

Research on Consumer and Family Involvement in Child and Adolescent Mental Health Services

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Executive Summary

This document is the written report of a project commissioned by the Werry Centre. It outlines the workforce development needs for people working in consumer and family member advocacy/advisory roles in the child and adolescent mental health sector.

A review of the literature reveals this to be an underdeveloped area of research both in New Zealand and overseas. However, there is a useful body of literature to support the opinion that children and young people not only know what they need from services but are also able to articulate those needs if given a supportive environment and the means to do so.

A review of relevant Ministry of Health policy documents confirms an intention to improve the responsiveness of mental health services to consumers. There is growing recognition that mental health services need to value and empower service users as genuine and respected partners in all aspects of policy and workforce development, planning, service delivery, monitoring and evaluation.

Our consultation with major stakeholders showed that, although consumer advisors and representatives currently employed by child, adolescent and family mental health services (CAFMHS) fulfil a range of roles, there are significant differences in the extent to which these roles are used in individual services. Current roles occupied by consumers in CAFMHS are:

- A *representative* who acts as a conduit of information between consumers and service providers. This is frequently seen as the role of family/whanau members
- A *supportive peer* who is able to model recovery, empower service users and inspire hope
- An *advocate* who helps resolve complaints
- An *advisor* who participates in staff recruitment panels and advises service providers on policy, planning and service development.

Based on the results of the consultation process this report makes the following recommendations:

- That Blueprint requirements for consumer involvement in CAFMHS should be reviewed
- That the application of Standard 9 of the National Mental Health Sector Standards should be reviewed
- That CAFMHS should be required to budget for a consumer advisory service
- That a national association that supports CAFMHS consumer advisors to work effectively is formed.

The report concludes with a list of recommendations that can be readily implemented by CAFMHS who are committed to developing effective and comprehensive consumer participation.

Literature Review

Background: Consumer Participation in Mental Health Services

Since the mid-1990s The Ministry of Health has had a philosophical commitment to consumer participation in planning, implementing and evaluating mental health policies and programmes (Ministry of Health, 1995, 2003). Participation has been shown to be empowering to consumers and critical to their recovery, and it helps individuals believe they control their own fate (Read, 2003). The National Mental Health Standards (Ministry of Health, 2001) aim to foster service-user participation, ranging from the involvement of individuals in their own care to formal roles to advise on service development. However, in some areas recommendations are not always translated into practice:

While we have made huge strides in involving consumers in service planning, evaluation and decision making at an organizational level, most would agree that we still have some way to go for consumers and families to be truly engaged and involved in the treatment process. (Dowland, 2003).

Jan Dowland, Chair of the Mental Health Commission, also described services as highly fragmented, with many gaps in services to children and young people. This is in spite of a 121% increase in funding for secondary Mental Health Services during the past 8 years, and in spite of the estimate that in New Zealand 12% of young people, aged 0–19 years, have a mental illness requiring treatment (Mental Health Commission, 1999).

The mental health of children and young people has been a major focus of health planning and spending since the Ministry of Health published *New Futures: A Strategic Framework for Specialist Mental Health Services for Children and Young People in New Zealand* in 1998. At the end of the same year, The Mental Health Commission (MHC) published the *Blueprint for Mental Health Services in New Zealand*. This document highlighted the needs of children and young people with severe mental health problems and identified a range of age-related access targets to specialist mental health services.

The Ministry of Health recommends New Zealand mental health services have policies and procedures specifically intended to maximize participation by consumers (Ministry of Health, 2001). Within this framework, staff at speciality services for children and young people, are expected to encourage families, whānau and/or support persons to be 'actively involved in the referral, assessment and treatment processes' of children and adolescents. This is both to ensure information is communicated to the child in a way that they can understand, and to help in the process of informed consent. The Blueprint (Mental Health Commission, 1998a) sets a benchmark of .4 full-time consumer and family positions per 100,000 of population for the 15–19 age bracket, but neglects to specify a similar requirement for those in the group below 14 years of age.

Not surprisingly, concern about the cognitive ability of children and the perceived and legal responsibilities of adult caregivers means mental health service providers tend to rely on the involvement of family or whānau when working with children and young people. However, as has been pointed out in a recent discussion document on consumer participation in mental health services (Mental Health Commission, 2002, p. 26), children are aware of their own likes and dislikes, and *'it is important to acknowledge that family/ whānau do not invariably act in the interests of the service users'*.

Article 12 of The United Nations Convention on the Rights of the Child recognizes that children have a right to participate in decisions that affect them, and that this 'participation by children is good for them and society as a whole' (Ministry of Youth Affairs, 2000, p. 51) Since signing the UN Convention on the Rights of the Child in 1993, the New Zealand Government has developed and implemented a variety of strategies and policies aimed at promoting the rights of children and young people. Some of the more recent interventions are of particular relevance to young people who have experienced mental illness.

In June 2002, The Ministry of Social Development and The Ministry of Youth Affairs published a framework designed to promote the participation of children, young people and young adults who were "marginalised" or who experienced disabilities (Ministry of Social Development, 2002a). It is important to note that in this and subsequent documents experience of mental illness is included as "psychiatric disability". In the same year the Ministry of Social Development published the Agenda for Children (2002b). It recognises that children are more than vulnerable dependents in need of adult protection and consequently more than passive recipients of services. The following year the Ministry's Agenda for Children

document advocated 'A Whole Child Approach' (Ministry of Social Development, 2003). This approach recognises children should not be separated from the environment in which they live and grow; this includes parents, family/whānau, friends and peers, broader community settings, and society as a whole. Public services are now required to incorporate this philosophy when developing policies and services that affect children.

