

Involving Families Guidance Notes

**Guidance for involving families and whānau
of mental health consumers/tangata whai ora
in care, assessment and treatment processes**

**Prepared by the Community Liaison Committee of
the Royal Australian and New Zealand College of
Psychiatrists**

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Foreword

We are very pleased to be able to present *Involving Families: Guidance notes*. These guidance notes have been designed to provide practical advice, guidance and support to all people working in the mental health sector. They also aim to assist families of people who have a mental illness during the contact they have with mental health services.

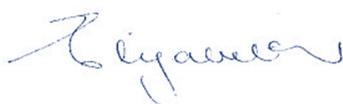
The definition of 'family' used in the guidance notes is a broad one, allowing for the person with a mental illness to define their family. Families have an important role in the care, assessment and treatment of their family member.

These guidance notes set out some of the ways in which families can be involved in the delivery of mental health services to their family member as well as ways that mental health services can more effectively work with families. They suggest ways that people working in the mental health area can ensure that families can access information, education and support in culturally appropriate ways.

These guidance notes have been a result of extensive consultation throughout the mental health sector during 1999. We acknowledge the contribution of all those involved in their completion.

In particular, we would like to thank the working party: Alison Masters, Susan Noseworthy, Barry Welsh and John Hopkins (writer) for their substantial work in putting the document together.

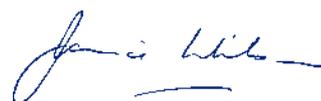
Good working relationships between mental health staff and families usually help the recovery of people with mental illness. We hope these guidance notes will contribute to that process.



Elizabeth Cunningham
National Manager
Māori Mental Health
Health Funding Authority



Kath Fox
General Manager
Mental Health
Health Funding Authority



Janice Wilson
Deputy Director-General,
Mental Health
Ministry of Health

Contents

Foreword	iii
Definitions	vii
Introduction	1
Facilitating family involvement in care, assessment and treatment processes	3
Understanding who the family is	5
Different life stages of tangata whai ora	5
Mental health staff as ‘family’	6
Understanding whānau	6
Roles of mental health staff and practical suggestions	7
1. Defining the partnership	7
2. Providing information, education and support	8
3. Planning/preparing for the future	11
4. Reviewing at critical points	12
Information, education and support	13
Children and young persons	13
Standards and principles	14
Standards	14
Principles	14
Specific situations	16
References	19
Appendix 1: Examples of family intervention and/or therapy models or programmes	20
Appendix 2: Health Information Privacy Code, Rule 11	21
Appendix 3: Development of these guidance notes	22
Process	22
RANZCP committees	23
Submissions on drafts	23

Definitions

The terms ‘consumer/tangata whai ora’ and ‘family/whānau’ were used in earlier drafts of this document. Adverse comment in submissions about the use of this style has led to one term being used to refer to all ‘consumers/tangata whai ora’ and ‘families/whānau’, except where the context dictates the use of another term.

Tangata whai ora

This term is used to refer to the person who is the subject of care, assessment and treatment processes in mental health. ‘Tangata whai ora’ means ‘a person seeking health’ – acknowledgements to Professor Mason Durie. ‘Tangata whai ora’ is frequently written as ‘Tangata whaiora’. The former is used here on the basis of advice from Te Taura Whiri i te Reo Māori, who indicate that ‘whai ora’ means ‘in search of wellbeing’ whereas ‘whaiora’ means ‘who has wellbeing’. ‘Whai ora’ is more appropriate to the context of these guidance notes.

Family

A family is a set of relationships that is defined as family by the tangata whai ora. Family is not limited to relationships based on blood ties, and may include:

- relatives of the tangata whai ora (including a spouse or partner)
- a mixture of relatives, friends and others in a support network
- only non-relatives of the tangata whai ora.

There may be risks, particularly of omission (eg, parents) in affirming the tangata whai ora as the sole ‘definer’ of family, and any risks must be assessed in each situation according to best clinical practice.

Any member of a family may be involved, whatever the definition of itself by the family, provided the tangata whai ora consents. In situations where there is conflict over definition of the family, mental health staff must be guided by best clinical practice.

Examples of families:

- a whānau, hapū and/or iwi
- a nuclear or extended Pākehā family
- a family from a Pacific people (eg, aiga, koputangata, magafaoa)
- a family from another culture (eg, refugees and other migrants)
- a family from a particular community (eg, gender-based, gay or lesbian, or deaf communities)
- a family made up of people such as a support group for a tangata whai ora.

Each of these family styles requires its own recognition and cultural safety as they participate in care, assessment and treatment processes.

Whānau

The National Mental Health Standards (Ministry of Health 1997a) define whānau as:

A consumer's family or an extended family/group of people who are important to the consumer.

As this does not explicitly capture the traditional meaning of the term, the following definitions have been adopted:

This may be a single person whānau, a nuclear whānau, a large extended whānau or another group which may not have blood ties but which lives as a cohesive unit (Public Health Commission 1995).

A collective of descendants of a common ancestor, usually of three to four generations and their partners and whakai who interact together on an ongoing basis (Ministry of Health 1997b).

Mental health staff

The term 'mental health staff' is used throughout to describe mental health and support service practitioners of all disciplines. It does not refer to medical practitioners alone. The term includes everyone contracted to provide mental health and/or support services to tangata whai ora in hospitals, clinics, medical centres, pharmacies, homes, schools, marae and in other institutional and community settings.

