

Family Inclusion in Mental Health Services: A Child and Youth Focus

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INTRODUCTION

The people who care for someone with a mental illness or addiction have a vested interest in the recovery of their loved one. Family or whānau are the most common support system for children, youths and adults seeking mental health care. Although importance of the relationship between a child or youth needing mental health care and his/her family seems obvious, it has not always been recognised as meaningful by mainstream mental health services. In Aotearoa/New Zealand and internationally new mental health policies have affirmed the family's status as a key stakeholder in mental health, and have proposed several benefits that should result from family inclusion in mental health services. Given that the relationship between a mental health service user and their family is often close, even if it is not always positive, and that an individual's mental health status can have far reaching consequences, the optimum outcome of a mental health intervention will also extend beyond the individual and enhance the wellness of the family affected by mental illness.

The Policy Framework for Family Inclusion in Mental Health Service.

The Mental Health Commission's 'Blueprint' for mental health and addictions services makes family inclusion a priority at all levels of service planning (Mental Health Commission, 1998). Standard 10 of the National Mental Health Sector Standards (Standards New Zealand, 2001) requires that families (as defined by the service user) are involved in mental health and addiction service planning, delivery, and evaluation. The mental health service is charged with the responsibility of taking steps to maximise family inclusion in these processes. New Zealand's national mental health policy documents (i.e., Te Tāhuhu, Te Kōkiri and Te Hononga) consider family inclusion essential in improving the quality and the effectiveness of service delivery (Ministry of Health, 2005b, 2006; Mental Health Commission, 2007). This emphasis reflects similar developments internationally, for example, in the United States, United Kingdom, Canada, and Australia. The main aim of He Korowai Oranga Māori Health Strategy (Ministry of Health, 2002a) is to achieve *whānau ora* by "*supporting Māori families to achieve their maximum*

health and well being” (p. 1). The family as a collective derives health benefits from family inclusion, and health outcomes are measured in terms of family well being. He Korowai Oranga Māori Health Strategy identified the highest quality service as being that which takes account of whānau views of mental health care into account.

Specific service delivery guidelines for New Zealand children and youth draw particular attention to the need to take an ecological perspective, and to see this group in the context of their relationships with people at home, school, and peer groups (Lumb, 2007; Ministry of Health, 2002b; Standards New Zealand, 2004; World Health Organization, 2005). The unique position of children and youth in society is that they are vulnerable and depend on the responsible adults in their lives to provide for their care and protection. Consequently the people assuming that care role are important in a child or youth’s physical and mental health. Although the nature and importance of a child’s connections with others will vary depending on his/her developmental status, a kaupapa of family well being or whānau ora is still considered relevant throughout childhood and adolescence. Whānau involvement in service design and evaluation is particularly emphasised for services providing for Māori children and youth (Te Rau Matatini, 2007) as it is consistent with Te Tiriti o Waitangi principles of partnership, participation and protection for Māori in health services.

The Current Review.

Under the Mental Health Commission Amendment Act 2007, the Mental Health Commission is mandated to advocate for the best interests of people with a mental illness and/or addiction, and their families. Within this context the Mental Health Commission has commenced a project initially exploring the role of families in child and adolescent mental health services. This project aims to promote the inclusion of families, whānau, and/or support networks in all levels of mental health service delivery. The current literature review is part

of the initial stage of the Mental Health Commission's child and adolescent family project. The objectives of this review are to consider the concepts of family described in current literature, and to better understand the benefits of family inclusion in mental health and addictions services. Family inclusion, for the purposes of this review, is focused on the processes mental health services undertake *with* families when providing care. Interventions provided *to* or *for* families, (e.g., family-therapy) have not been considered extensively. For the purposes of this review they are considered as examples of mental health care that have the scope to intervene with the family as a whole system.

Research examining the benefits of including family in mental health services for children and youth is relatively undeveloped. Therefore, while the specification for the current review required a primary focus on literature relating to mental health services offered to children and young people, it was not feasible to do this in isolation from the more general literature dealing with adult mental health. Within these boundaries particular attention was given to the potential benefits that could accrue from having family, however broadly defined, involved in mental health services. For this reason the emphasis of this review is initially on generic issues, many of which are drawn from and illustrated with references to services for adults. Following this we turn to a more specific focus on services for children and youth that includes information about both the processes and the potential outcomes/benefits of family inclusion. We also give some consideration to factors that may inhibit family inclusion in mental health.

Source Material.

The Mental Health Commission provided a number of references from adult and child/youth mental health literature from their own database searches. In addition, a specific search of the literature on *family inclusion* was undertaken using the key terms *family* and *mental health*, in combination with several

terms that denoted *inclusion* (e.g., involvement, collaboration, partnership, shared, integration). References were included for review if the title or abstract indicated that the content of the paper discussed family involvement in assessment, planning and delivering services, or any other 'collaborative' role. References were also included if they discussed the needs of families undergoing these processes.

Databases reviewed were those encompassed within EBSCO Research Databases (<http://web.ebscohost.com>), which includes PsychEXTRA, Psychology and Behavioural Sciences Collection, and the Australia and New Zealand Reference Centre. PsychINFO was also used. To ensure relevant New Zealand information was also gathered, a review of key mental health information websites was conducted. This included the Ministry of Health (www.moh.govt.nz), Mental Health Commission (www.mhc.govt.nz), The Werry Centre (www.werrycentre.org.nz), Paediatric Society of New Zealand (www.peadiatrics.org.nz), and the Families Commission (www.familiescommission.govt.nz). We also conducted a more general search of the World Wide Web to source relevant documents written by or on behalf of family organisations and agencies, and policies/procedures of mental health funders and providers.

We used RefViz 2.1, a reference visualization and analysis software programme, to search and categorise citations located on the PubMed on-line database. Using *family* and *mental health* as our base search terms (8,474 hits) we then added in additional search terms. Adding the term *inclusion* reduced the number of hits to 94, grouped within nine thematic categories. The most useful of these was the family-service-care category which contained 26 references. When the secondary search term was replaced by the word *partnership* the search generated 86 hits. Again, there were nine categories, four of which were clustered closely together. All references from these more detailed searches were reviewed.

GENERIC THEMES ACROSS ADULT AND CHILD/YOUTH MENTAL HEALTH

As indicated above there are a number of more universal themes and concepts associated with policy and practice, both proposed and actual, associated with family inclusion. While these will be expressed differently in relation to children and young people, the general principles remain broadly applicable to all groups. For example, while the legislative frameworks and clinical practice guidelines concerning privacy and informed consent may depend on age, the interface between consent, privacy and participation in service delivery remains an issue for consideration as a potential barrier to family inclusion. In this section we will focus on the more general themes associated with inclusion. These have been largely drawn from the adult domain as this is where most energy and action in support of family inclusive services has been expressed.

What is a Family?

Many domains of academic and social study include consideration of definitions of 'family'. It is not the place of this review to rehearse the range of social, cultural, economic and political conceptualisations of the family. Rather, supported by what follows, mental health policy has adopted a pragmatic, although not simple or uncontentious perspective, which views family/whānau as a group of people who *may* be 'related' by blood ties and/or legal bonds, but who form a community of concern in support of an individual at a given point in time. In most cases this will consist of an individual's traditional family members, but may also include other people depending on the nature of the difficulties being addressed.

Some formal structures to define or classify family groups focus on connections made by blood, or by legal procedures. For example, Statistics New Zealand uses a number of definitions of *family* to organise their census data. The primary definition of a family relationship is "*a relationship in which a*

person is related to another person by blood, registered marriage, civil union, consensual union, fostering or adoption” (Statistics New Zealand, 2006). The difficulty of this definition for mental health is that it does not encompass the degree of *importance* of these relationships. Blood or legality does not automatically imply that a relationship is positive and/or significant in an individual’s day-to-day life. A further difficulty is that it does not recognise those informal relationships within which longstanding friends, neighbours or other community members come to be the most significant ‘other’ within an individual’s life. That is, the neighbour who, for 20 years, has been considered a mother/grandmother, is accorded no formal status under this structure despite the experience and wishes of all those involved.

The concepts of family as defined in the mental health literature give credence to the individual’s right to define their ‘family’. The *Te Hononga 2015* document describes whānau as either a “*family unit*” or an individual’s “*chosen network of people*”, with each individual and each whānau defining their own family (Mental Health Commission, 2007). He Korowai Oranga Māori Health Strategy (Ministry of Health, 2002a) also goes beyond traditional definitions, noting that “*it is up to each whānau and each individual to define for themselves who their whānau is*” (p1). Some international perspectives follow a similar theme. Osher and Osher’s (2002) concept of family is that “*a family is defined by its members, and each family defines itself*”. They note that the term ‘parent’ can denote a legal caregiver, just as the term ‘guardian’ does in New Zealand, but it should not be assumed that these are the only people who care for and make decisions about a child. Other relationships of importance may be contained within adoptive, fostering or whangai situations, blended families, and non-custodial extended families. This broad definition acknowledges the diverse characteristics of important relationships and patterns of connection in people’s lives. While the right to define your own family group seems straightforward, in practice the concept is dynamic and there are many factors that may influence how a family group is determined.