Ten years after signing the Convention on the Rights of the Child, the New Zealand Government reviewed progress on its implementation. Having considered the Second Periodic Report (Ministry of Youth Affairs, 2000), a list of 'Issues to be taken up' was published (Ministry of Youth Affairs, 2003b). Precise information requested by the United Nations on numbers of children with disabilities, disaggregated by gender, age, and indigenous and minority groups was not available. What data were available suggested a substantial number of children in New Zealand have physical, intellectual, emotional, or psychological disabilities. The total number of children and young people aged 0 to 14 with disabilities residing in households is 90,000 with a further 800 in residential facilities. There is no up-to-date information on the prevalence of mental health problems in children; only the use of specialist mental health services is reported (Ministry of Youth Affairs, 2003b)

In 2003 The Ministry of Youth Affairs published 'Keepin' it Real', a resource designed to increase youth participation in all events and programmes that affect them. In this study, the practicalities of involving children and youth are addressed. Specific groups of young people who required extra facilitation, including Māori and Pacific and marginalized ethnic groups such as refugees, were examined (Ministry of Youth Affairs, 2003a). Mental health is an important health concern for Māori, since over the last 30 years Māori admission and re-admission rates to psychiatric facilities have dramatically increased (Maxwell-Crawford, Hirini, & Durie, 2003). Anecdotal feedback from child and adolescent mental health providers suggests Māori children and young people do not receive treatment for mental health problems until later stages of their illnesses, by which time their needs have reached crisis point (Maxwell-Crawford et al., 2003).

The Blueprint (Mental Health Commission, 1998a) makes explicit that the provision of these services for children should, wherever necessary, include kaupapa Māori services and cultural advisors for Pacific Island families. The kaupapa Māori perspective critically examines the historical and philosophical base of Western scientific methods, setting an agenda for planning and implementing 'de-colonized' programmes that reclaim indigenous control over indigenous issues (Smith 2001).

The MHC published their *Report of a Review of Consumer Opinion and Family Opinion about Mental Health Services* in 1998. The report found consumer concern over difficulty of access to crisis care, staff shortages, negative staff attitudes, inadequate training and a shortage of Māori and Pacific staff was fully justified. Consumers reported their views were considered inferior to the professional view, and their complaints about side effects and physical discomforts were not listened to (Mental Health Commission, 1998b). However, consumer participation is only possible when consumers and mental health professionals work in partnership (Read, 2003). Public expectations of health professionals and the health service have changed as service users have become better informed; no longer content with playing the role of 'patient', tension can develop between providers and these more knowledgeable 'consumers' (Ministry of Health, 2003).

If adult consumers feel belittled and unheard in a relationship characterised by an unequal balance of power, how much more diminished are the experiences of children and young people as consumers of mental health services? Parents and other caregivers are sometimes requested to provide proxy opinions, but these may or may not accurately reflect children's opinions of services (Stuntzer-Gibson, Koren & Dechillo, 1995). Consumers and families may have different needs and expectations, with consumers perhaps wanting less reliance on medication and their families more, and families emphasizing their own need for support, relief from stress, and consultation.

While the Ministry of Health in New Zealand encourages consumer participation in mental health services, it has been suggested there is an imbalance between the rhetoric of policy and the reality of consumer experience (Read, 2003). Certainly there are few published studies examining children or young people's satisfaction with mental health services or investigating participation of children or young people in the recovery process. Due to the circumstances of children's lives, children's mental health needs differ from those of adults and make them uniquely vulnerable. Typically, children with mental health problems are involved with several service systems, including mental health, special education, welfare agencies and frequently juvenile justice services, as well as attending school and living with their families (Glied & Cuellar, 2003).

Owing to the paucity of literature in this area, several studies that give children a voice in other contexts, such as disability and justice services, are included. Their findings are transferable as they are concerned with the same potential power differentials in relationships between service users and providers. The power differentials are likely to be significant

when the service user is a child or young person. This review also includes research into parents' and caregivers' opinions of service delivery and outcomes.

Client satisfaction surveys have not always been a reliable method of obtaining accurate evaluation of services for young people. Schwab and Stone (1983) pointed to the lack of adequate methodologies to assess treatment satisfaction for this group. Conceptual problems also arise due to the cognitive immaturity of younger children (Young, Nicholson, & Davis, 1995). However, Hennessy (1999) listed several instruments specifically developed for young people's mental health services; The Youth Satisfaction Questionnaire (Stüntzer-Gibson et al., 1995); The Satisfaction Scales (Brannan, Sonnichen, & Heflinger, 1996); and The Child Evaluation Inventory (Kazdin, Esveldt-Dawson, French, & Unis, 1987), designed for use with children aged 7–13 years. Loff, Trigg and Cassels (1987) adapted an adult satisfaction questionnaire; Rosen, Heckman, Carro and Burchard (1994) used a questionnaire designed for use with children and adolescents. Two other studies involving adolescent consumers used a specially designed Youth Consumer Evaluation questionnaire to evaluate client relationships with programme staff (Kirigan, Braukmann, Atwater, & Wolf, 1982; Solnick, Braukmann, Bedlington, Kirigin, & Wolf, 1981). Godley, Fielder and Funk (1998) assessed the satisfaction of 469 caregivers and 387 children and adolescents with child and family services in order to implement programme improvement. Martin, Petr and Kapp (2003) assessed consumer satisfaction with Children's Mental Health Services using a statistical survey. Shapiro, Welker and Jacobson (1997) developed the Youth Client Satisfaction Questionnaire, for use with adolescents attending a community mental health centre.