Introduction

These guidance notes have been prepared to assist mental health staff to work effectively with families, and they will also assist families to establish and maintain working relationships with mental health services and staff.

In discussing families, *Blueprint for Mental Health Services in New Zealand* (Mental Health Commission 1998) states:

People with serious mental illness are not ill in isolation. Their families, extended whānau, 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. Beyond the immediate family are other relatives, friends, neighbours, and workmates who may have a role in the life of the person and need, therefore, to be part of the healing or maintenance programme.

Many families wish to be involved in assisting the recovery of their family member. They want mental health staff to work in ways that are inclusive of families. This means that mental health staff need to work with the family and tangata whai ora – sharing information, planning, decision making, and providing support and education when necessary.

Whānau want mental health staff to recognise the important principle of whanāungatanga when working with tangata whai ora. Whanāungatanga is about the interconnectedness and interdependence of all members of the whānau, including the tangata whai ora. Whānau health is intrinsic to the health of each member and the health of each member is integral to the health of the whānau.

Mental health staff who are operating within this principle contribute their expertise to the strengths, knowledge and skills from working in partnership with the whānau rather than treating tangata whai ora in isolation or making decisions for tangata whai ora and the whānau. It is often observed that if mental health services develop effective ways of working with whānau, they will also work effectively with other families.

Research has conclusively shown that there are significant clinical, social and economic advantages in providing mental health services in a family inclusive way (World Schizophrenia Fellowship 1998).

There are many complex cultural, ethical, legal, financial, organisational and treatment issues affecting involvement of families in care, assessment and treatment processes. There has been and still is potential for conflict over aspirations, rights and responsibilities regarding consumer privacy and family involvement. These guidance notes cannot offer a complete solution to all situations. They do not attempt to cover all situations that may occur, nor are they prescriptive.

These guidance notes are not intended to be read as a 'recipe book' – they offer principles, guidance and practical suggestions to assist mental health staff to work alongside families – working *with*, not *for*.

Implementation of these guidance notes may have implications for resource allocation, organisational change and staff training. This may involve short-term costs, but this will lead to longer-term savings through improvement in services. Implementation of these guidance notes may be enhanced through involvement of family representatives in governance of mental health services (eg, in policy development, planning, service reviews and staff training).

Facilitating family involvement in care, assessment and treatment processes

Having mental health staff working alongside families will help to support and empower families to:

- assist tangata whai ora toward recovery
- deal with their own trauma and distress
- participate in the service provider's organisational systems and processes for planning, development, evaluation and management.

Family involvement may also assist the family and the tangata whai ora to maintain a positive relationship.

A working relationship between a family and mental health staff is a process, not an event. Families and staff change, develop, move on and shift their focus on the care, assessment and treatment process. Mental health staff need to remember the fluid nature of working with family – family and staff should continually assess the effectiveness of their partnership.

The cultural beliefs and values of all parties to the relationship are of considerable importance in negotiating what will work in care, assessment and treatment.

Families have an important role in care, assessment and treatment. Mental health staff need to ensure that families can access information, education and support in culturally appropriate ways.

There are many ways to establish and maintain effective working relationships. They can be initiated by:

- the family
- the tangata whai ora
- mental health staff on an individual basis
- service providers with groups of families to whom they provide mental health services
- national and regional health bodies such as health funders.

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

- consultation
- co-operation
- mutual respect
- equality
- sharing of complementary resources and skills
- clarity of expectations.

Taken together, these qualities connote staff working *with* families, not ‘doing for’ or ‘doing to’. Working with families involves staff sharing their knowledge and expertise. Staff should also acknowledge and respect the equivalent abilities in the family. There needs to be a mutually respectful process of sharing information, resources and skills (within the bounds of confidentiality established in each situation). It is not a one-way process of information gathering from the family so staff can ‘do the work’ and make all of the decisions. Positive models of working with families provide mutual participation by family, the tangata whai ora and staff – each acknowledging their own expertise and contributing towards recovery.

Models for working with families need to recognise that:

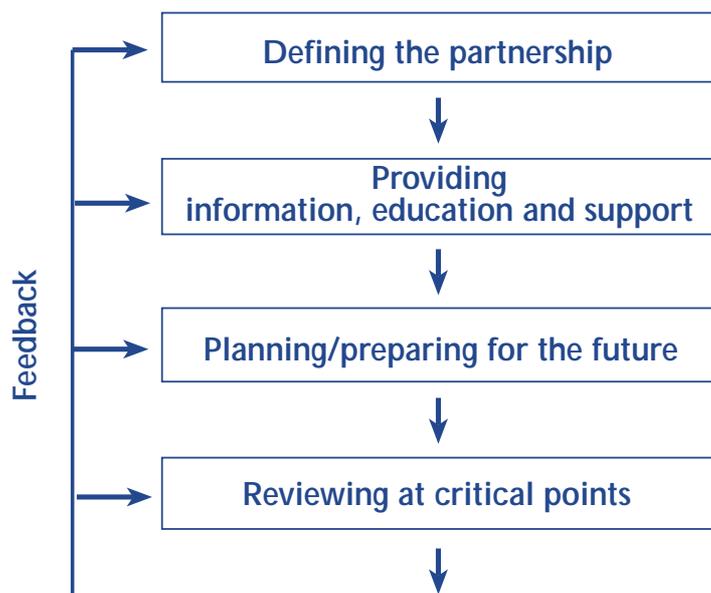
- the tangata whai ora is not ill in isolation from others
- current research demonstrates the value of involvement of the family in care, assessment and treatment processes
- mental health staff are restricted in their ability to provide the best services if they do not work effectively with families
- families come from a range of cultures, and ‘one size does not fit all’ – family and whānau definitions need to be flexible enough to meet the needs of the range of cultures in this country
- at the beginning of any relationship, staff need to recognise and start from the position that the family is in and move at their pace
- the tangata whai ora can refuse consent for mental health staff to share personal information with their family, subject to any exceptions provided for in the Health Information Privacy Code 1994
- most aspects of working with families are not prevented by the Privacy Act 1993 or Health Information Privacy Code 1994
- whether or not the tangata whai ora consents, families have a need and a right to certain forms of information and involvement within the requirements of relevant legislation and codes.

