is the Children of Parents with Mental Illness project (COPMI). This project sees the mental health service engaging with the children of adults with an existing mental illness to provide additional support, respite care and early identification services:

> A lot of the projects for families for children have holiday groups where they might go away for a weekend or regular couple of hours a week [with] fun activities – somewhere where kids can go to. Somebody the kids could contact and be heard by would be great. (Staff member)

Two staff members noted that sometimes the children had become the main caregiver to their parents, while they were young and still required care and support themselves. These staff members felt that if the family were supported as a family unit earlier, the children may be less likely to be inappropriately viewed by staff as main caregivers:

> I talked to teenagers who’d been invited to discharge meetings and they’re unaware they had a role as a caregiver. But it’s really not appropriate, I don’t think, to assume that kids will take over looking after the parents without good resources. (Staff member)

b. Systemic changes to support family-inclusive practice

Staff who are familiar with NMDHB’s Client Pathway and the standards, processes and timeframes this provides, suggested additional benchmarks that could be added in relation to families:

> They create these care plans and they go through all this stuff, and you could add a family meeting box in there. (Staff member)
>
> If you put a one-pager in with that first [next of kin Mental Health Act] notice that went out, you’d know that people would have the information. (Staff member)

Some staff disagreed and felt that systemic changes should be introduced via a best practice focus, rather than additions to paperwork, or additional standards and timeframes:

> I’ve never liked the tick-the-box approach to things so if you came out with a protocol that says you have to do blah blah blah then that wouldn’t be much fun. It’s more normalising it and […] seeing it as good practice to do these things. (Staff member)

Many staff members felt that mental health services still focused on catering for the needs of individuals, and family were very much an afterthought:

> I’d have to say everything you do really is individually client-focused and if the family happen to be there fine, but I don’t think there’s ever any explicit family focus except on those few occasions where it’s identified in a family meeting, then that does happen. I’d say there’s definitely a huge focus on the individual client. (Staff member)

c. Working with due regard to the consumer’s preferences

Most staff members said their main priority was the individual they were treating. When discussing catering to the needs of families, staff said they must consider the preferences and concerns of the consumer. Building trust, rapport and a therapeutic relationship with the consumer, while also attempting to help that person’s family, was one of the communication challenges staff often described:

> With my clients I would offer, ‘Would you like to bring your partner or parent?’ and, if they say ‘yes’, they’re welcome to bring them any time… Sometimes people come back the next week with the family member and then

> you don't see them again. Occasionally I get a phone call from people if they're worried about something or if they're curious about something, or just to check what's going on. (Staff member)

Several staff commented that consumers can be reluctant to involve family members at first, and take time to change their point of view:

> Over time they are willing to have family involved, but initially they're not. I think ideally it would be good if family members could get some information, whether that's through the clinician that's seeing the person or whether we've got some other people available to do that. (Staff member)
>
> For me I've done a lot of encouraging clients to contact family members because often when they're ill it's not something they really want to do. (Staff member)

d. Privacy issues

Most staff interviewed recognised the frustration families felt when the information they requested could not legally be provided. Most had a good knowledge of the requirements of the Privacy Act and under which circumstances information could be provided to families:

> Very often family members do get really frustrated around it and realistically they're doing the day-to-day living with the illness. (Staff member)

A number of people commented on their preference to give information, wherever possible:

> Privacy issues seem a big deal in the medical system [but] I've never been a huge believer in privacy and confidentiality. Obviously, there are professional guidelines and code of ethics etc, but I believe in sharing information. (Staff member)

e. Family meetings

Some staff members said that family meetings, once common in mental health care, had become rare because of a move away from formalised family therapy models:

> I think it's a real gap because sometimes if you can get everybody together early you save a lot of anxiety and stress later on, and a lot of frustration sometimes, if people could just sit down and feel like they're being heard. (Staff member)

Also, more recently, mental health staff members were not formally trained in facilitating groups or family meetings, so many avoided them:

> There's a bit of work in it but probably the bigger issue was that it's slightly anxiety-raising for a staff member because you're not quite sure what's going to happen and instead of just dealing with the one client, you've got a whole bunch of people [to deal with]. (Staff member)

Staff members suggested that the service could trial giving all new families the opportunity to have a family meeting:

> If people choose not to do it, that's fine, but they've had the offer. It would be interesting if everyone you dealt with initially was [offered] a family meeting; you could trial it and see how much of an uptake there was. (Staff member)

f. Training ideas

Most staff felt they understood their legislative responsibilities towards families, in terms of the Privacy Act and the Mental Health Act. During the past few years, the DHB had also provided useful training on working with families, they said.

But staff felt that the family-inclusive training needed to be supported by ongoing service development, in relation to family-inclusive practice:

> Yes I do think further training should be available to mental health staff… More about the principles of working with families and then looking at perhaps more ways we can do it as a service. (Staff member)

Staff could also benefit from training in group facilitation skills, to improve their confidence in facilitating family meetings:

> Group facilitation skills would be really good … having a case conference-type meeting where you put all the information out and see where it goes. But a lot of [family therapy]-trained people I've talked to have said that they think the other case managers [are not

> as] comfortable interacting with more than one client, that the idea of bringing everyone from one family into the room fills them with horror. (Staff member)

Theme 3: Support for families

a. Strengthening advocacy and clarifying roles

There are many roles, within and outside NMDHB, that focus on supporting families. Several staff thought that confusion about these roles and "who does what" prevented them from referring families:

> There's a family advisor, SF fieldworkers, social workers, and their roles seem to overlap and be quite person dependent. I'd be much more confident referring families if I knew exactly who did what. (Staff member)

Most staff members mentioned referring families to the family advisor and SF fieldworkers. Several staff also said that it would be useful to have another position, held by a mental health professional, which specifically targets families:

> Maybe you could have a role where you've got someone like a social worker who can cover and run [family meetings] as part of their job. (Staff member)

b. Proactive support opportunities

Staff produced a variety of practice-based ideas that would proactively support families. These included the service providing more information and advice:

> A lot of families say it's great having SF there as an external agency but what they'd like is something more proactive, internal and upfront where they can go to get information and ask advice. (Staff member)

A return to providing information evenings for new families:

> The [family advisor] used to run a monthly new families group with a couple of nurses from the Unit. They used to offer all new families to attend this meeting and you come along, have questions and answers, and have a cup of tea and meet other family members… It used to work really well and those things need to be revived a bit. (Staff member)

Enquiring about and providing additional support to dependent children of mental health consumers:

> On our assessment sheets now, when people come in, we do ask 'Do you have dependent children?' We […] need to have people who are proactive and contact the family and say we're here to give them information, see how they're doing. (Staff member)

More proactive and targeted support for families when their family member is discharged, particularly after lengthy admissions to hospital:

> That has been something that families have commented on, that sometimes leaving the service, like particularly from an inpatient unit to the community, that they feel like they had been looked after, had lots of support and advice and some time out to themselves and then all of a sudden there's a huge drop in the amount of service they get. Whereas I am sure having a staged, slow withdrawal would help a great deal. (Staff member)

Facilitating contact with out-of-town family members:

> We could do more thinking about [family] living out of town and maybe encouraging the use of email contact for people who live far away. (Staff member)

Theme 4: Relationships with family members in a best practice context

Because of the voluntary and self-selecting nature of this study, the staff members interviewed tended to be people who had a passion for working well with families and found this a rewarding part of their role:

> I think that's a wonderful focus to have and to remember that most families have known a different person to the one you're seeing. (Staff member)

Sometimes they wondered why other staff members did not feel the same way:

> It's such a personal thing isn't it; I quite often have [conversations with staff] who seem to have a [negative view of] families. I wonder about their own personal experience of family; what's their idea of family and how does that relate to the personal and professional overlap, and influence the way they work with or don't work with families? (Staff member)

a. Building trust and rapport with families

The importance of building a therapeutic relationship with family members was mentioned, but not with the same prominence that families discussed it:

> You are really important, you know your person, so they need to hear that straight up, 'We value your input.' I think you need to be very sensitive … a family member may feel like they're being criticised. (Staff member)

b. Overcoming stigma and fear of the system

Staff members felt that often the establishment of a good working relationship with family members was made more difficult by some family members' fear of the system. This appeared to be fear of the unknown:

> How do we cater for brand-new families coming in for the very first time who don't even know what questions they might ask, who know nothing about the system, have a lot of fears about engaging with the system and fears for their family member? (Staff member)

And it seemed to be based on past experiences with their own mental health care, or the care of other relatives, during other eras of mental health care:

> Everyone coming through the door is going to have a different set of experiences; you'll get people who have never had anything to do with the mental health service; you'll get people whose great aunty so and so was in Ngawhatu years ago and they're worried that this is what's happening with their daughter. There'll be a huge variation in experience, so I guess probably one of the key messages to families, is ask questions, feel welcome to ask questions. (Staff member)

Or, often the most difficult fear to overcome, a fear of the power of the system:

> It's a big deal isn't it; it's demystifying what is very clear to you and me. To the average punter it's going to be overwhelming; you've got all these authority figures and how do you deal with all this going on? Do people feel empowered to ask and challenge questions? (Staff member)

c. Overcoming misunderstandings

Staff members acknowledged that there was potential for misunderstanding and miscommunication in their interactions with families. They were aware that families are often under a great deal of stress and had varying levels of knowledge about mental illness and mental health services. This, coupled with the staff members' busy work environment, enhanced the likelihood of misunderstanding and miscommunications. Staff were concerned that at times they felt they had got it wrong:

> You can't make mistakes like that with family members because they should be one of your first priorities because it is their flesh and blood that you're dealing with. (Staff member)

They also had concerns about how misunderstandings could influence the effectiveness of relationships that families had with the service:

> They think that nurse was grumpy so they're sick of me and really it's not that, it's that their nurse wasn't available as they're busy with someone else. (Staff member)

d. Striving for clear, open communication, sometimes in difficult circumstances

Staff members said that their initial training and experience in the service emphasised maintaining a therapeutic relationship with the client. Engaging with families in a different version of a therapeutic relationship, and managing that relationship as a priority, was relatively new territory for some:

> So it seems to be, we need to get families on board very quickly and we do actually need them. (Staff member)

Being clear with families about the limitations of the service and the relationship was an issue also raised by staff:

> Saying to people, 'Yes, there will be times when you come and visit that I won't be able to talk to you, because as well as your son I've got four other people that I'm working with and it's particularly busy today and I'm sorry I won't be able to catch up with you.' You're managing that [relationship]. (Staff member)

Summary

The following table summarises the main themes and subthemes from Question 2. It clearly shows the similarities and differences in the perspectives of family members and staff. The priorities of families and staff members are further discussed in Chapter 5.