Cultural roles may dictate who is appropriate to be involved when a family member is unwell, what action they might take, and when support outside the membership group is sought. But it is important to note that culture is not static, and this theme is reflected in the discussions of how families have changed over time and circumstance. For example, Walker's (2006) review highlights that the Māori concept of whānau encompasses a diverse range of modern family structures, but whānau principles (e.g., manaakitanga or caring) remain salient. Agnew et al. (2004) point out the danger of assuming that every person from a Pacific nation will want family to be involved even though there is a traditional family structure inherent in this cultural group. Some participants in their study expressed concern that stereotyping mental health services in accordance with island-born adult values would exclude New Zealand born youth consumers.

Medalie and Cole-Kelly (2002) are among a number of writers who suggest that the definition of family changes depending on the circumstances which prevail at the time of need. For example, within the medical sphere they identify three primary definitions of family, each of which influences the focus of care; biological family (associated with the genetic transfer of disease susceptibility and expression), household (associated with infectious disease transfer), and functional family (associated with the impact of chronic illness). These authors then detail four secondary expressions of the family which can, under certain circumstances, attain primacy through the inclusion/exclusion of individuals; the family at a time of crisis, the bereaved family, the cultural/religious family, and the relationship family (dealing with interactions and conflict). The key points of their discussion are that the dimensions of a 'family' change over time and according to the context, and that understanding the dimensions of the family is crucial in establishing the physician-patient-family health care team.

What Is Family Inclusion?

The origins of family inclusion in health vary between countries, consumer groups, and focus of the challenges to good health. Family inclusion as a practice has gained traction as a solution to systemic problems in services, such as the attempts in the United States to improve child and adolescent mental health services after Knitzer's (1982) report on the ineffectiveness of their systems at that time. It has also gained importance within the development of best practice, such as in the area of schizophrenia treatment where the importance of family has been acknowledged for many years. Knowledge and understanding of mental health difficulties derived from Western scientific methodologies continue to accumulate, and holistic or contextual models are now de rigueur for children and youth. Increasing recognition of traditionally holistic views of health, particularly from indigenous or minority culture groups (e.g., Māori models of health such as te whare tapa whā), have also led to changes in policy and practice. Although changes are occurring in many different areas, they are part of an overall paradigm shift away from traditional individualistic models of mental health care and towards more family centred practice. There is also a shift toward families being involved at both a service delivery and a service development level.

Family Inclusion in the Treatment of Schizophrenia. The origins of contemporary views of family involvement can be traced back to early work on the origins of schizophrenia, and more particularly the writing of researchers and academics such as Brown and Rutter (1966), Brown, Birley and Wing (1972), and Vaughn and Leff (1976). This research, which outlined the influence of family life on the course of schizophrenia, focussed attention on the role that family relationships can play in both the development of, and relapse into mental ill health. These data influenced a decade or more of research and service development which located the family as both the origin of serious mental illness, and the environment within which mental disorder was maintained. A number of studies (for example, Falloon, Boyd, McGill et al., 1982; Leff, Kuipers, Berkowitz et al., 1982, 1985; Tarrier, Barrowclough,

Vaughn et al., 1988) examined reductions in relapse rates associated with interventions with the whole family, although these results have not always been fully replicated (Jeppesen et al., 2005).

This research spawned two decades of family work, including family education, as attempts were made to understand and moderate the impact of the family. Treatment moved from being exclusively focussed on the individual to having a substantial emphasis on family involvement. Pitschel-Walz, Leucht, Bäuml, Kissling and Engel (2004) have provided one of the most definitive current reviews of family interventions in schizophrenia treatment. These researchers completed a meta-analysis of 25 studies and found that relapse rates could be reduced by up to 20 percent if family members were included in treatment, especially if this involvement lasted for more than 3 months. The health gains were superior to interventions that focussed exclusively on medication-only standard treatments, and were accrued across a range of family intervention formats.

Glynn, Cohen, Dixon and Niv (2006) analysed what it is about family focussed interventions which may assist in their efficacy. They suggest that while the content of the programme can be helpful in reducing family stress and burden, and enhancing family social support, there are a number of common features which are positive such as showing empathy for all family members, enhancing knowledge, assuming a non-pathologising stance, and teaching communication skills. They also believe that many of the underlying principles of family inclusion are consistent with those of the recovery movement, e.g., community based, emphasising personal rather than health service goals, instilling hope, and enhancing natural social support networks. Despite these positive attributes Glynn et al. suggest that family intervention programmes are still based within an old treatment paradigm in which the client is being treated for a 'chronic illness' rather than having a true recovery focus. They advocate for the further development of family interventions that, (a) expand the definition of the 'family', (b) enhance the matching of service user to a

range of interventions, (c) broaden the focus of research to include evaluations of the family members as a part of the care team, and (d) move family interventions into the mainstream as a routine part of interventions for mental health problems.

Stanbridge and Burbach (2007) make reference to a large body of research that shows that family/carer involvement in a service user's treatment can have a beneficial effect on clinical outcomes. They observe that this is demonstrated particularly clearly with family interventions relating to the experience of schizophrenia and in the reduction of family/carer stress and burden. These authors also reported on the implementation of a carer and family inclusion strategy which established a Carers and Families Steering Group to implement strategies to, (a) improve family information and support services, (b) increase family/carer involvement in the assessment and treatment process, (c) raise staff awareness and skill in working with families, and (d) influence policy development. It should be noted that the report only focussed on the staff training component of this initiative, which was generally rated as being useful. The training, which was delivered by family therapists, covered topics such as the relevance of family perspectives, an introduction to systemic ways of thinking, and convening and engaging families.

Family have been shown to have a role in the treatment of other adult psychiatric disorders as well. For example, McCubbin (2006) provides a useful summary of various aspects of involving families, friends and carers in relation to people diagnosed with a personality disorder. The primary focus of McCubbin's chapter is on the benefits of family involvement, and/or the involvement of significant others such as friends. However, as a precursor the writer identifies a number of barriers to inclusion such as secondary stigmatisation, and the perception that family carers may have contributed to the development of the service user's problems. McCubbin identifies three primary reasons for engaging the family/friendship network within the intervention. First, their knowledge of the service user means that they are

often holders of information which may be useful in informing subsequent treatment choices. It is noted that to date there are few studies which have looked at the overall utility of collateral data, particularly whether the availability of such data enhances diagnostic accuracy or leads to better outcomes. However, the writer does acknowledge that involving carers can also extend the assessment, giving access to information that may not be easily collected under more routine circumstances. The second reason for involving carers is to reduce their level of distress, which may not only be of immediate benefit to the family but can have secondary prevention value. These benefits can be accrued even if the identified service user is not involved, or if their own treatment is not progressing as planned. Finally, interventions with the family may enhance resilience and stability to a level where the service users own well being is enhanced. This can occur through the greater availability and reliability of family members, who are now better supported and less burdened. However, in closing McCubbin cautions the consistency of the research findings related to family interventions. He indicates that more informed families are not necessarily less burdened, less distressed, less depressed, or less hostile to the service user, also that it should not be assumed that giving information is necessarily helpful.

The current state of our knowledge and understanding about family interventions associated with schizophrenia is encapsulated within the Cochrane Collaboration review authored by Pharoah, Mari, Rathbone and Wong (2006). In their summary they caution that while family interventions may contribute to reductions in relapse rates and hospital admissions, and increase medication compliance, there is not yet conclusive evidence that the benefits of family interventions can be relied upon. They suggest that additional research trials are required with research participants who are receiving a family intervention as part of routine care rather than under controlled research conditions.

Despite the general enthusiasm for family interventions in the research literature it is necessary to exercise a degree of caution. Dixon et al. (2001) point out that there can be a difficult tension between consumers and families with respect to their needs and wishes, and that this can greatly increase the complexity of devising and managing an intervention. Interesting data on this issue was also reported by Fischer, Shumway, and Owen (2002) who conducted a survey examining the relative importance of desired outcomes and services among service users, family members and clinicians. They found that for the various pairings less than a third agreed on the relative importance of a range of outcomes (e.g., increased energy, improved social relations, decreased hostility, increased independent living), and no more than half agreed on service priorities (e.g., regular appointments with a doctor, information/education for family members, help finding employment). These findings suggested that effective family inclusion is a task involving a high degree of skill and commitment.