Models should provide for agreement on the respective roles and responsibilities of each party, and agreement on planning and review cycles.¹

For Māori, partnership may be impossible if the mental health service is inappropriate to Māori, or does not recognise Māori values and processes.

¹ Some examples of family intervention and/or therapy models or programmes are listed in Appendix 1.

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



The dynamic nature of these working relationships means that each aspect should be seen as part of an ongoing cycle. A review (for example) may suggest that a particular family member has been inappropriately left out or should not have been included in the first place. This should be attended to for the future. Similarly, planning (or a review) may reveal gaps in the knowledge or skills needed by the family. There may be a need for more information or a different kind of education and support.

Understanding who the family is

The perspective of the tangata whai ora is a critical factor in the process of identifying the members of their family, and in most situations, they will be the 'expert'. Even then there may be some difficulties for 'mainstream' service providers in understanding what is meant by family or whānau, and it may be difficult to work effectively and safely in partnership with them. Some mental health service providers employ cultural support staff, who can help to identify the family and assist mental health staff and family to work together safely and effectively.

Initially it may seem that the tangata whai ora has no family, particularly if a restrictive definition is employed. Family may be absent for many reasons – sometimes as a result of previous interventions or the debilitating effects of previous diagnosis and treatment. The task may be one of re-building family, rather than understanding who are the existing members.

Different life stages of tangata whai ora

The different life stages of tangata whai ora are relevant when understanding the membership of the family. Each person has different needs from their family according to their stage of life and development. They also have different status within the family according to their age. Tangata whai ora and their family may have particular legal rights and responsibilities according to age criteria.

Mental health staff as ‘family’

Mental health staff (eg, staff of an iwi-based service provider, or in supported accommodation) may have a dual role. They may be part of or *be* the family of the tangata whai ora. There may be conflict in this dual role, and any actual or potential difficulties need to be identified and addressed.

Understanding whānau

Understanding the membership of a whānau needs to take account of the subtleties of whānau and their different traditional and contemporary ‘definitions’. Working effectively with whānau in care, assessment and treatment processes means working with tapu and whakapapa. The whānau may need to disclose information that may be thought of as whānau ‘secrets’. The whānau needs to feel safe before this can occur.

Key questions may be:

- ‘Who is missing from this whānau?’
- ‘Who is the person who will make the whānau feel safe?’
- ‘Who should I go with to the whānau hui so that the whānau will feel safe with me?’ (eg, being accompanied by a kaumātua or kuia).

Mental health staff need to recognise that the whānau is integral to whānau members, including the tangata whai ora.

To work effectively with a whānau, mental health staff need to establish an ongoing relationship with its members. A pōwhiri is a very important beginning to this process. Through the pōwhiri and later, staff need to:

- disclose who they are and make connections with the whānau
- show that they are there to provide the whānau and the tangata whai ora with their expertise in mental health
- be comfortable with their own expertise
- be trustworthy
- be safe for the whānau so they can share their ‘secrets’ (see previous paragraph)
- be safe for themselves.

This process will lead to openness, but it will also engender the expectation of continued process based on kaupapa Māori and the accountability and influences that emerge from kaupapa Māori. Within this expectation the ability for whānau, particularly kaumātua, to assert direction will be assumed. The process of full face-to-face debate leading to decisions will also be expected. Once agreement is reached, all participants will be responsible for both implementation and protection of the decisions.

Mental health staff have a responsibility to ensure the cultural safety of tangata whai ora, families and themselves throughout the process of care, assessment and treatment.

Roles of mental health staff and practical suggestions

The following are offered as practical suggestions for mental health staff. They concentrate on the dynamic process illustrated in the diagram on page 5.