Question 2: What would family members and mental health services staff prioritise as essential components of a 'family pathway' for mental health?

Family members' priorities	Staff members' priorities
1. Information – gaining knowledge a. simple information on initial contact, outlining more detailed resources available b. access to a variety of resources c. orientation to the mental health service d. a place to go to access further information	1. Information – providing knowledge a. providing specific information about the family member in care b. providing a range of good-quality generic information c. orientation to the service d. managing expectations of family
2. Proactive offer of access to a mental health professional a. named contact person b. proactive interactions with mental health professionals c. internal to service advocacy, information and support	2. Family inclusion in treatment a. earlier proactive engagement with families b. systemic changes to support family-inclusive practice c. working with due regard to consumers' preferences d. privacy issues e. family meetings f. training ideas
3. Active assistance with personal coping a. proactive checking on how the family are coping b. information and advice on looking after self c. linking with support services d. referral for own treatment/counselling	3. Support for families a. strengthening advocacy and clarifying roles internal to the organisation b. proactive support opportunities
4. Guidance and acknowledgement for those in main caregiver role a. named contact person to access for guidance, coaching and support in the caregiver role b. involvement in treatment plan and communication around main aspects of care (with client's permission) c. information on financial and other practical support	4. Relationships with families in a best-practice context a. building trust and rapport with families b. overcoming stigma and fear of the system c. overcoming misunderstandings d. striving for clear, open communication, sometimes in difficult circumstances

4.1.3 Question 3: How do the above ‘essential components’ compare with nationally recognised standards such as the Code of Family Rights, the National Mental Health Standards and the Blueprint for Mental Health Services?

The following table was constructed after comparing the themes from the two summary tables (pages 25 and 35) with key nationally recognised standards on family inclusion. Content was recorded if it matched the themes we established during interviews. This was done to establish if the information we found was reflected in documents that directed practice for the future.

As the table below shows, there were key links between what families and staff participants related in this project and key documents that articulate expected practice direction.

Demonstrating that the views of participants in this small-scale, local project match a number of nationally recognised documents increases the validity of the research and gives a firm base to plan enhancements to our local service in the future.

Document	Content relevant to essential components from themes (Appendix 6)
Schizophrenia Fellowship (1996) Code of Family Rights	The family/whänau has the right to: > a family-centred approach to treatment and support > be treated with understanding and respect > be taken seriously when expressing concerns about changes in a person’s behaviour > information about a family member’s illness > information on the range of relevant services and support available in the community > provide relevant information about a family member’s history, in confidence > inclusion in care planning, implementation and review > know the names and contact phone numbers of other members of the caregiving team > be consulted about a family member’s discharge plan > help for problems created or exacerbated by caring for a family member with a mental illness > time out when required to prevent burnout or cope with stress > seek other opinions regarding the diagnosis and treatment of a relative > culturally accepted treatment options which are inclusive of the family > mechanisms of complaint and redress > a mental health service that recognises the need for families to participate in shaping the service and invites families to take part in service planning, implementation and evaluation.
Mental Health Commission (1998) Blueprint for Mental Health Services in New Zealand: How things need to be	“There are significant advantages when support for families is provided as part of a continuing care programme. Services are more likely to be effective when they utilise the knowledge and experience of the people closest to the person who is ill.” (viii)
Mental Health Commission (2001) Recovery Competencies for New Zealand Mental Health Workers	Competency 10 A competent mental health worker has knowledge of family/whänau perspectives and is able to support their participation in services.

Document	Content relevant to essential components from themes (Appendix 6)
Ministry of Health (2005) Te Tahuhu – Improving Mental Health 2005-2015. The Second New Zealand Mental Health and Addiction Plan	Family members “experience agencies that operate in a way which enables them to support their family member’s recovery and maintain their own wellbeing” (p. 5).
Ministry of Health (2006b) Te Kokiri – The Mental Health and Addiction Action Plan 2006-2015	The costs and consequences of this support and the effects on whänau and friends are large and often hidden. Te Tahuhu – Improving Mental Health and this action plan acknowledge the importance of the participation of family and whänau and the partnership with the Mäori community, in the process of recovery (p. 8).
Mental Health Commission (2007) Te Hononga 2015 – Connecting for Greater Wellbeing	Whänau Ora: Mäori families achieving wellbeing (p. 19). Family wellbeing: All families achieving wellbeing (p. 20). Connectedness/Te Hononga – Everyone is connected to other people. In 2015, the significance of these connections will be acknowledged (p. 24). Right responses – In 2015, there will be a variety of responses tailored to suit individual and family/whänau needs. In 2015, there will be an increased range and continuity of services (p. 25). A valued and supported workforce – Staff will know how to work towards whänau ora/family wellbeing and meet the needs of family/whänau (p. 49). Family, whänau and carers – By 2015, responsiveness will also be evident in family-inclusive services and in the provision of direct services to meet the needs of family/whänau. These services will include those that provide information, education, advocacy and advice, as well as peer supports for family/whänau, family therapies and relief services. There will be additional focus on supporting those family/whänau in carer roles. Family/whänau members will be encouraged and supported to look after their own wellbeing, and the wellbeing of those close to them. At times, services will need to assist whänau members to access services for their personal needs, as well as involve them in supporting the service user (p. 69).
Ministry of Health (2008) Let’s Get Real: Real Skills for People Working in Mental Health and Addiction	One of seven ‘real skills’: Working with families/whänau – Every person working in a mental health and addiction treatment service encourages and supports families/whänau to participate in the recovery of service users and ensures that families/whänau, including the children of service users, have access to information, education and support (p. 4). Performance indicators for working with families/whänau (Appendix 7).

5. DISCUSSION

> You have to put scaffolding around a family right at the beginning, lots and lots of scaffolding so it keeps the family upright and if you put enough systems around them you can take the scaffolding away and they will stand tall. (Lynda Sigglekow, NMDHB Family Advisor)

5.1 Introduction

This chapter explores the interesting similarities and differences in themes generated from interviews with family and staff members. We also discuss the original idea of developing a family pathway, similar to the NMDHB's Client Pathway, in relation to the findings.

5.2 Relationships and communication

Clear lines of communication and access to trusted mental health service staff are very important to family members. This has been a key message from family members and other research (Dimmendal & Watson, 2005).

During this project, mental health staff members discussed how the service is geared towards the needs of the person requiring care. Assisting their family is sometimes given a lesser priority, especially in a busy practice environment.

In a system traditionally geared towards the immediate needs of an individual, staff members' skills are concentrated on building and maintaining a therapeutic relationship with the person experiencing mental illness. While staff recognise the need to use these skills to work with families, in a system that prioritises the individual, working with the family often takes second place.

When asking family members about their experiences of mental health services, every family member discussed the importance of being believed by mental health services staff. The importance of a key connection with a staff member whom they trusted and respected, and felt believed and respected them, was a very high priority.

When describing times where things were going well for themselves and their family member, family members often attributed these positive experiences to individual staff members, who communicated with them in a way they were comfortable with. This theme is consistent with the experience of other research. Goodwin and Happell (2007), who interviewed non-paid carers for their perspectives, identified the two main themes: the opportunity to be involved in care; and good communication with mental health professionals. Doornbos (2002) also found that family members felt it was important that mental health services staff took a positive approach to them, and offered support.

Ewertzon et al (2008), when designing a questionnaire to detect levels of family involvement and alienation in mental health services, defined the following three concepts that help a family member feel respected by mental health services staff:

1. Openness is characterised by the family member's experience of sincere information about the patient's state of health. The mental health professionals explain the situation so the family members understand.
2. Confirmation is characterised by the family member's experience that the mental health professionals listen to them as important people. The professionals welcome them and care about who they are.
3. Co-operation is characterised by the family member's experience that the mental health professionals value them and their opinions.

The interview transcripts also showed that there was a direct link between how satisfied families are with their relationship with the treatment team and their faith in the service provided to their family member.

Interestingly, families rarely mentioned practical arrangements or particular aspects of service provided or not provided. Their key focus was finding someone they could trust to look after their family member.

When mental health services staff were asked the same question about their priorities for a family pathway, relationships with families were considered a lower priority (see tables on pages 25 and 35). This was interesting, particularly as the staff members interviewed had an interest in working with family members.

Mental health professionals often take the perspective that they are assessing the consumer and family, and it has been interesting to note their look of surprise after we suggest that family members are also assessing them. The way staff present, communicate and work with consumers and families is key to family members' confidence and trust in the service.

Mental health services staff members have historically been trained to develop a therapeutic relationship with the person in their care (O'Brien, 2001) and to make an assessment of the wider family system. Mental health services remain mostly geared towards treating the individual. Relating to each other in this environment, often under other extreme pressures and circumstances, presents significant, ongoing challenges for staff members and families.