Family Inclusion in Collaborative Care. More recent literature focusses on family collaboration and partnership rather than a role limited to that of a recipient of care. There are several interesting examples of advocacy statements to this effect. New Zealand guidance notes on involving families have been available for practitioners in the mental health sector since 2000 (Ministry of Health, 2000). The purpose of these guidelines is to assist mental health professionals and families to work together. There is a particular emphasis on *doing with* families rather than *doing for* families, which denotes a partnership status. Principles inherent in the partnership are consultation, co-operation, mutual respect, equality, sharing of complementary resources and skills, and clear expectations. Examples of benefits alluded to by the guidelines include improving understanding of mental illness for the family, establishing process to assist the family with their own distress at the time, making assessment and intervention 'safe' for families to participate in, and improving the cultural appropriateness of the processes undertaken.

In the United Kingdom there are now a raft of policies and practice guidelines that require the provision of comprehensive mental health services, including the delivery of services to families (Department of Health, 2000, 2002). These frameworks outline the rights of carers to receive an assessment of their own needs. While this involves families within mental health services it does so by defining them as service users rather than partners in care. Such inclusion may well enhance outcomes for service users as it provides further support to their network of carers. However, it falls short of a mode of inclusion that challenges the inherent power imbalances traditionally part of patient-family-clinician interactions.

Ontario's Family Mental Health Alliance is an association of family organisations and individual family members working to support greater family involvement within mental health services in Canada. The Alliance's recent position paper, *Caring together: Families as partners in the mental health and addiction system* (Family Mental Health Alliance, 2006) provides a thoughtful summary of the support for inclusion required by families. Their rationale for additional and consistent family support and inclusion is based on the important role of the family in providing ongoing support for their family members with mental health difficulties, the negative impact on the wider family of mental health and addiction problems, the needs of families, and the perceived benefits of involving the family in care provision and decision-making. They cite the benefits of family support and involvement as being decreased hospitalisation and relapse rates, enhanced treatment adherence, increased recovery rates, decreased involvement with the judicial system, and financial savings to the mental health and addictions service systems. With these points in mind they challenge the Ontario state legislature to make provision for the enhancement of services to support families, facilitate the development of peer support and other family organisations, and involve families as partners in care and as partners in the systems that deliver that care. These latter two dimensions are of particular interest to the current review as they move away from the family as being involved in mental health

services as a recipient and focus on the family as partners in the care process.

Mottaghypour and Bickerton (2005) propose a specific model of care which conceptualises family involvement which they refer to as the Pyramid of Family Care. They developed their model as a general framework in recognition that there is no model to assist mental health professionals in incorporating the family into their everyday practice. The Pyramid of Care contains five levels. There are two base levels (I – Connection and Assessment and II – General Education) which comprise minimal involvement in care which can easily be offered to all families. Level 1 involves basic introductions, orientation and explanations of care packages, provision of documentation, the assessment of basic needs, establishment of a system of safety, and referral/liaison as needed. Level II incorporates reassessment and education. The remaining levels (III – Psychoeducation, IV – Consultation, and V – Family Therapy) are progressed dependant on need and include more specific and formal education on mental health issues and coping strategies, family-professional joint consultation with a specialist consulting team (innovative, but highly resource intensive), and formal family therapy aimed at facilitating change within the family interactional system. While there are novel components to this model it generally fails to see the family as a partner in the process of care, or as having a role in more systemic aspects of service decision making and provision.

Family Inclusion in Service Development. The experience that family members gain in dealing with mental health systems and in advocating for their family member equips them to play an active role in all aspects of planning, decision-making, implementation and service delivery. Simpson and House (2003) suggest that most advocates for increased user and carer involvement focus on the assumption that such involvement is good because it adds value by improving outcomes. However, they point out that such involvement can be seen as intrinsically valuable irrespective of any added

clinical value. These authors identify several factors which can hinder the involvement of both users and carers at the level of system design and implementation. These include, questions about how representative the views being expressed are, lack of interest from users and carers in taking on an expanded or representative role, tokenism or involvement in only trivial tasks, concern about the user's/carer's ability, high levels of stress, lack of experience, communication barriers, and role conflict. Simpson and House believe that these barriers do not render inclusion impossible, but do mean that innovative methods of inclusion have to be identified.

Simpson, House, and Barkham (2002) propose that each service development task is treated individually rather than assuming equal partnership in all aspects. This entails service users themselves deciding how much control they want over any particular service development goal. Some decisions would be expected to involve service users, whereas others would be expected to be left to the service providers' administration or management. Simpson and House (2003) propose an inclusion pathway where the service development goal is clarified, a mechanism of involvement for consumers/carers is chosen, potential barriers and solutions are identified, followed by implementation, monitoring and evaluation of the goal. The direct applicability of such a model to children and/or youth would depend on the goals set and how the requirements of the task fit with the developmental capabilities of a particular consumer.

Australia's National Consumer and Carer Forum (NCCF) also called for the development of a policy framework that accords both mental health service users and their carers a much greater role at individual, local state and national level planning (National Consumer and Carer Forum of Australia, 2004). Their view is that such involvement is essential if service delivery improvements are to be achieved. Like the report of Ontario's Family Mental Health Alliance (2006) the NCCF report lists as one of its core principles that consumer and carer participation should be promoted at all levels of mental

health care, recognising the needs of the consumer, and the separate needs of the family. They proceed to outline principles associated with the defining of roles for consumer and carer representatives, their selection and ongoing employment. The NCCF also makes explicit some of the guiding principles and specific practical examples which should be considered to ensure that adequate information flows between the service provider and consumers/carers.

Family Inclusion in Contextual and Holistic Models of Health. Changing trends in the conceptualisation of health have provided more reasons for mental health professionals to value family inclusion in practice. Western models of health and health care are increasingly acknowledging the importance of an individual's context, and thus his/her family. There are several examples of a contextual approach being taken in physical health, such as the community and family-based prevention projects aimed at stopping the rapid increase of obesity in New Zealand. The same trend is occurring in mental health. For example, in New Zealand the concept of recovery has been adopted by mental health as an ideal outcome. Recovery implies a broader definition of 'health' than the absence of medically defined symptomatology. Changing inpatient care is another example; a contextual and family-centred approach is now considered best practice for children and youth admitted to in-patient or residential settings (e.g., Regan, Curtin, & Vorderer, 2006; Walter, Petr, & Davis, 2006).

At the same time there has been increased recognition of more traditionally holistic models of health in an effort to design health systems that reduce inequalities experienced by many minority groups world wide. In New Zealand there are a variety of Māori (Ministry of Health, 2002a) and Pacific (Ministry of Health, 2005a) models of health that specifically accord families with a pivotal role in health. They provide a framework under which families can be included, and the Mental Health Commission suggests that the basic principles of these models, such as whānau ora, are universally applicable.

Two examples of relevant holistic models for New Zealand mental health professionals are described below.

Whānau is a keystone of health and well being for Māori, both individually and collectively. The concept of whānau in Māori models of health acknowledges the relevance of the family and extended family relationships. Whānaungatanga is the principle of interconnectedness or interdependence of whānau members. All models of Māori health (e.g., Te Wheke – the octopus, Nga Pou Mana – the pillars of empowerment, Te Pae Mahutonga – Southern Cross) emphasize these concepts (see Durie, 1994, for discussion). As interdependence of family, rather than independence, is seen as ideal family inclusion in a time of need is an expectation. One of the most widely known Māori frameworks of health that clinicians use in practice is te whare tapa whā. In this model the concepts of whānau (family and community), tinana (physical), wairua (spiritual), and hinengaro (mental and emotional) make up cornerstones of a house. Underpinning te whare tapa whā model is the idea that all areas of well being are interconnected. If there are problems in one, the whole system or house is affected.

Health models from Pacific Nations are also holistic, idealising a harmonious relationship between the spiritual, physical, emotional, and family aspects of life (Agnew et al., 2004; Ministry of Health, 2005a). Lui (2003) illustrates one Pacific Nation holistic model of health, couched within Samoan society where the basic unit is the family rather than the individual. The ideal within this culture is achieving positive and balanced relationships with your community (including their own and other families) and your environment. Lui defines health as “*the state in which a person’s physical, mental and spiritual needs are in balance and the person is able to meet their obligations to themselves, their family, village and community*”. Hence, the support of one’s family and community are critical in recovery.

There are more general models of Pacific mental health, of which the Fonofale model first put forward by Fuimaono Karl Pulotu-Endemann (see Agnew et al., 2004; Mental Health Commission, 2001; Ministry of Health, 2005a for discussion) is one of the most widely known. It encapsulates the commonly held values and beliefs of many nations. Similar to the *whare tapa whā*, the concept of a *fale* (i.e., house) is used to illustrate important components of Pacific people's health. The roof of the *fale* represents cultural values and beliefs in traditional methods of healing as well as Western methods, acknowledging that Pacific Peoples live within both worldviews. The foundations represent the family, which is the foundation for all Pacific Island nations. Family is broadly defined, and can be a nuclear family and/or extended family. Between the roof and the foundation are the four posts that connect culture and family. Three of these posts represent the spiritual, physical, and mental aspects of health. The fourth post is generic and relates to all other variables that may influence health (e.g., gender, social class and so on). The entire *fale* is surrounded by a cocoon that illustrates the relationship of people to their environment, to history, and socio-political contexts.