1. Defining the partnership:	
Roles/tasks:	Practical suggestions:
<ul style="list-style-type: none"> Recognise the role of the family 	<ul style="list-style-type: none"> Make sure that the team is committed to working effectively with family Ensure that it is easy for families to gain information, and access services and staff.
<ul style="list-style-type: none"> Clarify who is the family in each situation 	<ul style="list-style-type: none"> Find out from the tangata whai ora who the family is (eg, spouse or partner, parents, siblings, other relatives, friends, flatmates, ministers, support workers) Additional sources for identifying whānau are appropriate (eg, Māori staff, and other Māori resource people in the community) Remember that membership of a family or whānau may change over time.
<ul style="list-style-type: none"> Develop and maintain a partnership of equality with the family 	<ul style="list-style-type: none"> Make sure that you have the consent of the tangata whai ora to share their personal information with the family Listen to the family throughout care, assessment and treatment processes Be transparent in your involvement with all parties.
<ul style="list-style-type: none"> Be responsive to the cultural, emotional, physical, social and spiritual experience and needs of the family 	<ul style="list-style-type: none"> Make your workplace 'family and whānau friendly' Wherever possible, meet the family in the place of their choice Understand the importance of the pōwhiri process, ensure there are opportunities for it to happen and participate Connect with the family – use appropriate self-disclosure Use language that is comfortable for the family Ensure the team includes staff who are skilled in responding to cultural and spiritual needs (eg, conducting karakia, giving and responding to a mihi).
<ul style="list-style-type: none"> Respect the privacy and confidentiality needs of the family and the tangata whai ora 	<ul style="list-style-type: none"> Clarify with the tangata whai ora what information can be disclosed to the family, <i>and vice versa</i> Act according to the Privacy Act 1993 and the Health Information Privacy Code 1994 in relation to family Provide 'non-public' places where family can meet with the contact person or team.

1. Defining the partnership cont'd:	
Roles/tasks:	Practical suggestions:
<ul style="list-style-type: none"> Identify and introduce the mental health staff to the family 	<ul style="list-style-type: none"> Be accessible to the family on their terms Ensure that team members can meet, greet and host a family in a family-friendly way, including cultural and spiritual aspects such as mihi, karakia, and kai (eg, a cup of tea and biscuits) Introduce all relevant members of the team to the family.
<ul style="list-style-type: none"> Clarify staff roles and responsibilities with the family and tangata whai ora 	<ul style="list-style-type: none"> Ensure that all team members understand the role each team member will play Identify one team member as the contact person for the family Ensure that the contact person shares all information with the rest of the team Review job descriptions to ensure that team members can carry out any new responsibilities Negotiate how ongoing contact is to happen (eg, when, how, why contact will/can take place).

2. Providing information, education and support:	
Roles/tasks:	Practical suggestions:
<ul style="list-style-type: none"> Inform the family about the services that can be provided and the support that is available to them throughout the care, assessment and treatment processes 	<ul style="list-style-type: none"> Provide information as needed by the family: <ul style="list-style-type: none"> how the mental health service works each mental health worker's role and function what can happen throughout care, assessment and treatment how they can be supported (provide it in writing as well) Do not overload the family with information 'all at once', especially in a crisis. Provide information in writing so they can refer to it later Prepare (or obtain) information so it is ready for use: pamphlets, fact sheets, videos etc Offer information in a variety of ways so the family can choose what suits them; some may prefer discussion, others may prefer written information.

2. Providing information education and support cont'd:

Roles/tasks:	Practical suggestions:
<ul style="list-style-type: none"> • Provide relevant information, education and training regarding mental health and illness and the role the family can play in recovery, to enhance their understanding, skills, and confidence in the carer's role <p><i>Remember that adequate explanation may entail repeating the same information several times at regular intervals</i></p>	<ul style="list-style-type: none"> • Focus on holistic treatment, rather than medication management alone. Assist with issues such as accommodation, psychosocial therapy, supportive social networks, and employment or alternative options • Assist families to: <ul style="list-style-type: none"> – resolve family conflict – provide in writing how they can be supported. Be sensitive to emotional distress – identify/solve specific problems, reach stated goals – develop family members' relevant skills – problem-solving and skill development improves their ability to support the consumer, leading to less need for professional support – strengthen positive family ties – care for <i>themselves</i> – unlimited self sacrifice 'in the interests of the tangata whai ora' may damage their ability to care and cope – learn about the illness – refer families to community courses about mental illness – maintain/expand their support networks, friendships, activities and hobbies – particularly those that take them out of the home. Put them in contact with local support groups • Ensure there is a 'non-blaming' approach to families <ul style="list-style-type: none"> – Make sure you have the same realistic expectations: <ul style="list-style-type: none"> – what does the tangata whai ora and family expect of the treatment programme? – is this what the treatment team is able to provide?
<ul style="list-style-type: none"> • Provide support on an ongoing basis throughout the care, assessment and treatment processes 	<ul style="list-style-type: none"> • Act on the information provided by the family and tangata whai ora when they speak about early warning signs or side effects of treatment • Support the supporters – talk to and advise teachers, guidance counsellors, employers, GPs, tohunga and others who are supporting the family (with the family's consent) • Support families by assisting them to: <ul style="list-style-type: none"> – understand what is meant by 'recovery' – plan how to work towards agreed goals, review progress, deal with emergency, crisis and relapse – care for themselves as carers and help themselves 'get back to normal' after a crisis – work out how to interact with mental health staff – understand what they can expect from staff and service providers.