In spite of the development and testing of satisfaction questionnaires designed specifically to capture the opinions of young consumers, a significant literature focuses on evaluating services from the perspective of family members or caregivers, (O'Brien, Lutzker, & Campbell, 1993; Rubin, 1999). Some studies suggest this may be useful. According to Loff et al. (1987), the correspondence between children's and parents' evaluations of mental health services seems to show no significant differences. Stüntzer-Gibson et al. (1995) found a strong correlation between children's and parents' evaluations of day treatment and medication management but found only slight agreement on evaluations of case management and family activities. Other studies attempt to measure more active parental involvement in mental health outcomes for children, such as Resendez, Quist and Matshazi's (2000) longitudinal analysis of 'family empowerment'. The benefits of partnerships between

families and professionals are discussed in a survey of caregivers of children with severe emotional and behavioural disorders, (DeChillo, Koren and Schultze, 1994). Involving families in participatory research was described by Vander Stoep, Williams, Jones, Green and Trupin (1999). Including family members in all decisions and treatment processes underpins the 'Systems of Care' approach in the United States. Anderson, McIntyre, Rotto and Robertson (2002) provided information on developing and sustaining collaboration and coordination of 'systems of care' designed to meet the multiple and changing needs of children and adolescents with severe emotional disturbances and their families.

Measuring outcome effectiveness is one way of determining whether mental health services meet the needs of children and young people. However, outcome assessments are frequently undertaken without asking the opinions of consumers or their caregivers and focus on the family's level of functioning after service intervention (Kluger, Rivera, & Mormile-Mehler, 2001). Children, young people and their families and caregivers may ultimately benefit from these kinds of research projects, but they are written by experts for experts, rather than attempting any kind of collaboration with service users. For example, in Anderson, Lyons, Giles, Price and Estle (2003) testing of the Child and Adolescent Needs and Strengths-Mental Health (CANS-MH) scale the consumer was essentially passive in the research process. Other such surveys, on parents, children and adolescents, try to map the requirements for unmet needs and early intervention in 'at risk' individuals in mental health services, mostly in behavioural and emotional disorders (Blais, Breton, Fournier, St-Georges, & Berthiaume, 2003; Davis, Day, Cox, & Cutler, 2000; Flisher, Grosser, & Alegria, 1997; Martinez Sanchez, Saiz, Company, & Alberio, 2001; Vogel & Holford, 1999), but also in the field of early treatment of psychosis (Heinssen, Perkins, Appelbaum, & Fenton, 2000).

In contrast to the 'passive' involvement of consumers in outcome assessments (satisfaction surveys), three studies attempted more active collaboration through interviews designed to capture service users' opinions on how services might be improved. A Norwegian study, by Fyhn and Holte (1997), asked young consumers' advice on how to improve treatment for psychoses; Potter, Holmes and Barton (2002) asked children and young people what they would like a post-abuse service to provide; and Marsh and Fristad (2002) interviewed young people suffering from a variety of emotional and behavioural disorders. The studies highlighted discrepancies between the needs experienced by service users and the needs of service users as perceived by providers. A common theme was the desire of service users to be treated with respect and dignity and to be listened to. Byas, Hills, Meech, Read, Stacey, Thompson and Wood

(2002), having evaluated the Collaborative Outcomes Research Project (CORP) in South Australia, recorded consumers' assertion that their skills and expertise had not been acknowledged, and concluded researchers need to listen to consumers and actively involve them in the research process.

Two English projects are recent examples of professionals relinquishing power in order to work innovatively and collaboratively with young people with disabilities. The 'Ask Us' project was set up as a way to enable disabled children and young people to transform children's services in England. Instead of beginning with a proposal already worked out by adults, the starting point of the consultation was the views and feelings of groups of disabled people aged between 4 and 24 years (Stone, 2001) The children, young people and research facilitators used multi-media tools, such as audio and video tapes and digital cameras, to aid communication. Alternative means of communication were also employed on the 'Two Way Street' project. (Stone, 2001) The video produced at the end of the project showed young, disabled people advising professionals on how to communicate effectively with them. Although these projects involve young people with physical disabilities, they demonstrate the potential of using a variety of media to enhance communication with young people.

Two Australian projects have enrolled young people in collaborative relationships with service providers. The Early Psychosis Relatives' and Friends' Education and Support Groups were developed for young people who experience psychosis and for their relatives and friends. Young people aged between 14 and 30 years formed a partnership with seven peer workers, a carer, and fourteen service providers to evaluate an education and support programme for relatives and friends. They found the peer workers are the most valuable factor in the programme as peers were able to provide information about the 'lived' experience of psychosis denied to relatives and friends (Paine, 2000). The Northern Sydney Health Service set up the 'Youthealth' Project and employed twelve young mental health consumers to visit and consult with service providers on their 'youth friendliness.' This was an attempt to use young peoples' experience and expertise to improve service delivery and the public image of mental health care. Dargaville and Crumpton (2001) concluded the employment of young mental health consumers is critical to the success of the development of youth-friendly work practices

In New Zealand, despite the policy requirements for mental health services to engage consumer advisors actively, there is little published research in the area of consumer and family involvement in child and

adolescent mental health services. Evaluations of services for children and young people have been carried out in the area of child sexual abuse and criminal court processes (Davies, 1999) and educational programmes facilitated by The Ministry of Justice for children under the Domestic Violence Act 1995 (Cargo, Cram, Dixon, Widdowson, Adair & Jackson, 2002). Neither of these research projects is directly connected with mental health services, but both studies show that even in cases where children, young people and their families/whānau are severely traumatized, participating in research that respects their needs and opinions can be a valuable source of consumer empowerment.