Decision Making and Responsivity in Collaborative Care.

Many reviews of adult service users strongly emphasised the need for clinicians to be responsive to what service users wanted and were able to do, rather than taking an all-or-nothing approach to inclusion. Feedback from adult mental health and general health service users has identified a continuum of involvement running from those who wanted to be passive recipients with respect to decision making about services, through to those who wanted to be active participants (Adams & Drake, 2006; Benbasset, Pilpel, & Tidhar, 1998; Cleary, Freeman, & Walter, 2006; Edwards & Elwyn, 2006; Edwards, Elwyn, Smith, Williams, & Thornton, 2001). Adams and Drake (2006) found better functional outcomes for service users that reported having expressed themselves fully and having received all the information they wanted, but preferences may vary within each family depending on what

aspect of service delivery is relevant at the time. For example, consumers expressed that the view that professionals taking the lead was preferred when a mental illness became more acute. Edwards and Elwyn (2006) found that dissatisfaction with a collaborative process was more likely in situations where the level of inclusion did not 'fit' with the service users' expectations at the time.

Wills and Holmes-Rovner (2006) called for more research that integrates general theories of decision making (e.g., information processing theories) into mental health in order to better understand how collaborative decisions are made between professionals and service users. Research indicates that peoples' preferences are determined using available information, values, and consideration of the life context of the stakeholders of the decision. Edwards et al. (2001) and Adams and Drake (2006) reported the views of adult consumers regarding the style of discussion context, process, and content that best facilitated collaborative work. From their perspective the process of decision making unfolds over a series of sessions, reaching a point where service users were certain the best choices had been made. Not allowing adequate time for difficult decisions to be fully evaluated was considered to be unhelpful. Service users preferred having the same professional, someone who they trusted and respected, involved in all discussions. Satisfaction was higher when the service user felt that they were respected by professionals and perceived that they made a meaningful contribution themselves. Having the opportunity to involve others in the decision making process, which included family, other professionals, and support from self-help groups, was valued. Both Edwards et al. and Adams and Drake found that the content of a shared decision making discussion should cover a service user's available options or choices, and should include the most pertinent information to their situation. Complete information (e.g., potential harm of treatment choices included) presented in an accessible manner (e.g., using decision aids) was also reported to improve the service user's ability to participate.

There is an indication from the adult literature that professionals and families may place a different emphasis on what outcomes are important to measure in identifying the benefits of family inclusion. Adult mental health evaluations have measured benefits in terms of cognitive improvement (e.g., consumer knowledge, accurate risk perception), desirable behaviour (e.g., compliance) and emotional states (e.g., satisfaction, confidence, and empowerment). Edwards et al. (2001) found that service users defined a 'good' outcome based on their emotional experience during the process of collaboration rather than its longer term outcomes. Collaboration was considered beneficial when it reduced anxiety, increased certainty, and increased consumer confidence in the choices made. There was little emphasis on cognitive and behavioural processes.

While these findings are not from child and youth mental health literature, the ideas about being responsive and having flexibility in inclusion frameworks are likely to be as important in that sector. What processes best suit families and young people participating in collaborative care has yet to be determined. However, there are some striking similarities between adult service user reports and family reports in a study by Blue-Banning, Summers, Frankland, Nelson, and Beegle (2004). Parents of children who have a disability were asked what made a 'successful' collaborative care relationship. Six themes that could potentially be measured in outcome studies were found, all of which emphasised the parents' experience of the clinician during the process: 1) good communication characterised by listening, 2) commitment to the family and family goals, 3) equity in decision making and service implementation, 4) the use of best practice recommendations, 5) being trustworthy, and 6) showing respect to the family.

SPECIFIC THEMES FOR CHILD AND ADOLESCENT MENTAL HEALTH

Consistent with the adult literature, methods for family inclusion in child and youth mental health services consist of families as recipients of interventions,

families as partners in collaborative care, and families as partners in service development. The frameworks presented are intended to engage families in service delivery and development in a safe and positive way, thus increasing the efficacy of mental health interventions. The expected benefits of family inclusion in child and youth services are also similar to those noted in the adult literature, such as increased satisfaction with mental health service, improved understanding of mental health for the family, and most of all, improved mental health for children and their whānau.

Systemic Therapy Frameworks.

Commonly cited examples of specific intervention modalities targeting the family systems are family therapy and multi-systemic therapy. In addition, many of the best practice or gold standard interventions for child and youth mental health also have a parent/caregiver component to them but are not specifically ‘family therapy’ (e.g., Barrett, Farrell, Dadds, & Boulter, 2005; Chronis, Chacko, Fabiano, Wymbs, Pelham, 2004; Deblinger, Steer, & Lippmann, 1999; Shortt, Barrett, & Fox, 2001). Adjunct interventions such as parent education and skill building are conducted alongside individual therapy for children and youth, and are beneficial for the types of problems seen in child and adolescent mental health services (e.g., Ollendick, 1998). It is important to note that inclusion in intervention at this level does not automatically mean that families are ‘partners’ in the process of service delivery. Clinicians can give families treatment suggestions (or directives) without including them in the assessment, case formulation, goal-setting, and treatment planning phases of an intervention. Inclusion, as defined in this literature review, relates to the broad range of processes undertaken in service delivery, such as decision making, which might lead to one of these gold standard interventions being tried.

Family systemic therapy as a practice started with the idea that an individual’s problems begin to make a different kind of sense when examined in the context of the nuclear and extended family. These notions have been

promulgated and explored since the early 1950's, although they were only integrated into more consistent models of therapy in the mid-1960s. Today there are a large number of formal models for conducting therapy with families, and most individually focused psychological therapies place at least some emphasis on consideration of contextual and systemic issues. It would be inappropriate to attempt anything more than the most cursory acknowledgement of the substantial body of theorising and clinical research regarding family focussed therapy here. However, Sprenkle and Blow (2004) have reported on their own analysis of factors common to all psychological therapies, and those that were unique to marital and family therapy. They concluded that there were only three factors unique to family therapies, these being, (a) the conceptualisation of human difficulties into relational terms, (b) the involvement of more people than the identified patient directly in treatment, and (c) expanded therapeutic alliances with therapy 'group' members. It should be noted that emphasis is placed on the involvement of additional participants (e.g., family) within treatment, referred to as the 'direct patient system', as opposed to the 'indirect patient system' where other people are not physically present during the treatment but may have a significant impact on therapy progress and outcomes. It seems that such indirect involvement was not claimed as a unique component of family therapy, nor should it be, as it more closely aligns with general family inclusion as conceptualised within the current review.

Shadish and Baldwin (2003) conducted a review of 20 meta-analyses of marital and family interventions published during the period 1985–1999. These meta-analyses reported the results of 908 separate studies covering a range of family therapy modalities and fields of practice. In general they found the studies to show that marital and family interventions, whether therapy or enrichment focussed, were more effective than no treatment, i.e., produced change in the desired target areas; that the therapies produced clinically significant results in 40 to 50 percent of recipients; that results were similar irrespective of the therapy model used; and that (unfortunately) we do not

currently know much about which are the critical factors in achieving good outcomes with family therapy.

Celano and Kaslow (2000) suggest that 'family therapy' is often the treatment of choice for culturally diverse client groups because it places additional emphasis on factors which provide a context for their current difficulties. This is not to suggest that environmental and social factors are not significant in the genesis of difficulties when the service user is from the dominant cultural grouping, rather that such factors should always be considered as relevant when working with individuals from 'minority' cultural groupings. Based on the premise that normal family functioning is socially constructed and evaluated, it is important that all therapists and services avoid classifying family interaction patterns as pathological simply because they deviate from arbitrary social norms, or attribute dysfunctional family patterns to culture. However, as Durie (2005) points out, Western diagnostic systems are dependent on the norms of accepted society, which in New Zealand is more influenced by contemporary American and European culture than indigenous Māori culture. Durie (2003) advocates for a whānau-based intervention model ('paiheretia' or relational therapy) within which the whānau therapist can engage the 'family' in a range of culturally compatible interactions with the aims of reducing risk, enhancing known protective factors, and assisting in the acquisition of skills.

The majority of research on interventions for youth who have substance abuse difficulties has investigated family based and multi-systemic approaches (Waldron, 1998). Parents have been included in various ways, such as within a family therapy intervention, as a recipient of parent training, education, and skill development. Deas and Thomas (2001) reviewed studies of adolescent substance abuse interventions, noting that there are very few well controlled research projects comparing different modalities. There are considerable problems with the studies available due to small sample sizes, high attrition, and inadequate outcome measurement. Despite this, Deas and Thomas' review indicated family systems based therapies are efficacious. The

main benefit appeared to be a reduction or abstinence from substance use for the youth in treatment, but other potential benefits had not been measured in the outcome evaluations.