2. Providing information, education and support cont'd:

Roles/tasks:	Practical suggestions:
<ul style="list-style-type: none"> • Inform the tangata whai ora about the services and support that are available to them throughout care, assessment and treatment processes • Provide relevant information, education and training regarding mental health and illness, including the role the family can play in their recovery 	<ul style="list-style-type: none"> • Explain how the mental health service works • Plan with the tangata whai ora the nature of their involvement with family and staff, and how they will be supported at each stage of the process • Provide pamphlets or other information for tangata whai ora about: <ul style="list-style-type: none"> – their diagnosis and what it means – what is meant by recovery, how to work towards recovery, and how to review progress – medication and possible side effects of medication – early warning signs and what to do about them – helping themselves to 'get back to normal' after a crisis – how to interact with staff and what they can expect from staff and service providers – the role their family can play in care, assessment and treatment processes – the role of other supporters and advocates, and their contact details – any legal aspects of their care, assessment and treatment, and rights and responsibilities.
<ul style="list-style-type: none"> • Mental health staff need to prepare themselves to work in partnership with families 	<ul style="list-style-type: none"> • Ensure that you and your team understand the principles of working with families (eg, treatment co-ordination, problem-solving techniques, clear communication, setting goals, being accessible, being responsive to Māori, Pacific peoples, European, and other cultures) • Employ skilled staff • Seek any necessary education and skill training for you and the team in (for example): <ul style="list-style-type: none"> – current research findings on the value of involving families in recovery – attitudes to working with families – models for working with families (see Appendix 1) – the knowledge and skills needed by families – the skills and processes involved in educating families – the skills and processes for working with children and siblings of tangata whai ora.

3. Planning/preparing for the future:

Roles/tasks:	Practical suggestions:
<ul style="list-style-type: none"> Negotiate ways in which the family can participate in the recovery process with the tangata whai ora, especially in those aspects of recovery that directly affect their own lives 	<ul style="list-style-type: none"> Help the family to understand the big picture – offer information about the long term Assess the family for its resources, strengths, ways of coping, social networks and needs for support services <ul style="list-style-type: none"> – this will help you know what you can offer or contribute Negotiate crisis management contracts with tangata whai ora and family – agree with the tangata whai ora <i>before a crisis occurs</i> on the treatment and care that will be offered, what information can be shared with family and the nature of their involvement, should the tangata whai ora become unable to consent Suggest inclusion of a ‘tangata whai ora friendly’ person in these contracts – this person can be involved if there is conflict in the future Where appropriate, discuss the appointment of a welfare guardian or property manager with the family, or preparation of an Enduring Power of Attorney by the tangata whai ora Design and use ‘user-friendly’ tools for exchanging information, planning and care, such as: <ul style="list-style-type: none"> – information-gathering forms, and forms for families to send information to the contact person about recovery or early warning signs – an agreement form for treatment plans – relapse prevention and early warning sign plans.
<ul style="list-style-type: none"> Ensure that families are involved in wider issues in the provision of services 	<ul style="list-style-type: none"> Remember that families learn what works for them and what doesn’t – acknowledge their experience Involve families in consultations and discussions about how services should be provided and how they can be improved, (eg, planning, development, management and evaluation) Involve family representatives in service provider governance.

4. Reviewing at critical points:

Roles/tasks:	Practical suggestions:
<ul style="list-style-type: none">• Develop appropriate ways in which the family can participate in review processes at planned intervals	<ul style="list-style-type: none">• Listen to the family – learn from the carers – they have experience and knowledge• Remain in close contact during times of crisis, to offer concrete advice and assistance• Make your interventions or solutions practical and real – negotiate goals with the family and tangata whai ora, and work towards them step by step, within best practice guidelines• Ensure everyone knows what is happening for the person if there is a crisis or relapse – suggest concrete solutions which will improve the situation.
<ul style="list-style-type: none">• Ensure reviews inform all aspects of working with the family (eg, definition of family and staff; information, education and support)	<ul style="list-style-type: none">• Acknowledge family observations – families are accurate predictors of relapse• Use the outcome of reviews to:<ul style="list-style-type: none">– make sure you are in contact with ‘current’ family– ensure the team has current knowledge of the family and tangata whai ora– ensure the team is meeting the current needs of the family– review plans and develop new plans for the future.

Information, education and support

Excellent up-to-date information has been developed by service providers, consumer groups, advocacy groups and other non-governmental organisations to support education and training of tangata whai ora and families. Categories of information include:

- general information (eg, on mental health and disorders, and medication and other forms of treatment)
- particular information (eg, on a particular mental disorder or medication)
- local area information (eg, on local mental health and social services)
- information that can be individualised to a particular tangata whai ora and their family.

Mental health staff can set up support groups for families, or refer on to existing groups. These are tailored to inform, educate and support families. Support groups can be multi-family, and with or without tangata whai ora involvement. Many consumer advocacy organisations have set up support groups for tangata whai ora.

An important element of support groups is to demystify mental health and mental illness. Participation in support groups can extend the skills of families to address, challenge or combat discrimination whenever they encounter it. Support groups can also create a sense of hope and recovery, rather than a feeling of helplessness and hopelessness. Support groups need to be forward looking, good at problem solving and supportive of their members as carers or tangata whai ora.

Educational materials need to be designed for the audience for which they are intended (eg, children, young persons or adults). It may be useful to set up support groups to cater for the needs of particular age groups.