A seminal text that explored socio-cultural theory and the sociology of childhood to children's rights, 'Children's Voices: Research Policy and Practice (Smith, Taylor & Gollop, 2000) argued for a new focus on listening to the voices of children in the context of their everyday experiences. The authors suggested it was time for children to be regarded as active participants in, rather than passive recipients of, research, policy and provision of services. They discussed the importance of the United Nations Convention of the Rights of the Child as a framework for the development of policy and practice.

Smith, Smith, Boler, Kempton, Ormond, Chueh and Waetford, (2002) have researched the ways in which rural youth, both Māori and Pākehā, voice their understanding of what it means to be a young New Zealander aged 10–17 at the end of the 20th century. Although not specifically targeting young people who use mental health services, this study's methodology could easily be adapted for this group. Focus groups were conducted in the first phase. In the second phase a youth tribunal was formed with internet access for people in remote communities. Testimonies were heard from over a thousand young people, ranging from small children to 20-year-olds. The authors pointed out that research involving children, who are legal minors, requires particular ethical considerations that do not apply to adults. By law children have the right to free speech, but researchers do not have the automatic right to use their talk in the research project. Therefore, each session of the tribunal began with a talk on ethics, informed consent, and the right to withdraw consent at any time. The youth advisors confirmed that this process was perceived as a significant guarantee of safety on the part of the participants.

Another recent work in New Zealand, undertaken with children, young people and their families/whānau receiving mental health services, also employed focus groups (Merry, Lambie, Parkin, Seymour, Crengle, Pasene-Mizziebo & Stasiak, 2004). Māori and Pacific people were specifically included, with several focus groups set up around the country.

This research explored the use of outcome measures in children's mental health services, and their acceptability to consumers. Participants' comments indicated young consumers and their families were concerned about the way outcomes measures were administered, the feedback method for results, and who would have access to the results. Privacy issues were important to children and young people, as well as to family/whānau, with some children saying they did not want their caregivers to see their answers, but expressing an interest in seeing what their caregivers had written about them.

Margaret Mitchell-Lowe (2003) used semi-structured interviews, drawings and photographs to understand children's experiences as mental health service users. Nine Māori and non-Māori children were interviewed, all first-time attendees at a mental health clinic. The children felt free to expressed various anxieties and fears, and the author hypothesised this was because she followed the child's lead and was not there to get specific information.

Three projects looking at specific issues for Maori young people are worth noting. The Community Child and Family Mental Health (Kari) Centre, Auckland District Health Board, has set up 'Headspace' an online resource with information for children, young people and families/whānau on how to deal with life stressors (Kari Centre, 2004). Feedback from the site allows children's opinions to be heard. A research report undertaken by The Ministry of Justice (Cargo et al., 2002), with a particular emphasis on the experience of Māori children , suggests the best outcomes for these programmes can be expected if a holistic and family-oriented approach is taken. In particular, if programmes take place in the family home instead of in an institutional setting, caregiver-child relationships are strengthened. The Counties/Manukau District Health Board Centre for Social and Health Outcomes Research and Evaluation (SHORE) have established a team of Māori, Pākehā and Samoan researchers and health workers to develop community networks to establish environmental interventions for 'youth wellbeing' in mental health (McCreanor, Barnes, Anae, Edwards, & Jenson, 2003). The research team is still at the stage of disseminating their data to the communities involved and is waiting for feedback.

Conclusion

In New Zealand, National Mental Health Services' policy has valued and promoted the implementation of consumer advisory services since the 1990s. Research on adult consumers shows involvement in the care process is highly beneficial in the journey toward recovery, and participation by service users can have a beneficial impact on the way

mental health services are provided. In spite of the political goodwill and evidence of research, there are gaps in the depth and breadth of these services across the country.

One significant gap is in Mental Health Services for children and young people. There is scant evidence in the literature that children and young people have input into all levels of Mental Health Services – policy, planning, delivery and evaluation. However, several innovative projects describe a variety of methodologies – focus groups, tribunals, multi-media communication and on-line resources – aimed at promoting communication with young people who cope with challenging experiences. The same methodologies could be used to enhance the participation of children and young people in mental health service design and delivery.

Of particular concern for New Zealand is the very young demographic profile of Maori. When the impacts of recent socio-economic changes are taken into account, Maori are statistically likely to be high users of child and adolescent mental health services. A kaupapa Māori methodology is crucial to engaging this frequently marginalized population in a respectful and affirming way.

The purpose of the surveys and consultation that comprise the fieldwork in this research project is to determine whether the lack of research literature on consumer participation in Child, Adolescent and Family Mental Health Services (CAFMS) delivery is a true reflection of day-to-day reality. If it is, can the innovative methods discussed in this review, which are aimed at giving children and young people an opportunity to say what they need from services, be used to develop meaningful, rather than token, consumer advisory services for children and young people? Finally, the literature alerts service developers of the necessity to engage with young Maori service users in a way that is culturally appropriate.

Method

To provide data to allow the Werry Centre to make recommendations for consumer involvement in CAFMHS, including in-service planning and delivery. Three methods of data collection were used:

- Survey of Child, Adolescent and Family Mental Health service providers (CAFMHS)
- Stakeholder consultation by focus group
- Stakeholder consultation by individual interview

The quantitative and qualitative data obtained were analysed from an *utilisation* perspective. Patton (1986) argued that while quantitative data are measurable, it might be 'soft' or qualitative data that are meaningful, and outcomes should be determined by utility rather than measurability.