Despite the general applicability of family therapy approaches to working with all mental health service users, and the special appropriateness of using these models or their derivatives in interventions with children, youth, and those from different cultural groups, the reality is that family therapy is not universally available throughout New Zealand. While introductory training courses (2-5 days) are available, there are very few opportunities for practitioners to engage in full length certified professional training in family therapy. Also, a review of the mainstream family therapy journals, including the Australian and New Zealand Journal of Family Therapy and publications from the Dulwich Centre (Adelaide, Australia) indicated that New Zealand-based family therapists are not researching and writing about their practice. So, while most mainstream mental health services may claim to provide family therapy to their clients this will only be available to a small minority of service users. Few mental health workers in New Zealand have extensive training in family therapy models, and the therapeutic processes can be too time-consuming to allow routine application. Therefore, formal family therapy is only delivered to a selected sub-set of service users where their presenting difficulty has been shown to be amenable to a family therapy intervention, usually in preference to a pharmacological intervention. This service position is similar to that reported in Australia by Wagner, Munt and Briner (2006) who found that the provision of family therapy was sporadic and tended to coincide with the presence of a worker who was both interested in and dedicated to this field. These authors suggest that the dominance of individual models of care and lack of an adequate skill base lead to family therapy not being available in many services. Unfortunately, this means that individual models of intervention prevail, thus reinforcing the cycle of inadequate service evolution.

Partnership Frameworks.

Partnership is prioritised in several of the child and youth frameworks of family inclusion (Lumb, 2007; Osher & Osher, 2002; Stroul & Friedman, 1986, 1988). Partnership supersedes the concepts of participation, involvement or consultation as the latter three imply family/whānau are being given an opportunity to be involved, but the decision making power still rests with the agency. In contrast, partnership implies a two way relationship characterised by collaboration, respect and equality between services and stakeholders. Within a collaborative framework two or more stakeholders work together to achieve a common goal (DeChillo & Koren, 1994). Service users or tāngata whaiora and their families are active participants in all decisions and tasks undertaken on the path to recovery (Mental Health Commission, 2007; Ministry of Health, 2005b, 2006). This represents a move away from a traditional care hierarchy where the professional is assumed to have greater knowledge and power to decide what is best. Instead the role of the service provider is that of a consultant for the family – providing information and an opportunity to discuss options and preferences for care in a shared decision making process (Adams & Drake, 2006; Benbasset et al., 1998; Hodges, Hernandez, & Nesman, 2003).

Overall relatively little research has been conducted on the actual process of making families partners in child and youth mental health care. DeChillo and Koren (1994) reference the most commonly suggested components of a collaborative care process between clinicians and families; “1) *a caring non blaming attitude toward the family*, 2) *sharing information*, 3) *recognition of the family as a key resource*, 4) *recognition of the limits of other responsibilities*, and 5) *shared responsibility and power in the relationship*” (p565) In a study of adult mental health social workers, DeChillo (1993) found that higher levels of collaboration in care was predicted by the social worker’s attitude towards family inclusion. Inclusion improved when families had a positive perception of the social worker’s skill, mutual goals had been identified, social workers demonstrated positive regard for family strengths, and the two parties had

regular meetings. Collaboration predicted greater family satisfaction at the point of discharge. DeChillo and Koren (1994) subsequently investigated similar predictors of clinician and family collaboration in child and youth mental health. Families in child and youth services identified four key elements of a collaborative relationship. These were having a supportive relationship with the professional, having practical service arrangements, open exchanges of information, and sharing the process of gauging intervention success and failure.

Osher and Osher (2002) described a paradigm shift from '*cheerleading*', where families provide feedback only, to '*leadership*', where families are fully included and can use their experiences to set the goals and mechanisms for intervention. The focus of service delivery differs between the two paradigms. For example, the source of solutions in a provider-driven model is the professional and agency, whereas in the family-driven model it is the child, family, and their support team. Families are credited with expert knowledge from their experience. The benefits of family inclusion in the provider-driven model are based on agency function and symptom reduction, whereas in the family-driven model outcomes focus on quality of life and goals of the child and family. The authors do note that these two models can be thought of as anchors on a continuum, with actual practice falling somewhere in between.

It is not sufficient to simply have a mandate that families are to be included in mental health service design and delivery. More specific frameworks that provide guidance for all stakeholders (i.e., professionals, children, youth and families) are more likely to facilitate family inclusion, and thus collaborative care (Cleary et al., 2006; Cheney & Osher, 1997). Two examples of specific frameworks idealising the principle of partnership with families are illustrated below. The *Participating in Partnership* Framework has been included in this review as it is from New Zealand, and so has direct relevance to work

conducted here. *Systems of Care* has been included as it is the most well evaluated framework that is actually applied in clinical practice.

The Participating in Partnership Framework. The New Zealand guidelines for family inclusion (Ministry of Health, 2000) has one paragraph pertaining to work with children and youth. More recently, a New Zealand model of collaborative care, *Participating in Partnership* (PiP), has been put forward by The Werry Centre (Lumb, 2007). PiP uses the metaphor of a ladder to conceptualise the various levels of participation between services and families. Tokenism or ‘window dressing’ is at the bottom of the ladder, and occurs when families are included in services, but their contributions are ignored. The next steps are *informing*, followed by *consulting* and then *collaboration*, increasing the degree of partnership between the service and families. At the level of collaboration staff are informing, consulting with, and engaging with the family in all aspects of care. The top of the ladder is initiative support, or *partnership*. This is the ideal relationship where families and advocates/advisors for families take active roles in development of the service itself. However, in a review of CAMHS Services only 44 percent of services reported they have consumer advisors, and 45 percent had a family member involved at this level (Burdett, Birkin, Kent, & Ashton, 2004).

The Systems of Care Framework. In the early 1980’s a seminal review children and youth in the United States mental health system found significant service delivery problems (Knitzer, 1982, 1993; Knitzer & Cooper, 2006). Practice was not responsive to the needs of children and/or their families. For example, children experienced repeated evaluations rather than treatment, and ineffective out-of-home placements within both medical and welfare systems. The Child and Adolescent Service System Program (CASSP) was initiated in response to this review. It aimed to promote change at all levels of the child and adolescent mental health systems via the mandating of a major conceptual shift in professional conduct around child and adolescent mental health care. Up to that time families had been seen as having a direct causal

role in the child's problem, but under the CASSP paradigm professionals were required to re-think the role of families. They were challenged to focus on the families' strengths, and to form a partnership with families in caring for children and young people.

Under CASSP a series of projects using the System of Care framework have been funded. This approach aims to provide an individualised community-based service attending to relevant family and systems issues (Stroul & Friedman, 1986, 1988). Keeping services *'family focused'* is one of eight key principles of Systems of Care. This is defined as *"recognition that a) the ecological context of the family is central to the care of all children, b) families are important contributors to, and equal partners in, any effort to serve children, and c) all systems and service processes should maximise family involvement and address family needs"*. Systems of Care considers the well being of the child's family by making a strong commitment to interventions that preserve the family unit itself when possible. An example of this is having the child or youth stay at home and with paid family support services rather than use secondary care residential services.

Within Systems of Care collaboration is defined as *"bringing families to the table with providers and administrators as equal partners in the process"* (Osher, Defur, Nava, Spencer, & Toth-dennis, 1998). A variety of intervention options are available as the Systems of Care model is focussed on the process of planning treatment rather than having a specific treatment approach. Intervention decisions are made in a collaborative team consisting of local community providers and people important in the child's life (e.g., family, school). Depending on the developmental status of the child, and their mental health needs, the child or youth may be part of the care team (Osher et al., 1998). As expressed in the Werry Centre's PiP model, Osher et al. note that their definition of collaboration moves away from 'serving' families, and towards an expectation of working together as equals.

A large part of the Systems of Care framework is focused on interagency collaboration but family collaboration is considered essential within this. Within this domain the family's role changes from that of a consumer receiving a service to that of a consumer developing a service. Four roles for family are proposed; 1) families as team collaborators, 2) families as advisers and advocates to the service, 3) families supporting one another, and 4) families providing community-based services themselves. Jivanjee and Robinson's (2007) investigation of family participation in the implementation and evaluation of Systems Of Care projects found families had been involved in advisory groups, project development, survey/measurement development, interviewing and training other families who were also service users, data analysis and research dissemination. The number of tasks varied across projects, as did the level of influence families had over decision making.

The actual process of moving from provider-driven service to family-driven service is dynamic and dependent on individual as well as political contexts (Osher & Osher, 2002). Hodges et al. (2003) reviewed nine System of Care sites that were undertaking to actively build family collaboration into their service delivery processes. Overall this process was reported to be slow, despite considerable effort. The authors took the information obtained from service providers and service users, and proposed a five step model of the development of collaboration. It begins as individual action (e.g., one agency, single client focus), moving through to true collaboration (e.g., multiple agencies and families as full partners in service delivery). Brannan, Baughman, Reed, and Katz-Leavy, (2002) and Foster, Stephens, Krivelyova, and Gamfi (2007) evaluated adherence to the principles of Systems of Care in trained mental health sites, and compared the findings to untrained care sites. They looked at family focus in the infrastructure domain (e.g., organisational structures that support service delivery) and the service delivery domain (e.g., processes involved in planning and implementing interventions for children and families). System of Care sites were rated as providing more family focussed care than the comparison sites, indicating these projects do operate

with fidelity to the project principles. The authors note that the comparison sites did aspire too many of the same principles as Systems of Care, but as they did not have the funding, the actual practice of those values was not as consistent.