5.3 Focusing on information – what you need, when you need it

The information needs of families were a top priority for family and staff members. Both groups saw different aspects of information giving and receiving as their number one priority for a client pathway document (see tables on pages 25 and 35).

As expected, the family was focused on learning more about mental illness, the mental health service and how best to support their family member. The staff were focused on providing the right type and amount of information to families, at the best time.

It was interesting to note that neither group focused strongly on the potential for families to be an information resource to mental health services.

Mental health professionals need to engage with and listen to family members and carers because they know the person intimately, are key informants in making sense of symptoms and are the natural source of support to the individual (Lakeman, 2008).

In the technological age where we should be information rich, access to good-quality, useful information for families engaging with the mental health service is not a straightforward proposition.

Families talked about wanting to reliably access relevant, good-quality information, at different stages of their journey through the mental health service. From both the staff and family perspectives, it was important that information was provided at the right time, in the right way. Some people felt overwhelmed by the amount of information offered during a crisis, when they were unable to take it all in. Others, who were given the same information pack, talked about needing to search for more information, as they did not feel well enough informed.

Many family members talked about not being informed about the treatment and support the service provided their family member. Many had not had experience with mental health services before and felt that some basic information about the team or unit would have been reassuring and helpful.

In the inpatient setting, family members felt that a quick walk around the unit with a staff member, pointing out the public areas, where the toilets were and where they could access staff members and information, would have been helpful. Several family members related instances where they were 'told off' for going into areas they were not supposed to, when they had not been told the rules in the first place.

On an individual level, providing information to families about their family member was viewed as very important, but privacy and confidentiality issues were not as prominent as in other studies of this type (Dimmendal & Watson, 2005). Overall, staff members were very well educated about how to provide information to family members in a variety of consenting and non-consenting circumstances, and family members did not complain that the Privacy Act was used unfairly to exclude them.

Lakeman (2008) developed a one-page flow chart for staff, giving guidance for sharing information with families under consumer consent and non-consenting circumstances. For some staff interviewed, particularly new practitioners, a New Zealand adaptation of this chart could be useful.

All participants felt that more generic information about mental health and illness could be provided to families. This is consistent with other research that focuses on the information needs of family members (Cleary et al, 2005).

Currently, on entering the service, families are offered a family pack that contains the business card of the family advisor and a variety of pamphlets and orientation information. Several staff and families felt that a simpler initial approach, with a one-page information sheet, might have more impact, particularly when families enter the service during a crisis. The sheet could provide details of where to access more information.

Providing good-quality information as well as access to mental health services staff who can answer questions and provide advice was the essence of what family members expected from the mental health service. Staff members agreed that if organised and easily accessible resources were available, they would be more likely to provide these to families, and follow up with the family to answer questions and provide education.

5.4 Proactive and welcoming approach

Several family members felt that instead of having to continually ask for information, it could be offered more proactively, and staff members could acknowledge the value of their participation in care.

Many circumstances can influence a family to feel unwelcome in the mental health service, including: the physical environment; the acuity in a ward situation; the number of staff; the consumer not wanting contact. The systems focus on the needs of the consumer can add to families' feelings of exclusion.

In the past decade the service has introduced more 'family-friendly' measures such as dedicated family rooms, the possibility of family staying overnight or outside of visiting hours, and a more integrated referral system between organisations such as SF and DHB services. As part of this project, the service has considered providing families with a form to assess how their family is coping and what assistance, if any, could be helpful. The assistance could include a conversation within the family or with mental health professionals (Appendix 10).

Stanbridge and Burbach (2007) describe how stressed families can quickly be labelled as 'difficult', and, as interactions get more difficult, mental health staff then limit their contact. Families then move into actively pursuing staff for answers, information etc. In training with staff, Stanbridge and Burbach explain this as 'the pursuit cycle', and use this example to underline the value of working proactively and positively to prevent this scenario occurring (see p. 13).

It follows that if families feel acknowledged for their contribution and welcome in the service they will engage more with the service and feel more confident about the care their family member receives.

5.5 Focus on family's own mental health needs

Family members recognised the high levels of personal stress they experienced and the vulnerability of their own mental health. This is also well acknowledged in both government policy documents (Ministry of Health, 2006a) and international research (Magliano, et al, 2006).

Interestingly, during our interviews only one staff member mentioned family members' own health and stress levels as a consideration when working with families. Recognising the threat to a family member's own health and encouraging them to take steps to take care of themselves could be conveyed very positively by staff members. Staff may advise family members of the primary mental health care available, as well as other options for personal support such as talking with family and friends, employee assistance schemes and subsidised counselling services.

5.6 Professional guidance for those in the main caregiver role

When consumers experience a prolonged recovery from mental illness, family members would like access to professional guidance on how to fulfil a main caregiver role. Some felt that there was not enough acknowledgement of the support they provide, or enough support for them providing it.

When families are very involved in the day-to-day support of a family member experiencing a prolonged recovery, they commonly have many questions and face many dilemmas. They would find it helpful to be able to readily ask a professional the 'silly' questions that concern them, when making necessary adjustments in their lives and relationships.

Families talk about wanting to ask about things like, "Should I remind him to take his medication?" and, "Should I wake him up in the morning or let him sleep?" Families want to do the best thing possible to assist wellness, but often do not know what that best thing is.

This scenario is particularly common when young people develop a mental illness. An adolescent may have left home and started work or university study before developing an illness. When they return home or begin more regular contact with their family, the family become concerned about how their family member will stay well.

Staff suggested that a group and/or a roster of staff could be made available for advice. This could be helpful to family members, along with their ongoing relationship with community case managers.

5.7 A system that supports family-inclusive practice

The systemic barriers and limits to including families in care have been a recurring theme throughout this project. It is all very well to insist via standards and policy that families are included and involved in care, but how does the system support this? A particular standard may say, "Families will be given good-quality information about mental illness", but is this information readily available to staff or do they have to look it up or make it up themselves?

Family members regularly come into the services with misinformation they found by Googling schizophrenia or other diagnoses on the internet. Being able to provide staff with good-quality, well-researched information that they could confidently provide and discuss with families would be invaluable to the service. There is a large amount of information on what best practice in including families should look like, but far less practical and systemic support to translate these ideals into clinical practice (Cleary et al, 2006).

The initial idea for a family pathway sought to address the need for a mandated way for families to interact with the service and mental health professionals.

A model is needed that enhances partnership and collaboration between both the family/individual family member and mental health professionals. It is essential that the model draws on the knowledge and experience of both parties and also shows respect for the needs, desires, concerns and priorities of families (Dimmendal & Watson, 2005).

In combining the findings, discussion and implications for future practice from this project, Figure 3 was drafted as a model to present to staff and families. This model will guide the ongoing development of the mental health services' response to families.

Another key outcome from this research was focusing staff members on the importance of clear and reliable lines of communication with families. However, the themes generated from families and staff members did not fit neatly into the Client Pathway framework for several reasons.

Unlike consumer involvement in mental health services, family involvement is seen by the system as optimal but optional. There is no clear pathway through the services for families as there is for the consumer. This makes the rules for engaging with families and staff unclear.

For this reason the ASK diagram focuses on addressing the two main themes in this research: the relationship between families and the service, and providing good-quality, accessible information. The second part of this diagram, headed 'ASK', will provide an information station for families.

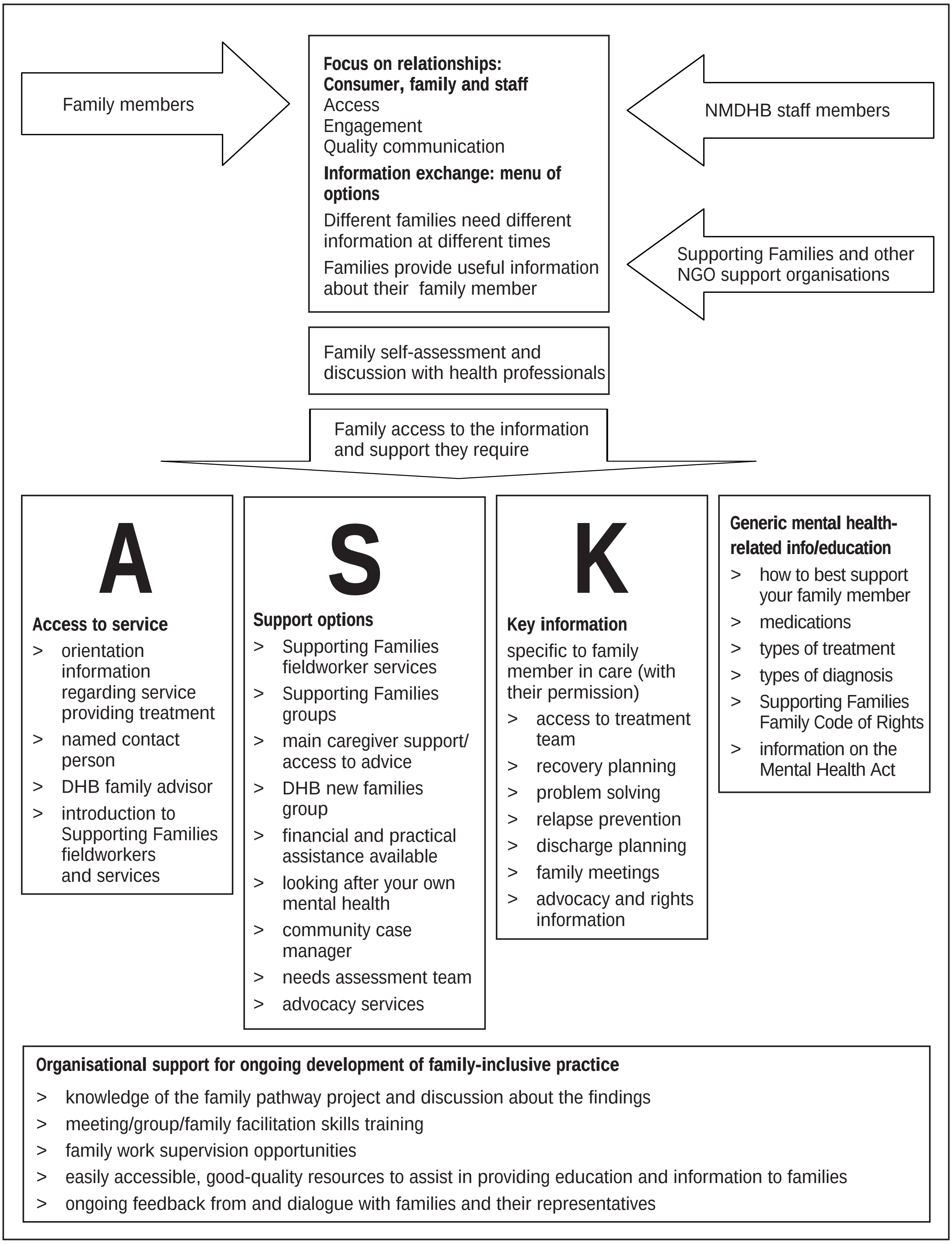
When families enter the mental health service, instead of a large pack of information they will be given a pamphlet about the service their family member is accessing and a pamphlet about the ASK wall (Appendix 11).