Participants:

CAFMHS survey

The purpose of the CAFMHS survey was to collect information on the extent and type of consumer participation in current service delivery. CAFMHS were accessed by approaching each of the four regional funding bodies to obtain a list of the services they contract to provide child and adolescent mental health services in their region. Seventy-one questionnaires were emailed to the identified services. Email was used because it is a time efficient contact method, which increases the likelihood of a response.

Recipients were asked not to return the survey if they were not CAFMHS, but rather to email us to remove them from the list. Twenty-three responses were received, three emails were undeliverable and the survey was "snowballed" to some other providers, numbers unknown. Follow-up emails were sent following questionnaire distribution, and the majority of non-responders were also telephoned up to four times to stimulate questionnaire returns.

The survey asked participants to provide demographic information on age range, gender and significant ethnic groupings of their client base, as well as the number of clients using their service. Participants were also asked whether their service employed consumers or their family members in advocacy, representative or advisory roles¹, and if so, the area of service in which that consumer is involved. The survey asked whether consumer advisers are voluntary or employed – either directly or as contractors. Further questions sought to establish training provided, skills

¹ Throughout this report the terms representative, advocate and advisor will be used interchangeably.

required, and perceived barriers to having consumers working in CAFMHS (see Appendix A).

Focus Groups

Seven focus groups were set up: Auckland (2), Christchurch (3), Tauranga (1), and West Coast (1). These locations were chosen as representative of rural and urban communities throughout New Zealand. They were accessed through the research team's personal contacts, and through word-of-mouth recommendations. One group specifically represented Māori and one group Pacific Island people. Participants in the focus groups, who were not aware of the data gathered from the questionnaire, were asked their opinions on five areas related to the role of a consumer/family advisor within a CAFMHS (see Appendix B):

- The role of the consumer/family advisor
- Training for the role
- Support for the role
- Personal qualities that are helpful for the role
- Barriers for consumer/family advisors.

The discussion was taped as a reference for the notes taken.

Interviews

Semi-structured interviews were undertaken with three stakeholders: an adult mental health consumer; a family support-service manager; a service provider manager. Interview questions were the same as those used in the focus groups.

Results

This section records data obtained from three sources: the survey questionnaire, the focus groups and individual consultations.

Of the 71 surveys sent out, of which an unknown number were “snowballed” to other providers, 23 responses were received. Of these twenty-three responses, ten services identified themselves as non-governmental organisations (NGOs), eleven identified themselves as District Health Boards (DHBs), and two respondents did not identify the type of organisation.

The focus groups comprised 29 key stakeholders; mental health staff, consumers and family, representing differing ages, ethnicities and genders (see Table 1).

Table 1: Characteristics of focus group and interview participants (n=32)

Age	Mean age 39 yrs	(Range 16–65)
Ethnicity	European/Pakeha	19
	Maori	9
	Samoan	2
	Irish	1
	Mixed	1
Gender	Female	26
	Male	6
Service use*	Current Service users	13
	Past service users	14
	Service Providers	13
	Family Members	9

* some participants reported themselves as falling into more than one category.

Question 1: After ascertaining the recipient was indeed a specialist provider of child and adolescent mental health services, the participant was asked:

- (a) the age range of clients
- (b) the approximate number of clients using the service at one time
- (c) the ethnic groups using the service in significant numbers
- (d) if the gender balance was 50/50 or otherwise.

(a) The age range of clients was from 0 to 25 years and services reported a client-base ranging from 12 to 800 people using a particular service at any one time.

(b) The highest proportion in any one category was in the 0–50 client base. 70% of services reported a client base of 400 or less, and 30% of services a much larger client base (see Fig. 1).

(c) The largest ethnic group using CAMHS services were Māori, followed by Pākeha/European, with smaller percentages of Pacific people and Asian groups, and with mention of Iraqi, Somali and Bangladeshi people (see Fig. 2).