Benefits of Family Inclusion in Child and Youth Mental Health.

What is known about the benefits of family inclusion greatly depends on what evaluators and researchers have measured in their outcome studies. At this time there is no application or investigation of the New Zealand PiP model. Therefore, international literature provides the best information on the benefits of family inclusion in child and youth services. Unfortunately even in this literature rigorous outcome evidence on the benefits of family inclusion in child and youth mental health is scarce. What outcome data there is consists mainly of family report, in the form of verbal feedback, satisfaction rating scales, and psychometrics measuring the general emotional and behavioural well being of youth. Given the gap between proposed and proven benefits of family inclusion, there may well be additional benefits that have yet to be explored. A key example of this is the impact of family inclusion on the well being of the whole whānau, which was not reported in any of the studies reviewed including the extensive Systems of Care reviews.

The most commonly anticipated benefit of collaborative care or partnerships with families is improved quality of care. Family inclusion is seen as a mechanism of therapeutic change, which leads to better outcomes in mental health. (Fristad & Sisson, 2004; Knitzer, 1993; Simpson et al., 1998; Simpson et al., 2002; Simpson & House, 2003). Osher and Osher (2002) suggested that when a child and family are included in the development of a service plan, greater understanding and agreement over treatment components can be achieved. Hodges' (2004) review of mental health assessment highlights that a lack of consensus between clinicians and families about the goals of intervention is a likely predictor of drop out. Osher and Osher (2002)

emphasised the importance of the family's belief that an intervention plan supports the strengths, needs, values and culture of the family. This belief is thought to facilitate family engagement in tasks such as attendance at appointments, administering medication, and completion of intervention homework tasks. As families engage in the process of intervention, improvement in mental health is expected to follow. In addition, potential benefits of delivering intervention with families are based on the premise that all families have strengths and skills which can be harnessed to support and enhance therapeutic processes. Given these strengths, all families have the potential to make a valuable contribution to the care of their child or youth. For example, a particular strength of families is the knowledge they have that can inform clinical practice. Families can provide valuable assessment information as they are the most knowledgeable about their child as an individual. However, this is not the only type of beneficial information families have. Fristad and Sisson (2004) highlight that both consumers and consumer support groups have an *'insiders'* perspective on the experience of mental health services. This can help professionals to focus on what is salient to the family in terms of needs and support.

Research Illustrating the Benefits of Family Inclusion. Hoagwood (2005) conducted a review of empirical studies that examined family involvement in child and youth mental health. Only 40 studies met Hoagwood's criteria for scientific rigour. Experimental studies and studies that identified potential mediators of involvement (e.g., empowerment) were examined. Due to the lack of studies in mental health, other health papers were also included. Hoagwood found three distinct groupings of evidence in the literature reviewed; 1) studies where families were the recipients of inclusive services (e.g., education, family support), 2) studies where families were co-therapists, and 3) studies where the mediators of inclusion were examined. All sets of studies indicated potential benefits for symptom reduction, but did not provide more conclusive evidence.

Several investigations have been undertaken of the Systems of Care model making this the most evaluated family inclusion framework. Many of the concepts in this model have been described generally, and how they are applied varies considerably from project to project. More flexible guidelines enabled the concepts to be adapted to the needs of the diverse range of families seen in the projects, but it also made the task of evaluation more complex. Furthermore, Systems of Care interventions were developed and tested in the field rather than under the 'gold standard' practice of rigorous clinical outcome research (Friedman & Hernandez, 2002). Despite this, Friedman and Hernandez point out that the Systems of Care Evaluations provide an opportunity for learning about the delivery of this type of service in the real world. For example, identifying the problems that can occur in the system, as well as the solutions that can be applied, goes beyond the simple question of whether an intervention 'worked' or not.

Manteuffel, Stephens, and Santiago, (2002) investigated the two-year outcomes for children seen in the first 22 Systems of Care Projects. Children presented with attention deficit hyperactivity disorders, conduct disorders, depression or dysthymia, and to a lesser extent, anxiety and adjustment disorders. The majority were described as having experienced high risk factors in their lifetime (e.g., sexual abuse, suicidal ideation). From intake to two years there was a statistically significant improvement in problem scales scores and functionality scores as measured by standardised psychometrics for childhood emotional and behavioural problems. Other benefits found were more stable living arrangements, and improved school performance and attendance. Reduced contact with law enforcement was found by Manteuffel et al. and also in a later review of systems of care by Foster, Qaseem, and Connor (2004).

Graves (2005) investigated families' experience of the Systems of Care model related to consumer satisfaction and improvements in child behavioural and emotional symptoms. Families who rated their service as closely adhering to

the Systems of Care philosophy were more satisfied with their intervention. Perceived adherence to the Systems of Care model also predicted improvement in both internalising (i.e., mood or anxiety difficulties) and externalising (e.g., aggression, rule-breaking, inattention/hyperactivity difficulties) behaviour for the children over a 12-month period, indicating some benefits in terms of symptom reduction. Foster et al. (2007) subsequently evaluated similar clinical and functional outcomes for children seen in Systems of Care, and compared those to children seen in other services. Results from standardised psychometrics measuring children's mental health and behaviour showed that individuals at all service sites improved over time. Statistical corrections aimed at compensating for the differences in population characteristics between System of Care sites and their controls were used to more accurately compare the sites. Overall Systems of Care did achieve better results, with one matched pair finding statistically significant differences.

In the United Kingdom, Walker (2003) conducted a qualitative evaluation of the effectiveness of a community-based family-support team, where the intent was to reach families who may have traditionally found it difficult to access helping services. These services were designed to be inclusive, and in the evaluation families reported that they had helpful choices offered and were encouraged to negotiate what support they preferred. Parents reported positive outcomes in their own capacity to discuss and negotiate support. They described an improvement in their understanding of their child's difficulties and developmental needs. Concurrent positive changes in their child's behavioural and emotional well being were also noted. Walker included the target children in their focus groups, asking for their perspective of the service. They liked being able to make choices, and being listened to as part of the intervention process.

Staudt (2003) conducted a review of interventions designed to increase service access and improve treatment retention. In general, providing family support while clients were on the service's waiting list improved the rate of

attendance at first appointments, but not subsequent appointments. Staudt also observed that barriers occur at multiple systemic levels, which can change over the course of intervention so need to be constantly re-assessed. The rate at which families engage in and stay in mental health services can be improved when services promote empowerment and self-efficacy for families (Hoagwood, 2005; Reich, Bickman, & Heflinger, 2004). These processes are also thought to facilitate family inclusion in assessment and intervention by breaking down barriers to service participation traditionally identified by parents/caregivers. Taub, Tighe, and Burchard (2001) found that decreases in children's externalising behaviours were linked to improvement in family perception of empowerment within their mental health service.

Much of the work on family inclusion has been conducted outside mental health, in areas such as disability (e.g., learning disability, autistic spectrum disorder) and chronic illness (e.g., diabetes, obesity) (Hoagwood, 2005). Caution should be taken when generalising across the literatures, however there is some overlap between the areas and the research findings reported may have implications for family inclusion in mental health. Overall reviews of family studies in these areas conclude that family inclusion has considerable potential to enhance outcomes, but there is no *consistent* pattern of results that family interventions are better than individual interventions (Martire & Schulz, 2007).

The Role of Moderating Variables in the Benefits of Family Inclusion. Overall the outcome studies reviewed in the child and youth literature indicate that family inclusion is not a 'one size fits all' approach. Several reviews have highlighted the need to consider each problem set, each family system, and each person in it as unique. Lefley (1997) summarised several studies indicating that family strengths and needs differ in accordance with the type of mental health concerns, the child's stage of development, and parent/caregiver stage of life, all within their own cultural context. Further still, each person in the family had different strengths and needs depending on

their role in supporting a family member experiencing mental illness. Similarly, Hoagwood's (2005) review of processes of involvement found several potentially important moderating variables. The relationship between the family and the service provider impacted on outcomes, but the effect depended greatly on the type of problem, at what stage of therapy the data was collected, and whether specific or global outcomes were measured. Martire and Schulz (2007) highlighted some moderators that are likely to influence the impact of family inclusion on outcomes in chronic illness. Family interventions were more likely to be successful when the full participation of relevant family members was achieved and the burden of illness on the family was addressed.

WHY FAMILIES ARE NOT INCLUDED?