Each unit in the mental health service has a wall of pamphlets and other resources, which are organised into categories. These easily recognisable walls, regularly updated by the family advisor, can be a useful starting point for families seeking information. Families are invited to access it at any time, and to follow up with questions to staff members.

Also, presentations back to staff and interested family members, and discussions about the results of the study, may influence how individual staff members respond to families. Family members who have participated may also get further opportunities to be involved in the development of the service.

An approach that might guide the ongoing development of a family-inclusive model is the work of Stanbridge and Burbach. Their work provides useful guidance for promoting systems-focused change and best practice with families.

FIGURE 3: Key priorities when including families – the family pathway



Family members

Focus on relationships: Consumer, family and staff

Access

Engagement

Quality communication

Information exchange: menu of options

Different families need different information at different times

Families provide useful information about their family member

NMDHB staff members

Supporting Families and other NGO support organisations

Family self-assessment and discussion with health professionals

Family access to the information and support they require

A

Access to service

- orientation information regarding service providing treatment
- named contact person
- DHB family advisor
- introduction to Supporting Families fieldworkers and services

S

Support options

- Supporting Families fieldworker services
- Supporting Families groups
- main caregiver support/ access to advice
- DHB new families group
- financial and practical assistance available
- looking after your own mental health
- community case manager
- needs assessment team
- advocacy services

K

Key information

specific to family member in care (with their permission)

- access to treatment team
- recovery planning
- problem solving
- relapse prevention
- discharge planning
- family meetings
- advocacy and rights information

Generic mental health-related info/education

- how to best support your family member
- medications
- types of treatment
- types of diagnosis
- Supporting Families Family Code of Rights
- information on the Mental Health Act

Organisational support for ongoing development of family-inclusive practice

- knowledge of the family pathway project and discussion about the findings
- meeting/group/family facilitation skills training
- family work supervision opportunities
- easily accessible, good-quality resources to assist in providing education and information to families
- ongoing feedback from and dialogue with families and their representatives

5.8 Limitations of the research

It is important to note that this research is small scale and was conducted in one region, Nelson Marlborough. Along with the limitations of scale, the voluntary, self-selecting nature of this research means that the study sample does not represent all family members or all mental health services staff members.

Family participants who volunteered to be interviewed could be described as people who were at some point dissatisfied with the mental health service provided to their family member. Their motivation for contributing was to influence future service improvements. Other researchers have also described this motivation (Ewertzon et al, 2008; Goodwin & Happell, 2007).

This means that families more satisfied with their interactions with mental health services were not interviewed. Also, family members who have experienced serious issues with the mental health service may have chosen not to be involved due to the project's links to the service.

Staff members who were interviewed expressed a strong interest in working effectively with families and improving the service's response to families. They were able to describe a range of innovative and thoughtful practice approaches (noted in findings). Some also had a family member who had used mental health services. Again, because of the voluntary nature of this study, staff members with a negative outlook on working with families did not offer to be interviewed.

Another serious limitation of this study is that no Mäori whänau or staff were interviewed for this study. This was related to prioritising other whänau-related commitments and, in one case, opting to take part in another research project. A study that solely targets the unique cultural perspective of Mäori whänau may be more relevant to Mäori participants and would undoubtedly be a useful addition to the research available.

Another limitation was that no staff members from the Child and Adolescent Mental Health Service or Addictions Service volunteered to be interviewed. These are key areas of mental health service delivery to the community and they are not represented in the study.

We also interviewed fewer people than we expected. We had planned to interview a maximum of 40 people but after lengthening our recruitment period, had to stop interviewing after 22 interviews with 23 people (we had one couple). But we found that the themes within each group (families and staff) were very consistent, and consider the findings to be an accurate picture of the views of participants.

Another area that could be considered a limitation is the lack of involvement of consumers as research participants. This was raised by the ethics committee and is discussed in Chapter 2. The intention of limiting interviews to family and staff members was to focus the research on the mental health service's response to family members.

6. CONCLUSIONS

Effective working relationships between families and mental health staff depend upon:

> consultation

> co-operation

> mutual respect

> equality

> sharing of complementary resources and skills

> clarifying of expectations.

(Ministry of Health, Involving Families Guidance Note, 2000, p. 3)

Considering the current trends in providing mental health care, family members are likely to become crucial to good outcomes for mental health consumers.

Phrases such as ‘family inclusive’, ‘family friendly’, ‘whänau ora’, ‘partnership’, ‘collaboration’, ‘family rights’, ‘support’ and ‘advocacy’ are scattered throughout policy and research documents. But there is little practical guidance or systemic support for implementing them.

Many observations from this project may assist staff members and family members to improve standards of practice, service and care. The priorities for working with families are summarised in the diagram on page 58. This diagram may help guide services that are considering what their mental health service provides to families supporting someone with mental illness.

Both groups say that good-quality information, provided when it’s needed and backed by interaction with staff, is a key priority for future development. The ‘ASK’ part of the diagram could help the services assess and improve how well they provide information to families. NMDHB is currently considering options for providing this information so that it is accessible and available to all families using mental health services.

The strong emphasis that family participants place on positive relationships and communication with staff members should influence future developments in the service.

Support for family members, both practical and psychological, is also an area of focus. But staff members also require support from the organisation to act on some of the key messages from this study.

Bringing together the ideas and priorities identified by family and staff, as part of a systems-focused, service-wide strategy that supports best-practice expectations, can potentially provide significant improvements to service.

Future research in this area could target evaluating changes to practice that have been introduced by services, in an effort to improve responses to families. Working collaboratively with staff and family member participants and a reference group of interested stakeholders, including consumers, is recommended for future projects to continue to describe and develop future practice and service delivery that will be both practical and effective for all involved.

GLOSSARY

Addictions Service:	The District Health Board Alcohol and Other Drugs assessment and treatment service.
Consumer:	The term 'consumer' is used in this study to describe people who have previously experienced or currently experience mental ill health and who are recipients of mental health services (adapted from Phillips, 2006). It is recognised that this term does not have wholesale approval by those who access mental health services and that other terms such as 'service user' and 'tangata whaiora' are also commonly used to describe people accessing mental health services.
Consumer advisor:	Most DHBs employ one or several consumer advisors. These roles are usually focused on promoting consumer inclusion, advocacy and peer support in mental health services. The roles usually also advise the organisation at a more strategic level.
Family advisor:	Most DHBs employ a person to advise on the inclusion of families in mental health services. Family advisor roles vary but usually include a mix of advisory services to both families and the organisation. They are also a key link with organisations such as Supporting Families and Kina Trust.
Family inclusion:	The principle that in most cases including and involving families in aspects of mental health care and treatment will support and benefit the consumer's recovery and the family's overall wellbeing. This principle needs to operate within a number of complex legal and ethical frameworks that consider the rights and responsibilities of the individual consumer, the family and the clinicians providing treatment and support.
Gateway Housing Trust:	A supported housing trust for mental health consumers in Nelson Marlborough.
Main caregivers:	Family members, most commonly mothers of adolescent/adult children and sometimes partners/spouses. Where prolonged recovery from mental illness means that the person accessing services needs ongoing support, their family members are often in a position where they provide ongoing practical and emotional support that actively assists recovery. Most commonly, but not always, main caregivers live in the same household or nearby and, if not living together, see each other several times a week.

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APPENDIX 1: Consent form

Family pathways to care and support in Nelson Marlborough District Health Board, Mental Health Services

I have read and I understand the information sheet dated 22/4/2008 for volunteers taking part in the study designed to learn more about the perspectives and needs of family members of mental health service users.
I have had the opportunity to discuss this study. I am satisfied with the answers I have been given.

I understand that taking part in this study is voluntary (my choice) and that I may withdraw from the study at any time and this will in no way affect my ongoing healthcare requirements or healthcare employment.

I have had this project explained to me by _________________________________.

I understand that my participation in this study is confidential and that no material which could identify me will be used in any reports on this study.

I have had time to consider whether to take part.

I know whom to contact if I have any questions about the study.

I consent to my interview being audio-taped. YES / NO

I wish to receive a copy of the results YES / NO

Please note a significant delay may occur between data collection and publication of the results.