Figure 1: Number of clients using each service unit

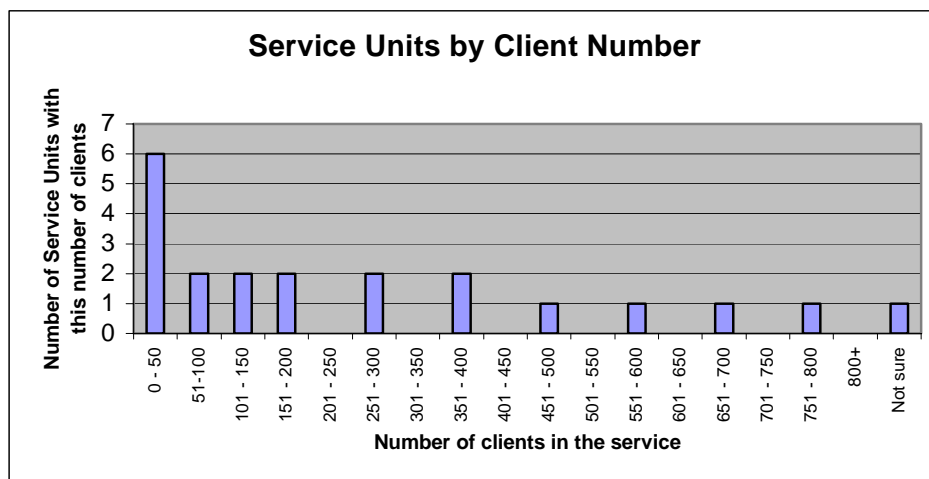
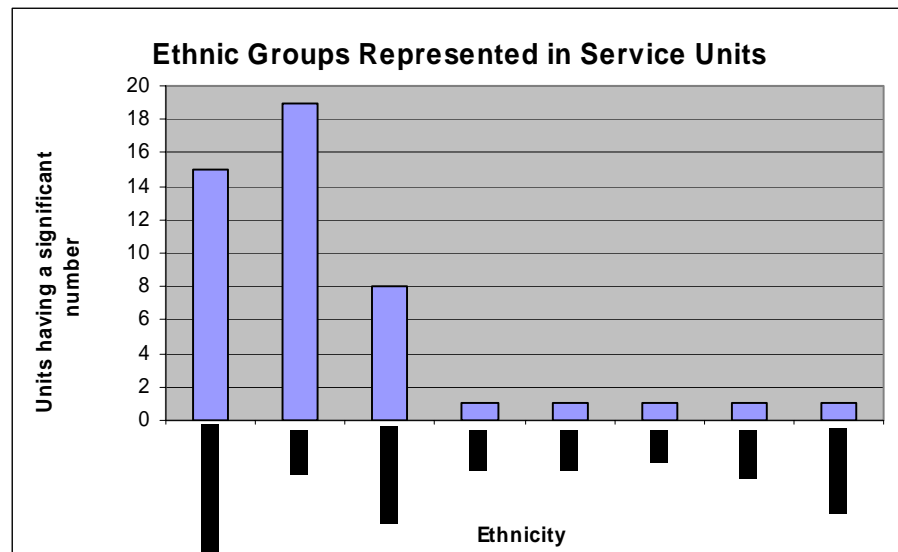


Figure 2: Ethnic groups represented in service units

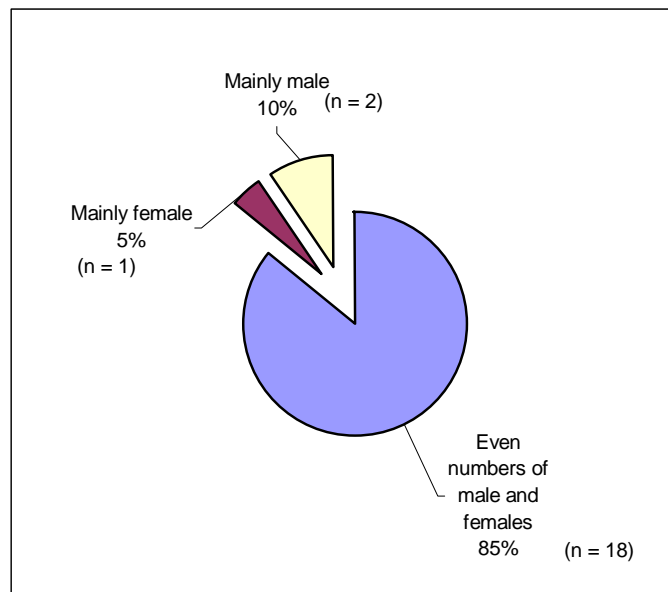


Focus Group comments on this question

The Māori focus group was concerned that Māori, who make up a large number of young consumers in CAMHS, should receive the option of a 'by Māori, for Māori' approach as best practice, with cultural issues given special attention. This would also suggest there is a role for *tangata whaiora* advisors, that is, Māori consumer advisors. This role is a recognised part of consumer participation in adult services.

The gender balance within Units surveyed is predominantly 50/50 (see Fig. 3):

Figure 3: Percentage of service units and reported gender balance of clients



Question 2: *Do you have consumers working in an advocacy, representative or advisory role? If so, how many are voluntary? How many are employed/ contracted?*

Less than half (44%) the CAFMHS reported they had consumer advisors. Especially notable is the high ratio of clients per consumer representative: for example, one unit employs a single FTE advisor for up to 600 clients (see Table 2).

Table 2: Number of clients in unit and number of consumer advisors

Number of clients in unit	Number of consumer advisors (FTE)
13	0.1
50	0.5
85	0.2
100	Not specified
179	0.5
300	Not specified
400	1
450–500	7
500–600	1
800	Not specified

Most CAFMHS with consumer advisors said they had a single advisor, some of whom were part-time (it was unclear from the responses whether this person was advising the service, the consumers or both). Of the 11 DHBs, six reported consumers working in an advocacy, representative or advisory role. Of the 10 NGOs, four have consumers working in an advocacy, representative or advisory roles (see Table 3).

Of the 23 CAMHS in our sample, 70% reported their consumer advisors were voluntary workers, and 30% that they are contracted or employed. Comments on questionnaires indicated most CAFMHS did not consider they had adequate funding to pay consumer advisors or representatives.

Table 3: Consumer representation reported by provider type

Provider Type	Number of responses	Number reporting consumer representation
DHB	11	6
NGO	10	4

Focus Group comments on this question

Most focus groups acknowledged it was not a good idea to have only one consumer advisor or representative, as this does not provide sufficient support. Participants in the focus groups suggested koha was not enough and that consumer advisors need to be reimbursed for more than their expenses. There was also a comment that part-time employment such as 25 hours per week is not enough time to complete the job. It was suggested the perceived inequality in standing between consumer advisors and service providers is exacerbated by inequalities in hours worked and monetary re-imburement.