While achieving collaborative working relationships with service users or tāngata whaiora and their families is an ideal in all mental health work, there was a theme of inconsistent application in practice. Surveys by The Werry Centre and the Mental Health Commission have shown that family inclusion is not yet consistent in clinical practice in New Zealand (Burdett et al., 2004). Riebschleger (2005) surveyed clinicians about their pattern of contact with families in the United Kingdom. The median number of hours spent with families of consumers was 2 per week. The types of tasks were those aimed at gathering information or managing a crisis. In contrast, very little time was spent in family inclusive tasks at an individual or service level. The clinicians with higher family contact hours were those who did child and youth work as well. Singh and Curtis (1997) reviewed routine family assessment and planning team meetings, which involved professionals, parent representatives from the service, and the actual families undertaking interventions with their children. The level of family friendliness varied depending on the task at hand. For example, in 100 percent of observations families were treated in a courteous manner, but in only 37 percent of observations families were allocated time to talk to the group. These findings raise the question of why

families are not included, particularly because there are a number of factors supporting this practice.

Fadden (2006) suggests that in the United Kingdom there are a number of factors supporting the inclusion of families within mental health interventions. These factors are the availability of good empirical evidence for efficacy (meta-analyses and reviews), supporting policy/practice frameworks (Department of Health, 2000, 2002; National Institute of Clinical Excellence, 2002), and good practice (needs of the family, common sense, moral imperative). However, despite evidence supporting the value of having family involved as a part of mental health treatments there are factors associated with the three systems involved (family/service user, clinicians, and the service organisation) that challenge inclusion. Fadden suggests that both service users and families are disempowered by hierarchical organisational systems that place the clinician in the position of authority, and that this may be compounded by a prior history of unsuccessful dealings with health practitioners and fear of the negative consequences of making a complaint. The way mental health problems for children are traditionally conceptualised by clinicians has promoted a sense of stigma and discrimination, which left families feeling blamed (Knitzer, 1993; Lloyd & King, 2003) perpetuating the hierarchy and power imbalance. Fadden's position is that for change to occur, that is, for services to become more family focussed and inclusive, it will be necessary to effect change at the level of the service user/carer, practitioner, and organisation.

Lack of a goodness of fit between the family's expectations of a service and what actually happens poses a challenge to a collaborative care process. As noted above, service users appreciated a continuum of inclusion rather than an all-or-nothing approach. Consequently in some circumstances families may be unwilling to participate in a particular mental health service. Differing needs and wishes between service users, those responsible for their care, and clinicians is a commonly raised challenge (Cleary et al., 2006). Lloyd and King

(2003) noted that there are real conflicts of interest between service user and families which can result in a unilateral decision made by the clinician in the perceived best interest of the service user. In Riebschleger's (2005) survey of the mental health clinicians, 58 percent indicated that unreasonable behaviour on the part of a family member was a barrier to inclusion. Twenty-nine percent of clinicians had experienced family members as adversarial. Examples of unreasonable or adversarial behaviour were not given in the paper.

In chronic illness, the unwell person themselves may see family assistance as negative (e.g., interfering or controlling) (Martire & Schulz, 2007). For example, well intentioned family support can also result in individuals becoming physically inactive or dependant if families do every task for them. Martire and Schulz's review suggests that traditional family interventions may be better replaced by those that promote '*autonomy support*' – an approach characterised by warmth, empathy, understanding, good communication and a range of options for making health behaviour change, and '*social control*' – which involves efforts to motivate, model, reinforce, use logic and point out the positive consequences of healthy choices. This is only beginning to be explored in health, and evidence for utility in child and youth mental health is not yet available.

Although the ideal is to have families involved, it needs to be acknowledged that this can be a daunting experience for families. Families may be asked to participate in forums that are designed for clinicians, complete with procedures and jargon that is unfamiliar to them (Lumb, 2007). This is one example of a scenario where families may be left feeling intimidated rather than comfortable to put their view forward.

Families face the challenges of requirements of work while also caring for a child or youth experiencing mental health concerns. Inclusion can increase the amount of burden on families who are already in a high demand situation. In a

review of families employed as consumer representatives Jivanjee and Robinson (2007) identified the need to have flexibility in employment arrangements so they could manage their commitment to the mental health service and their own family needs. Examples of this were flexible work hours, and tools such as laptops and cell phones that allowed working from home. Family representatives in Jivanjee and Robinson's review also reported that the service development work affected them emotionally, making the work more challenging. Full integration into the team via regular contact was thought to facilitate 'mutual learning' between families and professional staff. This approach was proposed to help evaluators and family members alike in learning to manage the emotional impact of their work.

The 2005 stocktake of Family Advisor positions completed by the Mental Health Commission found that less than half of the 21 District Health Boards employed a Family Advisor. Their role varied, but generally included acting as a consultant/advisor to management, providing peer support to families, and advocacy. The report outlined a concern that most Family Advisors had received little specific training in their roles and many operated with little or no supervision. However, perhaps more critical is that few clinicians saw the Family/whānau Advisor role as being important. The authors of the report provide a useful summary of the themes and issues raised in their investigation. A number of these were associated with resources (i.e., unmet need, not enough time or staffing, lack to training). However, with respect to the current review it is the issue of role definition that may have longer term significance. Specifically, should the focus of the Family Advisors should be primarily on advocacy and support for individual service users and their families, or on organisational issues such as service development, policy and planning, quality improvements, complaints and audit. If this is a dilemma for family members who are employed in an advisory capacity, it may be unrealistic to expect a similar level of commitment from family/whānau whose primary motivation is obtaining the best possible outcome for their own family member.

It is not only the service user/family side of the relationship that may struggle with family inclusion. The attitude of the individual clinician toward inclusion has been found to be the strongest predictor of whether or not a collaborative care process is followed (DeChillo, 1993; Lloyd & King, 2003; Lumb, 2007) highlighted that the culture of a service is pivotal in how its practitioners behave. They advocate for top-down role modelling of the collaborative relationship, and in-service training for all new staff. Genuine acceptance that the family has the right to inclusion, and may enhance services for their child, will help to avoid service tokenism. Fadden (2006) emphasises the need for on-going professional training and supervision with respect to family inclusion, but also suggests that such activities need to be valued by professional groups and employers, and that adequate time and resources need to be allocated to complete the additional tasks that follow from the adoption of a family inclusive perspective.

Kass, Lee and Peitzman (2003) also suggest that mental health practitioners seldom collaborate with families despite evidence, at least within the care of those with schizophrenia, that this can be beneficial and enhance outcomes. The research reported by these authors relates to training initiatives developed by the *National Alliance for the Mentally Ill* to educate mental health workers in family engagement. They surveyed 76 courses using a range of questions related to attitudes towards families, practice change, barriers to collaboration, and usefulness of the training. The results show that the most commonly indicated barriers to family involvement was lack of time, conflicted feelings about treating the client versus the family, and a belief that family involvement can be harmful to clients. The least commonly cited reason was lack of organisational support for family work. The course attendees were also asked to rate what they thought were the barriers for families. The most commonly perceived barriers were that the family had lost hope or given up, the stigma of mental illness, feelings of guilt or shame, and that the service user doesn't want the family involved. Cost, cultural barriers, and lack of time were not perceived as barriers. It is interesting to note that the authors made

little of systemic barriers to inclusion, although it is unclear whether this was a significant focus of the survey format being used. They conclude,

“Professionals of mental health care must truly move beyond the status quo to look realistically at the barriers to forming working relationships between professionals, families, and clients. There is an urgent need to recognize that all people are experts in their own right and have much to offer in the way of meeting the challenge of mental illness.” (Kaas, Lee, & Peitzman, 2003, p. 753-4).

Fadden (2006) also observes that there may also be organisational barriers to family inclusion, such as adherence to traditional individual models of care, and a funding system that does not recognise or resource family inclusive services through the provision of appropriate training and workload configuration. This can result in the needs of families being given a low priority and the notion that family involvement is only important in some cases. Fadden also suggests that many health services are becoming change-weary as ‘innovations’ are adopted at an overwhelming pace. In response to this Fadden emphasises the importance of management and organisational understanding and support for system change which allows for family inclusive services. Such change should be planned carefully, implemented sequentially, fully resourced, and evaluated. It is acknowledged that such change cannot be made quickly, but requires time and persistence; it is not the realm of the ‘hero innovator’.

Supporting this idea, Adams and Drake (2006) found that even clinicians who believed in a shared decision making process found this difficult to apply in a medical setting with adult patients. Similarly, the key barriers to family contact for the clinicians in Riebschleger's (2005) study were organisational. Lack of time available for the clinician's to do family inclusion tasks, the perception that family inclusion was not seen as important by the management staff at their service, and regulations such as restrictions on sharing of consumer information were noted by half of the respondents. Edwards and Elwyn (2004)

also found that lack of time was a key factor affecting patient involvement in the medical sector, and was more pivotal than specific training.