I would like the researcher to discuss the outcomes of the study with me YES / NO

I ______________________________________ hereby consent to take part in this study

Date

Signature ______________________________________

Researchers: Lois Boyd and/or Lynda Sigglekow

Contact phone number: Lois 546 1366 and Lynda 546 1442

Project explained by ______________________________________

Project role ____

Signature ____ Date

APPENDIX 2: Interview schedule – Family members

Family Pathways to Mental Health Care – Interview schedule – Family members

PLEASE REMEMBER YOU DO NOT HAVE TO ANSWER ALL QUESTIONS – JUST LET THE INTERVIEWER KNOW WHICH ONES YOU DO NOT WISH TO ANSWER

Background information

Interviewer will start by providing some background information about the study and how it developed thus far.

The following information will assist in analysing the main body of data collected, during the rest of the interview.

Age of participant – Under 20, 20-30, 30-40, 40-50, 50-60, 60-70, over 70

Gender of participant

Ethnicity of participant

Where do you live within the Nelson Marlborough DHB catchment area? Ie, Nelson city, Motueka, Blenheim

What is your relationship to the person using mental health services? Ie, partner, mother, father, sister, brother, cousin

Do you know if your family member has a mental health diagnosis? If yes – what is this diagnosis?

Do you regard your family member's illness as mild, moderate or severe?

How long have they had contact with the mental health service?

How long have you, as a family member, had contact with the mental health service?

What parts of the service have you had contact with, as a family member? Eg, Inpatient, Community, Child and Adolescent, Addictions Service

What is your current frequency of contact with mental health service staff?

What is your current level of contact with your family member? Eg, live together, live apart.

How frequently do you see your family member? Daily, weekly etc.

Research questions for discussion

1. What are family members' issues and experiences of the support and assistance THEY receive/have received from Nelson Marlborough DHB Mental Health Services?

   Question commentary: *The focus of this question is your experience of the service, as a family member. We want to know about how the service worked with you as a person supporting your family member and whether or not YOU received appropriate support/assistance/information/education.*

   We are working on the principle that providing the right kind of service to family members will have a big impact on the service delivered to clients, which is why we have phrased the question in this way.

   We already have good information about what families want for their family member via a research study conducted in 2003 by Suzanne Dimmendal and published in the New Zealand Journal of Counselling*. Information from this study will be utilised in this project.*

   For this question the focus is on what you need.

   WE ASK THAT YOU DO NOT PROVIDE US WITH ANY SPECIFIC DETAILS ABOUT YOUR FAMILY MEMBER OR THE SPECIFICS OF THEIR SITUATION AS THIS IS NOT THE FOCUS OF OUR STUDY AND WE DO NOT WISH TO BREECH YOUR FAMILY MEMBER'S PRIVACY. IF YOU INADVERTENTLY PROVIDE SUCH DETAILS THE RESEARCHER WILL REMIND YOU OF THIS REQUIREMENT AND THE AUDIO-TAPE WILL BE STOPPED AND TAPED OVER.

2. What would family members and mental health service staff prioritise as essential components of a 'family pathway' for mental health services?

   Question commentary: *As an outcome of this research we will propose a family pathway for the mental health service that will contain recommendations for future service development and practical information and support for staff and families about successfully working together. This question is designed to gather your ideas, large and small, about what would contribute to a good-quality experience of mental health services for family members.*

APPENDIX 3: Interview schedule – Staff members

Family Pathways to Mental Health Care – Interview schedule – Staff members

PLEASE REMEMBER YOU DO NOT HAVE TO ANSWER ALL QUESTIONS – JUST LET THE INTERVIEWER KNOW WHICH ONES YOU DO NOT WISH TO ANSWER

Background information

Interviewer will start by providing some background information about the study and how it developed thus far.

The following information will assist in analysing the main body of data collected, during the rest of the interview.

Age – Under 20, 20-30, 30-40, 40-50, 50-60, 60-70, over 70

Gender

Ethnicity

How long have your worked in the mental health service?

Where do you work within the Nelson Marlborough DHB catchment area?

What clinical area of the mental health service do you currently work in?

In your average working day how often are you interacting with family members? Daily/Weekly/Monthly/Less than monthly

How important is it, to you, when working with a service user, to be in contact with their family? Very important, Important, Sometimes important, Not important

Do you consider your current level of expertise in working with families to be Low/Moderate/High?

Do you think that further information/training and resources should be available to mental health service staff, regarding working with family members?

Research question for discussion

1. What would family members and mental health service staff prioritise as essential components of a 'family pathway' for mental health services?

   Question commentary: As an outcome of this research we will propose a family pathway for the mental health service which will contain recommendations for future service development and practical information and support for staff and families about successfully working together. This question is designed to gather your ideas, large and small, about what would contribute to a good-quality experience of mental health services for family members.

   WE ASK THAT YOU DO NOT PROVIDE US WITH ANY SPECIFIC DETAILS ABOUT CLIENTS OR FAMILIES THAT YOU HAVE WORKED WITH. WE DO NOT WISH TO BREECH THE PRIVACY OF CLIENTS OR FAMILY MEMBERS IN ANY WAY. IF YOU INADVERTENTLY PROVIDE SUCH DETAILS THE RESEARCHER WILL REMIND YOU OF THIS REQUIREMENT AND THE AUDIO-TAPE WILL BE STOPPED AND TAPED OVER.

APPENDIX 4: Information sheet – Families

Participant information sheet – Families

Family pathways to care and support in Nelson Marlborough District Health Board (NMDHB), Mental Health Services

Introduction

You are invited to take part in a research project exploring the experiences and issues of family members of people receiving mental health services at NMDHB. My name is Lois Boyd and I'm a mental health nurse who is being funded by the Families Commission, as part of an Innovative Practice Research Fund, to undertake this research project. I am working with a reference group made up of NMDHB Mental Health staff members with a particular interest in working with families and representatives from Supporting Families in Mental Illness, both in Nelson and Marlborough. The management of NMDHB Mental Health Services have given permission for this study to be carried out and have expressed strong interest in the results and recommendations.

It is hoped that information gathered will add to the continuous quality improvement of the services provided to families who are caring for a family member being treated by the DHB.

As the principal investigator of this study I am contactable on (03) 539 3586 or by email on Lois.Boyd@nmhs.govt.nz

The study

The aim of this study is to learn about the experiences and issues of both family members and staff members in relation to improving services provided to families.

I want to hear from any family member of a current NMDHB mental health service client who would be interested in sharing their experiences and ideas about how the service can best respond to family members.

I am hoping to interview 20-30 family members for this project.

Your participation is entirely voluntary (your choice) and you are free to withdraw from the study at any time without giving a reason. Your involvement in this study will not affect in any way the treatment or care your family member receives.

If you agree to be interviewed this will be done at a time and place convenient to you.

The final finishing date for reporting this study is September 2008.

How can I become involved?

Complete the form attached and post in the self-addressed envelope provided. You will be contacted in one week's time to make an appointment for interview. I will also post you a consent form and schedule of interview questions at this time.

You are welcome to bring a support person/people to the interview with you.

Before the interview starts you can ask any questions you wish about the study and you will then be asked to sign the consent form.

The interview will take approximately 30 minutes to one hour and I will take written notes and an audio-tape recording. You do not have to answer all the questions, and you may stop the interview or ask further questions about the study at any time. The interview notes and tapes will be typed up and returned to you for checking and any changes you require, before they are included in the study data.

Information collected in this study will be compiled in a research report and will also be used to make recommendations to mental health services on improving service responses to family members.

Confidentiality

No material that could identify you or your family member will be used in any reports.

The notes from your interview will be stored in a locked filing cabinet in my office. The notes are filed as coded, numbered documents. Once the final report is published all tapes and paperwork from interviews will be safely destroyed.

Benefits and risks of the study

Information gathered by this study will promote and inform improved responses to family members of clients involved with mental health services and inform a family pathway document for mental health services.

Potential participants should consider the level of stress that participating in this study could possibly expose them to. The interview questions may prompt discussion about past issues that have been difficult or traumatic. Potential participants are reminded they need not answer all interview questions and that I will offer a debriefing interview after the research interview. Alternatively participants may wish to arrange a debriefing interview with someone else they would be more comfortable with. The debrief interview would not be recorded or form any part of the research data.

Results of this research will form a research report that will be submitted to the Families Commission by September 2008. It is expected that aspects of the study will be presented at an appropriate mental health services conference and articles published from the research report. Copies of the final report will be provided to all participants.

If you have any questions or concerns about your rights as a participant in this research study you can contact an independent health and disability advocate. This is a free service provided under the Health and Disability Commissioner Act.

Telephone: (NZ wide): 0800 2787 7678 (0800 2 SUPPORT)

Email: (NZ wide): advocacy@hdc.org.nz

This study has been given ethical approval by the Upper South A Regional Ethics Committee.

Reimbursement to participants, for travel expenses only, is available if you are travelling to meet with us. This will be to a maximum of $40, paid by petrol voucher. I will ask you about this when I phone to discuss your possible involvement in this study.

Please feel free to contact me (03) 539 3586 if you have any questions about this study.

Family pathways to care and support in Nelson Marlborough District Health Board, Mental Health Services

Please place the following contact details in the self-addressed envelope attached to this sheet if you are interested in volunteering for this study.

I understand that by providing my details below I will be contacted in one week’s time to see if I am still interested in being interviewed for this project.

Signed ________________________ Name ________________________

Address ________________________ Contact phone number ________________________

____

APPENDIX 5: Information sheet – Staff

Participant information sheet – Mental health service staff

Family pathways to care and support in Nelson Marlborough District Health Board, Mental Health Services

Introduction

You are invited to take part in a research project exploring the experiences and issues of family members of people receiving mental health services at NMDHB. My name is Lois Boyd and I'm a mental health nurse who is being funded by the Families Commission as part of an Innovative Practice Research Fund, to undertake this research project. I am working with a reference group made up of NMDHB Mental Health staff members with a particular interest in working with families and representatives from Supporting Families in Mental Illness, both in Nelson and Marlborough. The management of NMDHB Mental Health Services have given permission for this study to be carried out and have expressed strong interest in the potential results and recommendations.