Children and young persons

Tangata whai ora may have children. Special needs of children (or young persons) need to be considered in partnerships between mental health staff and families:

- children have particular needs for information, education and support
- they may have information that could help in the partnership
- fear of involvement with mental health services and loyalty to a parent need to be sensitively dealt with when discussing a parent's behaviour and mental state with a child.

Mental health staff may require training to work effectively with children of tangata whai ora. They also need to find out whether children and their carers are involved with other agencies in the community – co-ordination with the other agencies is an essential component of the working relationship.

Standards and principles

Standards

The *National Mental Health Standards* (Ministry of Health 1997a) contain a significant number of references to carers, families and whānau. The standards consistently indicate the duty of providers to involve families in the provision of mental health services, whilst preserving the autonomy of the tangata whai ora.

Principles

1. The wellness of tangata whai ora includes supportive relationships. Wellness is extremely difficult to achieve in isolation from people (other than mental health staff) who support and care for the tangata whai ora. The whānau is integral to each whānau member, and wellness may not be achieved without its involvement.

Partnership between the tangata whai ora, their family, and mental health staff is likely to produce the best results in the process of recovery, as well as significant social and economic advantages. This is supported by available research (World Schizophrenia Fellowship 1998).

Families should have access to information, education, training and support to enhance their understanding and ability to care and advocate for the tangata whai ora.

2. Families are entitled to access to mental health staff and to provide them with information that may assist in care, assessment and treatment processes (whether or not the tangata whai ora consents). This may include information about the tangata whai ora and the family.
3. Families are entitled to seek other opinions regarding the care, assessment and treatment of the tangata whai ora.
4. Families are entitled to access to the tangata whai ora during care, assessment and treatment processes (provided that the tangata whai ora consents) and are entitled to be consulted by mental health staff about care, assessment and treatment processes (subject to the consent of the tangata whai ora regarding sharing of personal information).
5. Tangata whai ora who have capacity to make decisions are entitled to refuse to have contact with their family and to withhold or withdraw consent for mental health staff to provide personal information about them to their family.

This may be in conflict with family values and cultural perspectives, but it is supported by legislation and privacy codes.
6. Where the tangata whai ora has the capacity to withhold consent to sharing personal information with their family and does so, the family is still entitled to initiate contact with mental health staff and provide information that is relevant to care, assessment and treatment processes.

The family is also entitled to such non-personal information as is envisaged in Principle 2. If the tangata whai ora has withheld consent to sharing personal information with their family, information provided by mental health staff must be general in nature and not compromise confidentiality/privacy.

7. Where a tangata whai ora is unable to consent or refuses to consent because of their mental state, it may still be good clinical practice for mental health staff to make contact with their family to seek their involvement in care, assessment and treatment processes.

This should be justified by a considered opinion about what the tangata whai ora would want if they were able to consent. Engagement of an advocate for the tangata whai ora may be appropriate.

Specific situations

There are four main situations to consider in any relationship between families and mental health staff:

1. the tangata whai ora consents to family involvement in their care, assessment and treatment processes
2. the tangata whai ora refuses consent to share personal information with their family
3. the tangata whai ora is unable to consent because of their mental state
4. the tangata whai ora is a child or young person, and their ability to grant or withhold consent is in question.

The Privacy Act 1993 and the Health Information Privacy Code 1994 are relevant to situations 2–4. More detailed information about privacy considerations is available in the Privacy Commissioner’s guidance notes (Privacy Commissioner 1997) and will not be repeated here.

1. The tangata whai ora consents to family involvement in their care, assessment and treatment processes

Family involvement, with the tangata whai ora’s consent, usually contributes positively to the tangata whai ora’s recovery. However, the right to be involved – and agreement that this should happen – does not always mean that mental health staff can enter into an *effective* working relationship with a family. Mental health staff may intend to do so, but may lack the appropriate knowledge and skills.

The section in these guidance notes *Facilitating family involvement – roles of mental health staff and practical suggestions* provides information on ways in which mental health staff can work with families to form good working relationships.

2. The tangata whai ora refuses consent to share personal information with family

Certain legislation, standards and codes support the right of the tangata whai ora to maintain their personal privacy and they are entitled to refuse consent for their family to have access to their personal information. This means, for example, that mental health staff cannot give out specific information about diagnosis, medication or treatment without the consent of the tangata whai ora.

However, consent is a process not an event, and it is necessary to regularly review with the tangata whai ora whether their views on sharing their personal information with family remain the same.

Even if the tangata whai ora limits access to their personal information, this does not prevent mental health staff from having a working relationship with the family. The family is still entitled to support and some kinds of information from the mental health service. There are limits to the information mental health staff can disclose to the family, unless it comes within one of the exceptions in Rule 11 of the Health Information Privacy Code 1994.² They are, however, able to share non-personal information.

² For further information, refer to Appendix 2 to these guidance notes, the Health Information Privacy Code 1994, and Privacy Commissioner (1997)

It may be useful to tell family that consent will be reviewed on a regular basis, and the tangata whai ora may also change their views as treatment progresses. Staff should inform family that other useful information can be given at a general level and also refer them to support groups that can assist.

The family is still entitled to *give* information to mental health staff to assist in care, assessment and treatment.

Mental health staff are able to receive information that may help towards the tangata whai ora's care, assessment and treatment. Arrangements should be made for regular contact so that family can pass on information (if that would be helpful in the circumstances) and so that the consent issue can be updated with the family.