Family members and services/organisations report different goals in service evaluation processes. Family representatives in Jivanjee and Robinson's (2007) study described traditional evaluation processes as being focused on the need to provide evidence for political and funding purposes, with the idea that increasing resources via these systems would benefit families over time. In contrast, some family members wanted participants in the evaluations to benefit from participating in the process of evaluation itself. Resourcing has also been found to impact on the inclusion of families at a service implementation and evaluation level. Jivanjee and Robinson's participants highlighted that budget allocations dictated whether families were fully included via employment as a team member or partially included via an advisory position with stipend.

Privacy.

Health information is subject to ethical guidelines and legal regulations that protect a person's right to privacy. When practising within a family inclusion framework, privacy principles must be integrated into a collaborative care process with the individual service user and his/her family (Cleary et al., 2006). Fear of breaking the 'rules' of confidentiality or privacy can increase clinician's reluctance to work collaboratively. Strict adherence to these 'rules' can be seen as a deliberate obstruction to and exclusion of families from the process of care. In the case of child and youth consumers, confidentiality is also seen as important. Roose and John (2003) highlighted children wanted their families to be involved in their treatment but were also concerned that this would impact on the confidentiality of what they talked about. Children are in a uniquely vulnerable position due to the power imbalance between themselves and the systems around them. Part of the clinician's responsibility is to ensure that the child or youth's views are also considered in service

provision. Families may have different views and different needs to their child or youth, which also need to be taken into consideration if assessment and treatment decisions are being made collaboratively.

NZ guidance notes state that most aspects of working with families are not prevented by health information and privacy legislation (Ministry of Health, 2000). Even without the service user consent, families are still able to be involved with the service itself. For example, they can access non-personal information, such as educational materials about mental illness and information about support groups that may be of assistance to them. Gaining informed consent to share information is a 'process' not an 'event'. The view of the *tāngata whaiora* may change and so there is a need for constant reassessment of the privacy requirements of a service user.

Bogart and Solomon (1999) provide a brief summary of the privacy concerns within the American mental health service environment. They exemplify practitioner concerns by strongly cautioning against family involvement that may compromise the rights to privacy of service users, who may already have a history of infringement of their rights. However, these authors also support the principals of family involvement. Their response is to provide brief guidelines for the development of appropriate procedures and training to guide practitioners in this area.

Training.

The literature notes a dearth of training experiences that would up-skill new clinicians to meet these challenges and work *with* the families of the children they are trying to assist. Insufficient training for both current and upcoming clinicians increases the likelihood that the principles of partnerships with families will not be used in a clinician's day-to-day practice (Lumb, 2007). Clinicians trained in family focussed practice have been shown to apply this skill set more often than those who have not been trained (Hernandez, 2001).

Despite the seemingly inherent impact of training on practice, only 10 percent of clinicians Riebschleger (2005) surveyed saw a lack of skill as a barrier to family contact in day-to-day work tasks. The issue of training is not restricted to clinicians. Another barrier to employment Riebschleger noted was finding a family member who had the relevant service development skills, such as evaluation skills. The current benchmarks for salaried positions were based on academic qualifications, rather than the set of skills and experience that a consumer perspective would contribute to a team. Training for families had been undertaken to address these issues in some cases.

Kina Families and Addictions Trust was established in New Zealand in 2002 with the express aim of supporting the development of family/carer inclusive services for those with addiction difficulties. One focus of their work has been the development of practice guidelines for those working with couples, family and whānau. The resulting document, *Family Inclusive Practice in the Addiction Field* (Kina Families and Addictions Trust, 2005) is an excellent resource which guides practitioners through the general principles of family inclusion. In addition to providing background material on family inclusion, the document also outlines a range of basic skills to assist in working with couples, families, whānau, and significant others. While no data is yet available about how the guidelines are being used they have the potential to form a useful foundation for professional training and practice development.

SUMMARY AND CONCLUSIONS

The overarching theme across the adult and child/youth literature is that family/whānau has a critical role in the mental health of their loved ones. Definitions of family are dynamic, leaving the person seeking mental health care to decide who constituted their 'family'. The significance of relationships was more pertinent in who was included in a 'family' than legal or blood ties. However, in the case of children, the adult who fulfils the legal role of care and protection is likely to be very important. Although the nature of the child or

youth's relationship with parents or caregivers changes with his/her age and developmental status, they continue to be involved in mental health care in some way. In reality it is those within the family as traditionally conceptualised who are the most common carers for children, youth, and adults with a mental illness. The interdependent nature of family relationships means the negative impact of mental illness affects them too.

Family inclusion as a concept was found to be prevalent in many areas of mental health literature. It is mandated in mental health policy, both internationally and in New Zealand. It is established in guidelines and best practice recommendations as being a necessary element in understanding and supporting children and youth who are experiencing mental health problems. To a lesser extent there are frameworks that provide more specific models for how families can be included. The key theme in all of these documents is the development of a partnership between professionals, children and youth, and their families/carers. Partnership is achieved when families are included in all aspects of service delivery, including decisions made about the goals and processes of any interventions undertaken with their child and/or themselves. Ideally the partnership also extends to service development where families who have experienced the current mental health systems provide their perspective on how the needs of service users can best be met.

The proposed benefits of family inclusion fall under two main themes. Firstly, there are the intrinsic benefits of the process itself. Via family inclusion at both a service delivery and service development level, families are exercising their right to have influence over the systems that directly affect their own and their child's life. They are also taking responsibility for the care and protection of their child as is appropriate for adult family members. From this perspective the benefit of family inclusion is good ethical practice, and as such should be sufficient to motivate professionals to engage in this process. Adult service users reported that the emotional benefits of the collaborative decision

making, such as increased confidence and reduced anxiety about care plans, were the most important to them. Including families as partners in decision making has the potential to reap the same benefits. Supporting this was the finding that inclusion reduced the potential stress that can occur for families within the process of undertaking mental health care and increased satisfaction with service delivery. Non-specific clinical factors that facilitated these benefits were reported by families and service users to be good communication, mutual respect and trust. Family inclusion is inherent in the models of health for Māori and Pacific cultures, and so improved cultural appropriateness of mental health care is another intrinsic benefit of the family inclusion process for these groups.

Secondly, and most often, the proposed benefit of family inclusion was improved efficacy of mental health care resulting in improved mental health outcomes. Systemic therapies provided to families (e.g., family therapy) are the most extensively evaluated framework of family inclusion. These types of therapies have data indicating their efficacy in improving child and youth mental health, which is relatively robust compared to other frameworks of family inclusion. Unfortunately evaluations of systemic therapies cannot provide insight into the benefits of including families within a partnership framework as it is unclear from much of the currently available research data whether a process such as of mutual goal setting or shared decision making has been undertaken. Partnership frameworks do have some supporting data, but much more is needed to conclude that it produces the benefits purported in theory. Reduced symptomatology and improved functionality are two benefits that have been demonstrated for children and youth seen within the Systems of Care framework, but similar outcomes in family well being are not reported. Increased engagement by families in intervention tasks has also been demonstrated as a result of family inclusion. This is an important finding as children who are supported to engage fully in an intervention are thought to be more likely to benefit from it.

One pertinent theme found within the literature was a lack of family inclusive practice despite there being multiple reasons for mental health professionals to do so. Mandates found in policies and practice guidelines are consistent with fashionable contextual or holistic conceptualisations of mental health, and there is evidence that family inclusion has benefits for children and youth. Ideas have changed, but the numerous barriers to family inclusion noted in the literature show that mental health systems in the field are moving at a slower pace. Practices that used Systems of Care were found to be more consistent in modalities of family inclusion than other services, even though all staff valued the principals of family inclusion. The key difference appeared to be that staff at the System of Care practices were *funded* and *trained* in family inclusive approaches. Providing services with appropriate resources will increase the feasibility of a partnership framework in mental health practice. The clinician was found to be the strongest predictor of successful family inclusion, so training in the theory and practice of family inclusion seems pivotal as well. Helpful training for clinicians, such as that which could be based on the Kina Trust's guidelines, will support them to tackle real challenges faced in everyday clinical practice, such as balancing the child and youth's right to privacy, gaining informed consent, being responsive to the family's desired level of inclusion, and resolving differences in professional and family goals for intervention.

The lack of literature specifically pertaining to family inclusion in child and youth mental health meant that it was necessary to look to the adult research to inform this review. Research with adult service users and their families did provide some direction as to the potential benefits and challenges of family inclusion. However due to the fundamental differences between child, youth, and adult mental health it would be remiss to apply these findings in child and youth work without further investigation. Similarly ideas taken from general health, healthcare for chronic medical conditions, and disability research also need to be investigated to ensure they are equally meaningful in mental health. Across all the literature reviewed the area that had received the least

attention was how family inclusion impacts on the well being of the whole family as well as the individual child or youth. The proposed benefits for families themselves have not actually been measured in many of the outcome studies available. This is perhaps a particularly important area for research for New Zealand, as a key theme in our mental health strategy is the achievement of whānau ora.

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