It is hoped that information gathered will add to the continuous quality improvement of the services provided to families who are caring for a family member being treated by the DHB.

As the principal investigator of this study I am contactable on (03) 539 3586 or by email on Lois.Boyd@nmhs.govt.nz

The study

The aim of this study is to learn about the experiences and issues of both family members and staff members in relation to improving services provided to families.

I want to hear from any staff member who currently works in the NMDHB Mental Health Service and who would be interested in sharing their experiences and ideas about how the service can best respond to the needs of families of current service users.

I am hoping to interview 20-30 staff members for this project.

Your participation is entirely voluntary (your choice) and you are free to withdraw from the study at any time without giving a reason. If you choose not to take part this will not affect in any way your employment at NMDHB.

If you agree to be interviewed this will be done at a time and place convenient to you.

The final finishing date for reporting this study is September 2008.

How can I become involved?

Complete the form attached and post in the self-addressed envelope provided. You will be contacted in one week's time to make an appointment for interview. I will also post you a consent form and schedule of interview questions at this time.

You are welcome to bring a support person/people to the interview with you.

Before the interview starts you can ask any questions you wish to about the study and you will then be asked to sign the consent form.

The interview will take approximately 30 minutes to one hour and I will take written notes and an audio-tape recording. You do not have to answer all the questions, and you may stop the interview or ask further questions about the study at any time. The interview notes and tapes will be typed up and returned to you for checking and any changes you require, before they are included in the study data.

Information collected in this study will be compiled in a research report and will also be used to make recommendations to mental health services on improving service responses to family members.

Confidentiality

No material that could identify you will be used in any reports.

The notes from your interview will be stored in a locked filing cabinet in my office. Once the final report is published all tapes and paperwork from interviews will be safely destroyed.

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Information gathered by this study will promote and inform improved responses to family members of clients involved with mental health services and inform a family pathway document for mental health services.

Potential participants should consider the level of stress that participating in this study could possibly expose them to. The interview questions may prompt discussion about past issues that have been difficult or traumatic. Potential participants are reminded they need not answer all interview questions and that I will offer a debriefing interview after the research interview. Alternatively participants may wish to arrange a debriefing interview with someone else they would be more comfortable with. The debrief interview would not be recorded or form any part of the research data.

Results of this research will form a research report that will be submitted to the Families Commission by September 2008. It is expected that aspects of the study will be presented at an appropriate mental health services conference and articles published from the research report. Copies of the final report will be provided to all participants.

If you have any questions or concerns about your rights as a participant in this research study you can contact an independent health and disability advocate. This is a free service provided under the Health and Disability Commissioner Act.

Telephone: (NZ wide): 0800 2787 7678 (0800 2 SUPPORT)

Email: (NZ wide): advocacy@hdc.org.nz

This study has been given ethical approval by the Upper South A Regional Ethics Committee.

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Family pathways to care and support in Nelson Marlborough District Health Board, Mental Health Services

Please place the following contact details in the self-addressed envelope attached to this sheet if you are interested in volunteering for this study.

I understand that by providing my details below I will be contacted in one week’s time to see if I am still interested in being interviewed for this project.

Signed ________________________________ Name ________________________________

Address ________________________________ Contact phone number ______________________

____

APPENDIX 6: Te Tahuhu and Te Kokiri

The overall purpose of Te Tāhuhu – Improving Mental Health: The Second New Zealand Mental Health and Addiction Plan

Te Tāhuhu – Improving Mental Health sets the high-level strategic framework to guide existing and future action that Government expects to be the focus of mental health and addiction policy and service provision from 2005 to 2015.

Underpinned by the New Zealand Health Strategy and the New Zealand Disability Strategy the 10 leading challenges in Te Tāhuhu – Improving Mental Health focus on improving whānau ora, recovery and wellness for people, families, whānau and communities affected by mental illness and addiction.

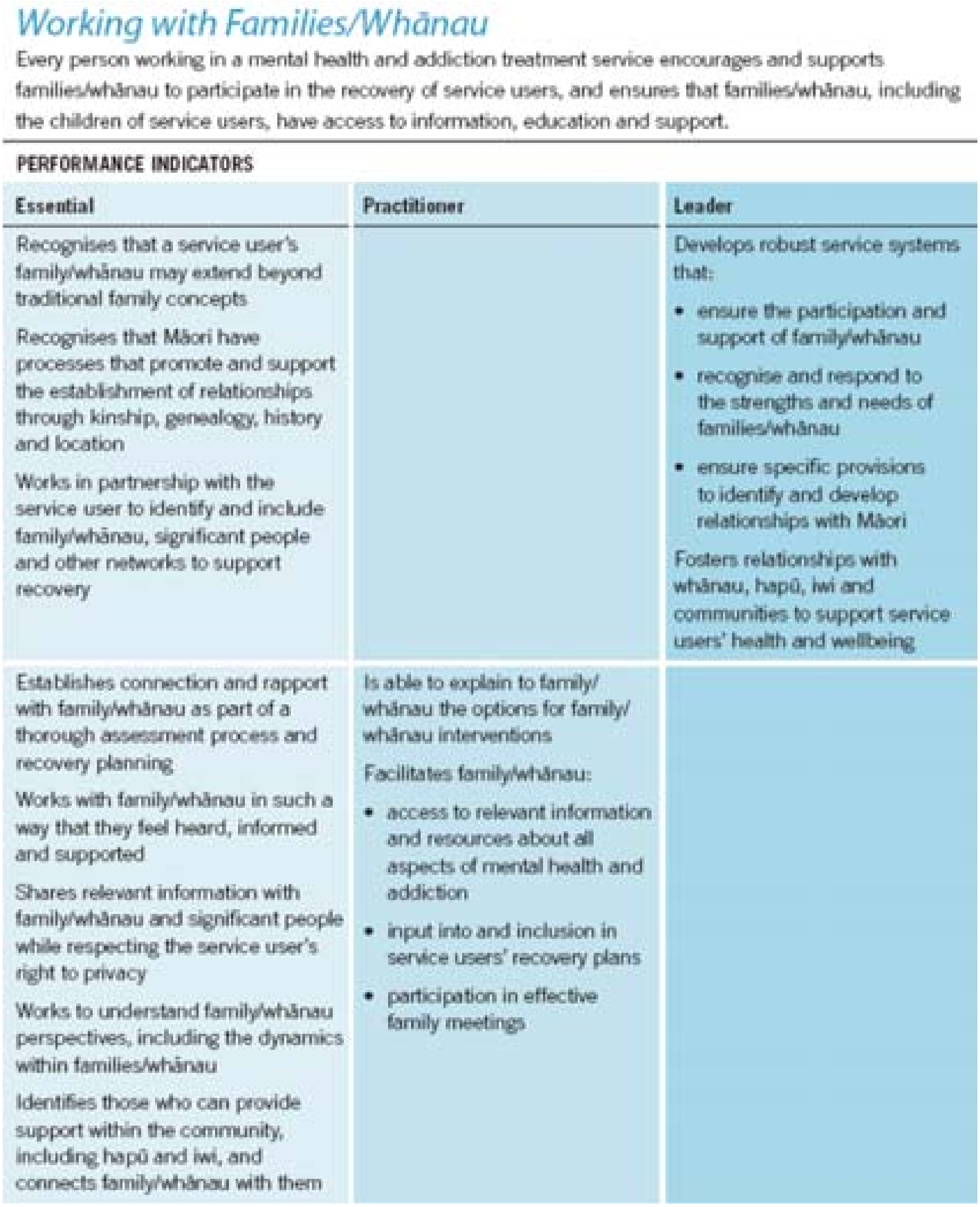
Figure 1: Te Tāhuhu – Improving Mental Health