Mental health staff should clarify with the family what information they would like shared with the tangata whai ora. It may be valuable to review this information with the tangata whai ora so the process can be as open as possible. Staff should inform the family that this will be done. Respect for privacy and confidentiality rights should apply equally to family and tangata whai ora.

3. The tangata whai ora is unable to consent because of their mental state

In these circumstances mental health staff have to make a professional decision in the interests of promoting the wellness of the tangata whai ora. Staff may have to predict what the tangata whai ora would have wanted had they the capacity to decide for themselves. Mental health staff should obtain relevant information from the family to assist them in making this decision, particularly in situations where mental health staff have not been involved in the past with the tangata whai ora and their family.

Such decisions do not justify disclosure of *all* tangata whai ora information (unless this has been agreed to by the tangata whai ora in terms of the Commentary to Rule 11(2)(b) of the Health Information Privacy Code 1994). Mental health staff should err on the side of caution – they should only share information that is essential for the family to have so they can positively contribute to care, assessment and treatment processes.

Mental health staff may decide that the tangata whai ora would not want personal information shared with family. In these circumstances, the family is still entitled to access to other non-personal information.

Whatever decision is made, it is not final. Decisions need to be regularly reviewed – with the tangata whai ora in particular when capacity is regained.

It is good practice for mental health staff to develop contracts with tangata whai ora that record what each tangata whai ora wants to happen if a crisis occurs and they lose the ability to consent. Contracts should record agreement on:

- the treatment and care that will be provided
- the nature and extent of personal information that can be shared with family
- the nature and extent of involvement of family.

It is also important that mental health staff remember the application of the Protection of Personal and Property Rights Act 1988, and its use in situations of incapacity.

4. The tangata whai ora is a child or young person, and her/his ability to grant or withhold consent is in question.

Most of the considerations under situation 3 also hold true in this situation. For a fuller discussion of consent in child and youth health, refer to Ministry of Health 1998.

References

Mental Health Commission. 1998. *Blueprint for Mental Health Services in New Zealand: How things need to be*. Wellington: Mental Health Commission.

Ministry of Health. 1997a. *The National Mental Health Standards*. Wellington: Ministry of Health.

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Ministry of Health. 1998. *Consent in Child and Youth Health: Information for practitioners*. Wellington: Ministry of Health.

Privacy Commissioner. 1997. *Mental Health Professionals and Patient Information: Guidance notes for agencies in the mental health sector*. Auckland: Office of the Privacy Commissioner.

Public Health Commission. 1995. *He Matariki: A strategic plan for Māori public health: The Public Health Commission's advice to the Minister of Health 1994–95*. Wellington: Public Health Commission.

World Schizophrenia Fellowship. 1998. *World Schizophrenia Fellowship Strategy Document: Families as partners in care*. World Schizophrenia Fellowship.

Appendix 1: Examples of family intervention and/or therapy models or programmes

Please note that this is not an exhaustive list.

EPPIC Centre Melbourne. *Psycheducation Module for Families in First Episode Psychosis*.

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

Falloon IRH. 1993. Single family psychoeducation and cognitive-behavioural therapy. In: IRH Falloon and G Fadden (eds). *Integrated Mental Health Care*. Cambridge: Cambridge University Press.

McFarlane has written about multiple family group psychoeducation, for example:

McFarlane WR, Link B et al. 1995. Psychoeducational multiple family groups: four year relapse outcome in schizophrenia. *Family Process* 34:127–44.

McFarlane W. 1991. Family psychoeducation treatment. In: A Gurman and D Kiniskien (eds). *Handbook of Family Therapy Vol 2*. New York: Brunner/Mazel.

Also:

Marsh DT. 1998. *Serious Mental Illness and the Family: The practitioner's guide*. New York: John Wiley & Sons.

Appendix 2:

Health Information Privacy Code, Rule 11

The Privacy Act 1993 and the Health Information Privacy Code 1994 do not provide a complete prohibition on sharing tangata whai ora information with families. Rule 11 of the code places limits on disclosure of health information, but it also permits disclosure under certain circumstances.

The following is a brief summary:

- Mental health staff should only disclose information to the tangata whai ora or to their representative, or in situations where this is authorised by the tangata whai ora or their representative.
- Mental health staff can disclose information collected for a mental health purpose if disclosure is one of the purposes. Staff *'may consider a purpose for obtaining health information is to pass on necessary information about care of the patient to caregivers or other people who should be aware of certain aspects of care, such as medication requirements. The Code permits this disclosure as it is one of the purposes for which the information was obtained.'* ... *The (tangata whai ora) should be told of the purpose when the information is collected.'* (Privacy Commissioner 1997:21.)
- Staff may disclose information in a number of situations, particularly where there is some serious or imminent threat to public health or safety or the life or health of the tangata whai ora or someone else involved in the situation. This means that in situations where there is a danger to the health of the tangata whai ora or others, then it is permissible to disclose their health information for the purpose of responding to the danger – staff may be permitted to 'breach confidentiality'.
- It is important that service providers have policies on disclosure of personal information and that tangata whai ora are aware of them.

Appendix 3:

Development of these guidance notes

Process

The project was managed by the Royal Australian and New Zealand College of Psychiatrists (RANZCP) NZ Community Liaison Committee.