2a. Are these consumer advisors

- *current service users of your service?*
- *past service users?*
- *users of adult services?*

The response from the questionnaires told us seven services had advisors who were current service users, five services had advisors who were past service users, and three services had advisors who were users of adult services. However, 50% of services reported more than one advisor, and it

was not clear exactly how many advisors fell into which category of service use (see Table 4).

Table 4: Status of Consumer Advisors

Status of consumer advisors	Number of Services
Current service users	7
Past service users	5
Adult Service Users	3

Focus Group comments on this question

Participants in the focus groups pointed out that if a person is a current service user it can be difficult to balance the dual role, i.e. a clinician being both therapist and colleague. To avoid the power differentials involved in this situation, some suggested that to be able to participate safely the consumer advisor should have left the service. Others acknowledged that, even for past service users, people or situations can act as triggers and can be traumatising. This is especially the case with visits to acute inpatient units. Groups noted this problem would be exacerbated if the consumer advisor were young, as staff can be prejudiced and the consumer advisor would not be taken seriously. Even when consumer advisors are adults it is possible staff can dismiss their input, leaving the advisor feeling disempowered.

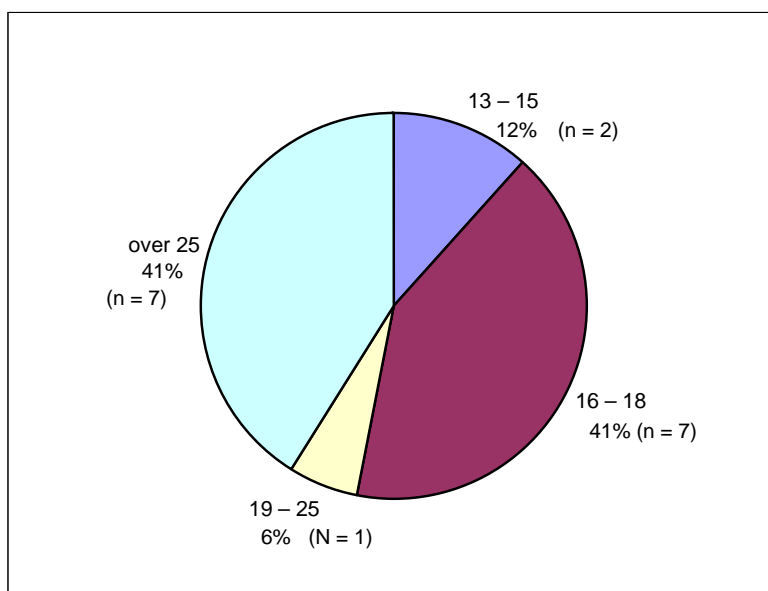
Support was seen as vital to the success of a consumer advisory service, with group members suggesting that it is too isolating to have only one consumer advisor in a service. Solutions suggested included:

- External supervision
- Regular regional meetings of consumer representatives and advisors
- Employment of advisors by an independent agency, rather than advisors being employees of Mental Health Services.

2b. What age are the consumer advisors?

There were no consumer advisors under 12 years of age. Two services reported advisors aged between 13 and 15, seven services reported advisors aged between 16 and 18, one service reported advisors aged between 19 and 25, and seven services had advisors aged over 25 years of age (see Fig. 4). Again, 50% of services reported more than one advisor, and it was not clear specifically how many advisors sat within each age bracket.

Figure 4: Number of services reporting consumer advisors in each age range



Focus Group comments on this question

The groups believed that advice is currently often received from adult consumers who use adult services. The groups were insistent that this state of affairs needed to change, because the needs and views of adults are different from those of children, adolescents, youth and their families. The voices of children and youth need to be heard. For children, the advisor could be a former service user who was also a family member. For adolescents and youth the advisor also needs to be a past service user and someone who is either still in that age group, is able to connect with young people, and who can see the world from a younger person's perspective. For youth consumers the advisor could therefore be in their late teens or early 20s.

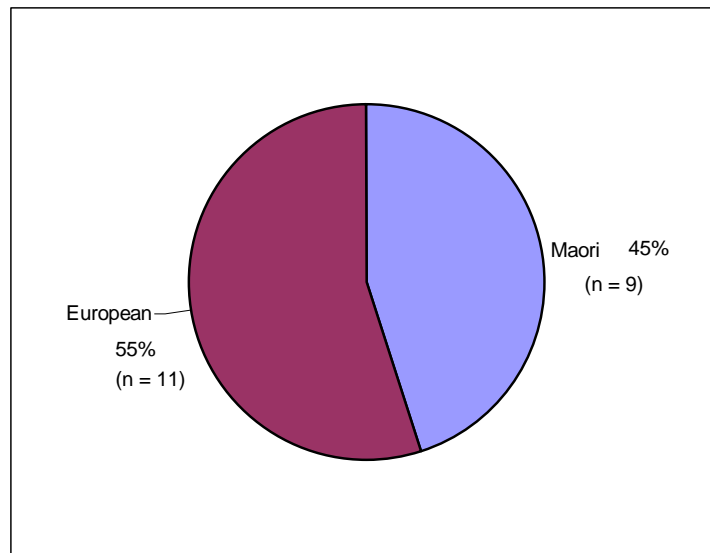
Consumer advisors noted the need for good supervision and support; this is even more important for young advisors who will need mentoring. The Pacific Island focus group thought that an advisor in CAFMHS should be a mature person who could provide advice, emotional support and mentoring. The Māori focus group, who did not consider a consumer advisor should be a young person, thought that overall the advisor should form strong and effective relationships with tamariki who are past and

present service users and should channel information to their focus/advisory groups, so tamariki have adequate representation.