From Te Tahuhu. Reprinted with permission from the Ministry of Health

From Te Kokiri. Reprinted with permission from the Ministry of Health

Figure 2: Weaving the 10 leading challenges to improve mental health

APPENDIX 7: Let's Get Real Performance Indicators



Working with Families/Whānau

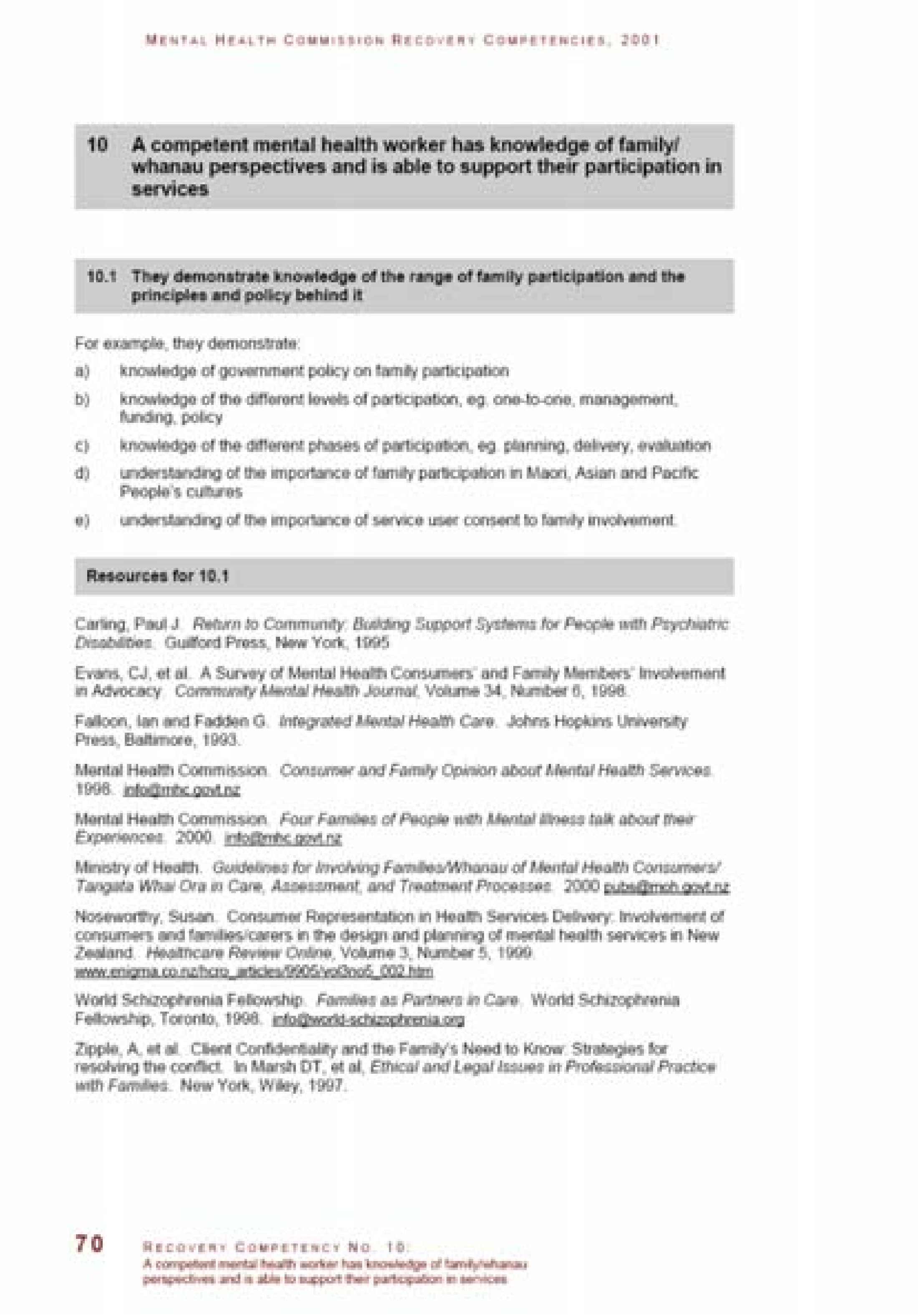
Every person working in a mental health and addiction treatment service encourages and supports families/whānau to participate in the recovery of service users, and ensures that families/whānau, including the children of service users, have access to information, education and support.

PERFORMANCE INDICATORS

Essential	Practitioner	Leader
Recognises that a service user's family/whānau may extend beyond traditional family concepts Recognises that Māori have processes that promote and support the establishment of relationships through kinship, genealogy, history and location Works in partnership with the service user to identify and include family/whānau, significant people and other networks to support recovery		Develops robust service systems that: • ensure the participation and support of family/whānau • recognise and respond to the strengths and needs of families/whānau • ensure specific provisions to identify and develop relationships with Māori Fosters relationships with whānau, hapū, iwi and communities to support service users' health and wellbeing
Establishes connection and rapport with family/whānau as part of a thorough assessment process and recovery planning Works with family/whānau in such a way that they feel heard, informed and supported Shares relevant information with family/whānau and significant people while respecting the service user's right to privacy Works to understand family/whānau perspectives, including the dynamics within families/whānau Identifies those who can provide support within the community, including hapū and iwi, and connects family/whānau with them	Is able to explain to family/whānau the options for family/whānau interventions Facilitates family/whānau: • access to relevant information and resources about all aspects of mental health and addiction • input into and inclusion in service users' recovery plans • participation in effective family meetings	

Reprinted with permission from the Ministry of Health

APPENDIX 8: Mental Health Commission Recovery Competencies



MENTAL HEALTH COMMISSION RECOVERY COMPETENCIES, 2001

10 A competent mental health worker has knowledge of family/whanau perspectives and is able to support their participation in services

10.1 They demonstrate knowledge of the range of family participation and the principles and policy behind it

For example, they demonstrate:

a) knowledge of government policy on family participation

b) knowledge of the different levels of participation, eg. one-to-one, management, funding, policy

c) knowledge of the different phases of participation, eg. planning, delivery, evaluation

d) understanding of the importance of family participation in Maori, Asian and Pacific People's cultures

e) understanding of the importance of service user consent to family involvement.

Resources for 10.1

Carling, Paul J. *Return to Community: Building Support Systems for People with Psychiatric Disabilities.* Guilford Press, New York, 1995

Evans, CJ, et al. A Survey of Mental Health Consumers' and Family Members' Involvement in Advocacy. *Community Mental Health Journal*, Volume 34, Number 6, 1998.

Falloon, Ian and Fadden G. *Integrated Mental Health Care.* Johns Hopkins University Press, Baltimore, 1993.

Mental Health Commission. *Consumer and Family Opinion about Mental Health Services.* 1998. info@mhc.govt.nz

Mental Health Commission. *Four Families of People with Mental Illness talk about their Experiences.* 2000. info@mhc.govt.nz

Ministry of Health. *Guidelines for Involving Families/Whanau of Mental Health Consumers/Tangata Whai Ora in Care, Assessment, and Treatment Processes.* 2000 pubs@moh.govt.nz

Noseworthy, Susan. Consumer Representation in Health Services Delivery: Involvement of consumers and families/carers in the design and planning of mental health services in New Zealand. *Healthcare Review Online*, Volume 3, Number 5, 1999. www.enigma.co.nz/hcro_articles/9905/vol3no5_002.htm

World Schizophrenia Fellowship. *Families as Partners in Care.* World Schizophrenia Fellowship, Toronto, 1998. info@world-schizophrenia.org

Zipple, A, et al. Client Confidentiality and the Family's Need to Know: Strategies for resolving the conflict. In Marsh DT, et al, *Ethical and Legal Issues in Professional Practice with Families.* New York, Wiley, 1997.

70 RECOVERY COMPETENCY NO. 10:
A competent mental health worker has knowledge of family/whanau
perspectives and is able to support their participation in services

Reprinted with permission from the Mental Health Commission

APPENDIX 9: Census data

2006 Census data (Statistics NZ website)	Tasman	Nelson	Marlborough	Comments/significance
Number of people who usually live in each region	44,625	42,888	42,558	130,071 spread across three catchment areas with significantly different community profiles, services and requirements for mental health care.
Population ranking in size out of 16 regions of New Zealand	12th	14th	15th	All three regions sit just above the lowest population per region.
Numbers of Mäori who usually live in the region	3,063	3,615	4,275	10,953 Mäori live across the three regions.
Population ranking in size out of 16 regions of New Zealand	15th	14th	13th	All three regions sit just above the lowest Mäori population per region.

Downloaded 7 March 2009, from http://www.stats.govt.nz/census/census-outputs/quickstats/aboutAPlace.htm

APPENDIX 10: DRAFT carers' self-assessment sheet

DRAFT family members' self-assessment and information checklist

This sheet is designed to help you to think about what you and your family may need from the mental health service, other agencies and your community while you are supporting your family member to recover from mental illness.

The list below is designed to prompt you and your family to think about your own unique family circumstances and what information and assistance you might need at this time. You may wish to go through these with a staff member or a Supporting Families fieldworker, or you may feel more comfortable talking about this within your family.

There are some really useful supports and sources of information for families in the health system and our local community.

We do our best to communicate with families about assistance and information available to support you and your family. This is most effective when we understand your unique circumstances, strengths and stressors as a family.

Please use the following prompts to think about anything you may wish to raise with us that is important to the care of your family member and/or your ability to support them in their recovery.

You may wish to do this in writing or request a meeting with the staff working with your family member.

Access to information and advocacy:

Do you have a contact person in the mental health service you can contact with questions about your family member? Do you know who is available to support you in working with the mental health service and getting the best information and treatment for your family member?

Current practical and emotional support:

Who is helpful to you – family and friends? Do they know about and understand your family member's issues? Do they realise how this impacts on you?

Current caring role:

How involved are you in caring for your family member? Would you like to be more/less involved and why? Is this likely to be different in the short term/long term?

Wider responsibilities:

Are there issues with disruption to other responsibilities in your life such as work, study, children, looking after other family members?

Future caring role:

Do you see things being different in the future, because of your family member's illness?

Education and training about mental illness and health:

Do you want to learn more about mental illness and how best to support your family member? Would it be useful to talk with people who have been through a similar experience?

Personal safety and risk management:

Do you have any concerns about your or your family's safety? Do you know what to do if you have emergency concerns? Who to contact? How best to get help?

Own physical and mental wellbeing:

Do you have concerns about your own health and stress levels?

Finances:

Has family income been affected by illness? Would you be eligible for WINZ subsidies or travel assistance?

Emergencies/alternative arrangements:

If you are busy with your family member, are others available to assist with children, work commitments and other things happening in your life?

Respite and social life – do you have an opportunity to have some time to yourself? How have your friends reacted to your current situation?

Complaints and challenges:

Are you aware of how to get any questions or concerns about your family member's treatment heard by the service? Do you know how to lay a complaint if you wish to?

Information you would like to provide to us or ask a staff member about:

Review on your own, with your family or with a staff member, and set some goals if required to address any concerns or areas requiring assistance.

Identified need	Plan	By whom/when	Completed/outcome

APPENDIX 11: DRAFT family information sheet

An introduction to the mental health service

Where families can find useful written information

Every family involved with the mental health service will have a unique set of circumstances, experiences, knowledge and skills.