- 1) A working group prepared the various drafts of the guidance notes - Susan Noseworthy (family carer perspective), Barry Welsh (consumer perspective) and Alison Masters (clinician perspective), supported by John Hopkins (writer).
- 2) A first draft of the guidance notes was prepared by February 1999, utilising available national and international information.
- 3) The first draft was critiqued by the RANZCP NZ Community Liaison Committee and Te Kaunihera mō ngā Kaupapa Hauora Māori (see later for membership of these committees and their linkages).
- 4) Comments were given to the working group for development of the second draft, which was then subject to a bi-national consultation process involving the RANZCP Board of Professional and Community Relations Committees at the College Congress in Australia (12–16 April 1999).
- 5) A draft was presented and discussed at the June 1999 Mental Health Advocacy Coalition meeting.
- 6) From February 1999 drafts were widely circulated to family advocates and advocacy groups, consumer advocates and advocacy groups, health professionals, Māori advisors, and health funders, with the request for feedback.

The following organisations received a draft for consultation:

Family support services, including Schizophrenia Fellowship Branches
GROW
Health Funding Authority
Hospital and Health Services
Māori Mental Health Services
Mental Health Advocacy Coalition
Mental Health Commission
Ministry of Health
Non-government Mental Health Services
Pacific Island Mental Health Services
Southern Mental Health Client Network

Standards Implementation Body, National Certificate in Mental Health
(Mental Health Support Work)

Wellington Mental Health Consumers Union

- 7) Feedback on the draft was incorporated into the final document.

RANZCP committees

Two Royal Australian and New Zealand College of Psychiatrists Committees from the Board of Professional and Community Relations commented on drafts of these guidance notes. The committees were:

- the Community Liaison Committee, with membership of psychiatrists and representatives from consumer and family/carer advocate organisations – GROW, ANOPS and Schizophrenia Fellowship.

Membership:

Annie Cripps, GROW, Auckland

Noel Fernando, Healthcare Hawkes Bay

Alison Masters, Early Intervention Service, Wellington

Wayne Miles, Waitemata Health, Auckland

Susan Noseworthy, Schizophrenia Fellowship NZ Inc, Christchurch

Barry Welsh, Consumer Advisor, Health Funding Authority Southern, Christchurch

- Te Kaunihera mō ngā Kaupapa Hauora Māori, with membership of psychiatrists and Māori involved in the mental health sector who sit on the committee with the support of their iwi.

Membership:

Bill Katene, Porirua

Wi Keelan, Healthcare Hawkes Bay, Napier

Chas McCarthy, Wellington

Erihana Ryan, Healthlink South, Christchurch

Phyllis Tangitu, Lakeland Health, Rotorua

Rees Tapsell, Mason Clinic, Auckland

Bridget Taumoepeau, Porirua Hospital, Porirua

Sue Tawhai, South Auckland Health, Otahuhu

Submissions on drafts

Submissions were received on drafts from the following individuals and groups:

Christopher Carroll, Analyst, Mental Health Commission

Rick Cohen, Healthlink South, Christchurch

Ann Colegate, Kapiti Support Group, Schizophrenia Fellowship Wellington

Carolyn Copland, Wellington

Betty Cowie, Advocacy Co-ordinator, Schizophrenia Fellowship Otago

Lorrina Cranstoun, Mental Health Services for the Elderly, Auckland Healthcare

Annie Cripps, GROW, Auckland
Valda Cross, Balclutha
Elaine Crozier
Nick Crozier
Anna Cubis, Field Officer, Mental Health Trust
Rosemary Ellis, Chair, Schizophrenia Fellowship New Plymouth
Noel Fernando, Healthcare Hawkes Bay
Henriette Fleischer, Nelson
John Gillespie, CCAFS, Auckland Healthcare
Judy Gray, Auckland
Ian Hammond, Auckland
Rosemary Higgie, Chair, Schizophrenia Fellowship Wanganui
Michael Lynch, Fieldworker, Schizophrenia Fellowship Nelson
Chas McCarthy, Capital Coast Health and Te Kaunihera, Wellington
Sandra McGill, Howick
Wayne Miles, Waitemata Health, Auckland
Robert Miller, Dunedin
Sue Nightingale, Healthlink South, Christchurch
Tony O'Brien, Australia and New Zealand College of Mental Health Nurses, Auckland
Heather Ottley, Dunedin
Murray Patton, Health Funding Authority Northern
Julie Pease, Healthlink South, Christchurch
Don Quick, Healthlink South
Jenny Robertson, Committee Member, Schizophrenia Fellowship Wellington
Diane Robinson, Co-ordinator, PROP (People Relying on People)
Elizabeth Rock, Reefton
Erihana Ryan, Healthlink South and Te Kaunihera, Christchurch
Margaret Setters, Auckland
Lynda Smith, Field Officer, Caring for Carers
David Stephenson, Healthlink South, Christchurch
Phyllis Tangitu, Lakeland Health and Te Kaunihera, Rotorua
Rees Tapsell, Mason Clinic and Te Kaunihera, Auckland
Jo-Anne Vaughan, Golden Bay
Cindi Wallace, Director, Schizophrenia Fellowship Auckland
Rob Warriner, Auckland
Andrea Williamson, Pathways, North Shore, Auckland
Tessa Westenra, Hamilton