Our role is to assist in the recovery of your family member and part of this involves us interacting with you, as a family.

We want to be able to provide you with information and support that will be useful to you as a family, without overwhelming you with information you don't need.

As a family you will give and receive information from our staff, as your family member is involved with the service. We encourage you to talk with our staff about anything you have questions about or require more information on.

Sometimes you might want some information to take away to read or consider.

After talking with lots of families and staff members, as part of some local research, we have put together the ASK wall.

What is an ASK wall?

ASK stands for:

Access to Service/Advocacy

Support

Key Information

We display information under each of these headings, using the same format throughout the mental health service.

Each team, unit or mental health service building has an ASK wall specifically for families to access.

The idea is that information families might need is available to you, when you need it. You choose what you need.

Each ASK wall provides a variety of information, organised in a way you can easily access, that will be helpful to and supportive of family members involved in our service

Using ASK

Come along to the mental health service your family member is using and ask about the wall.

Help yourself to as much or as little information as you require.

Feel free to take additional copies for other family members, if it would help.

Ask our staff to assist you if there is anything you read that you don't understand, or would appreciate further information about.

This information has been developed by staff and families working together and sourcing good-quality information. In this age of modern communication there is a lot of misinformation out there about mental illness. It is really important to be selective about what you read.

Not all information is written – there are great DVDs, websites, groups to attend etc that could be useful for you – again, ask our staff and Supporting Families fieldworkers about other ways of sourcing the information you require.

Other pamphlets available on the ASK wall that you may find helpful include:

Key Contacts:

DHB Family Advisor (Ph number)

Supporting Families Fieldworker (Ph number)

Mental Health Service your family member accesses

Ph number________________________________

Key Contact people

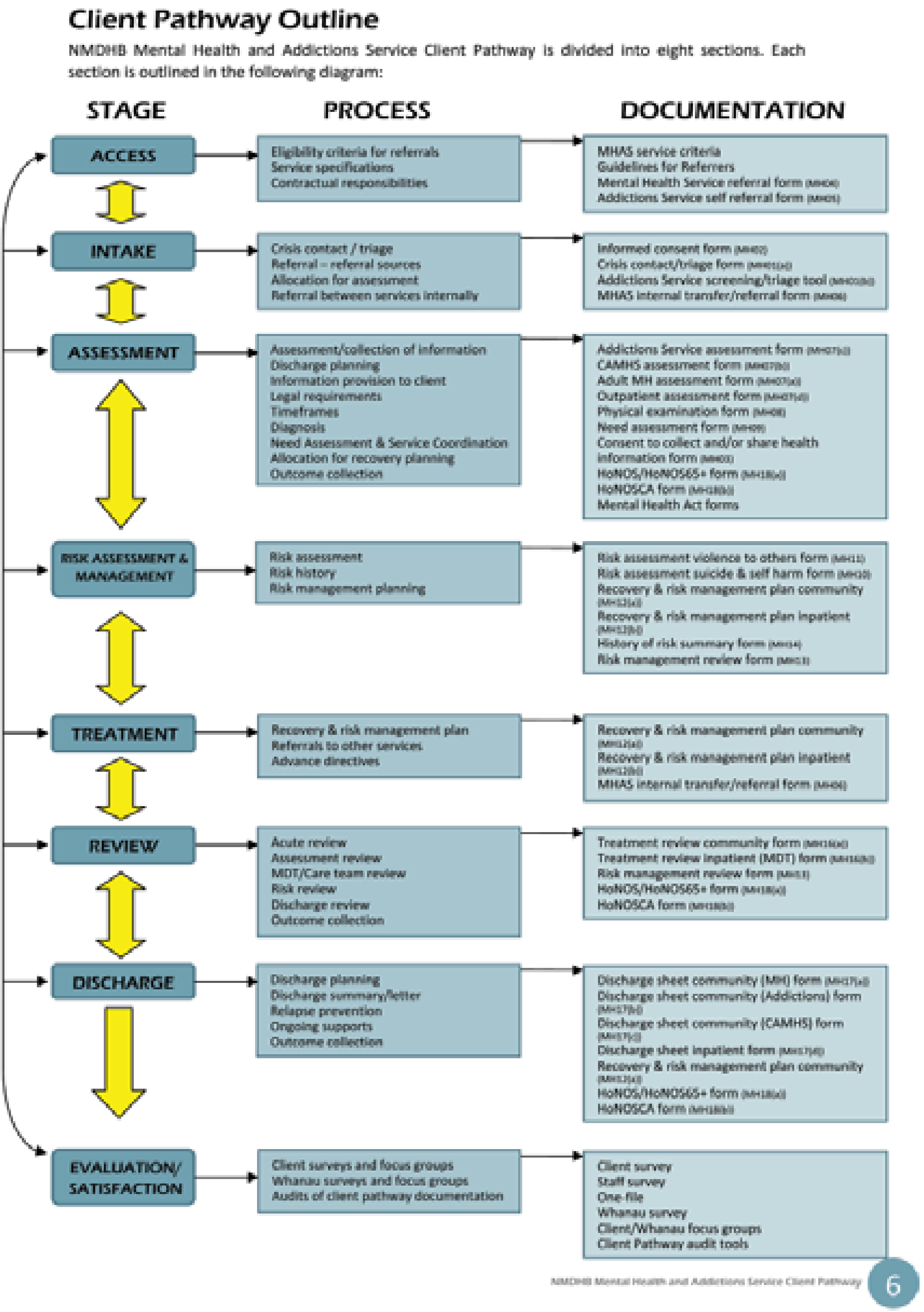
____

____

____

____

APPENDIX 12: NMDHB (2007) client pathway outline



Client Pathway Outline

NMDHB Mental Health and Addictions Service Client Pathway is divided into eight sections. Each section is outlined in the following diagram:

STAGE	PROCESS	DOCUMENTATION
ACCESS	Eligibility criteria for referrals Service specifications Contractual responsibilities	MHAS service criteria Guidelines for Referrers Mental Health Service referral form (MH04) Addictions Service self referral form (MH05)
INTAKE	Crisis contact / triage Referral – referral sources Allocation for assessment Referral between services internally	Informed consent form (MH02) Crisis contact/triage form (MH01(a)) Addictions Service screening/triage tool (MH01(b)) MHAS internal transfer/referral form (MH06)
ASSESSMENT	Assessment/collection of information Discharge planning Information provision to client Legal requirements Timeframes Diagnosis Need Assessment & Service Coordination Allocation for recovery planning Outcome collection	Addictions Service assessment form (MH07(a)) CAMHS assessment form (MH07(b)) Adult MH assessment form (MH07(c)) Outpatient assessment form (MH07(d)) Physical examination form (MH08) Need assessment form (MH09) Consent to collect and/or share health information form (MH03) HoNOS/HoNOS65+ form (MH18(a)) HoNOSCA form (MH18(b)) Mental Health Act forms
RISK ASSESSMENT & MANAGEMENT	Risk assessment Risk history Risk management planning	Risk assessment violence to others form (MH11) Risk assessment suicide & self harm form (MH10) Recovery & risk management plan community (MH12(a)) Recovery & risk management plan inpatient (MH12(b)) History of risk summary form (MH14) Risk management review form (MH13)
TREATMENT	Recovery & risk management plan Referrals to other services Advance directives	Recovery & risk management plan community (MH12(a)) Recovery & risk management plan inpatient (MH12(b)) MHAS internal transfer/referral form (MH06)
REVIEW	Acute review Assessment review MDT/Care team review Risk review Discharge review Outcome collection	Treatment review community form (MH16(a)) Treatment review inpatient (MDT) form (MH16(b)) Risk management review form (MH13) HoNOS/HoNOS65+ form (MH18(a)) HoNOSCA form (MH18(b))
DISCHARGE	Discharge planning Discharge summary/letter Relapse prevention Ongoing supports Outcome collection	Discharge sheet community (MH) form (MH17(a)) Discharge sheet community (Addictions) form (MH17(b)) Discharge sheet community (CAMHS) form (MH17(c)) Discharge sheet inpatient form (MH17(d)) Recovery & risk management plan community (MH12(a)) HoNOS/HoNOS65+ form (MH18(a)) HoNOSCA form (MH18(b))
EVALUATION/ SATISFACTION	Client surveys and focus groups Whanau surveys and focus groups Audits of client pathway documentation	Client survey Staff survey One-file Whanau survey Client/Whanau focus groups Client Pathway audit tools

NMDHB Mental Health and Addictions Service Client Pathway 6

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Innovative Practice Research

1/06 *Hello, I'm A Voice, Let Me Talk: Child-inclusive mediation in family separation,* Jill Goldson, December 2006.

2/08 *Growing Research in Practice (GRIP) – An innovative partnership model,* Neil Lunt, Christa Fouché and Deborah Yates, January 2008.

3/08 *Engaging Mäori Whänau – Evaluation of a targeted parenting programme,* Heather Gifford and Gill Pirikahu, May 2008.

4/09 *The Spinafex Effect – Developing a theory of change for communities,* Kathryn Handley, Sheryll Horn, Ripeka Kaipuke, Bruce Maden, Elizabeth Maden, Barbara Stuckey, Robyn Munford and Jackie Sanders, February 2009.

5/09 *Pathways Through Parental Separation: The experiences of a group of non-resident fathers,* David Mitchell and Philip Chapman, June 2009.

6/09 *Living with Chronic Illness: Support for family members who live with heart failure,* Dr Lisa Whitehead, October 2009.

7/10 *Connections: Supporting family relationships through schools and workplaces,* Sue Quinn and Anna Mowat, November 2010.

8/10 *Paths of Victory: Victory Village (Victory Primary School and Victory Community Health Centre), – A Case Study,* David Stuart, Families Commission, November 2010.

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