2c. What ethnicity are the consumer advisors?

Across the 23 responding services nine Māori and 11 European consumer advisors were reported. There were no reports of Pacific Island, Asian or other ethnicities as consumer advisors (see Fig. 5).

Figure 5: Ethnicity of consumer advisors



Focus Group comments on this question

The Pacific Island focus group wanted any consumer advisors and representatives working with Pacific Island clients to be Pacific people. The Māori focus group, as other groups, was also concerned with cultural issues: the choice of a 'by Māori, for Māori' approach was regarded as best practice. An awareness of the importance of place was also emphasised, such as the choice to conduct meetings on a Marae.

Question 3: *Are family members involved in advocacy or advisory roles in CAFMHS?*

Of the 11 participants who responded to this query, 45% have family members involved. Comments indicated the parent/caregiver and family/whānau are regarded as consumers, along with the young clients, as a significant amount of the work must also take place with the parent/caregiver. It was recommended that a parent advisory group would be a useful addition to CAMHS services.

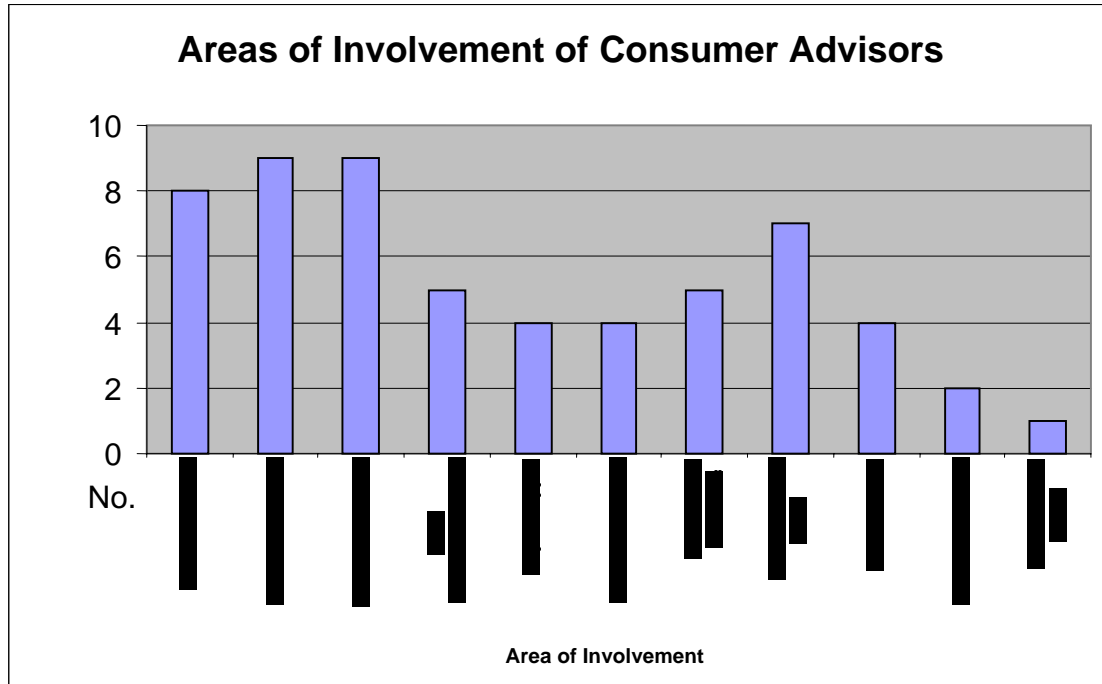
Focus Group comments on this question

Focus group input shows children younger than 12 are not generally regarded as individual consumers; rather, they and their family/whānau are regarded as a 'consumer group'. Rather than focusing on the individual in isolation, the importance of incorporating the family/whānau as a whole was stressed, but it was pointed out that the family/whānau might have different needs and views from the child and this fact needed to be taken into consideration. However, the groups believed the family/whānau affected the child's capacity to change. The family/whānau might also have information that the child may not be able to articulate. The Māori focus group referred to its young consumers as tamariki rather than clients, accentuating the commitment to family/whānau that this group emphasises.

Question 4: *What areas of service are consumer advisors involved in?*

Consumer advisors are involved in a wide range of service areas in CAFMHS (see Fig. 6).

Figure 6: Areas of service in which consumer advisors were reported to be involved



Focus Group comments on this question:

Participants agreed the areas of service in which individual consumer or family advisors are currently working are far too wide-ranging to be effective. The scope of the role needs to be clearly defined and sufficient people employed to cover it. Explicit support and advocacy should be separate from advisory work, but it would be of great benefit to be able to provide these services, based on different job descriptions.

Ideally, participants hope sufficient consumers could be employed to:

- provide a conduit of information between consumers and services
- connect with young consumers and enable their voices to be heard
- model behaviour and recovery for young service users
- provide input into all policy, service development, and procedure decisions.

Participants in focus groups identified four distinct groups who use CAFMHS:

- children under 12
- adolescents aged 13–15

- youth aged 16–25
- family/whānau.

Participants stated that, given the number of consumer advisors currently employed, the differing needs of service users in these groups could not be met. A need was perceived need for separate consumer advisors in each CAMHS to cater for each of these four groups.

Question 5: *Do you have terms of reference or job descriptions for consumer advisors?* Five respondents to the questionnaire answered in the affirmative, five in the negative, and 13 did not answer. Three service providers complied with our request for a copy of the relevant documents.

Service Provider 1 requires their consumer advisors to meet the following specifications:

- Personal experience as a consumer of mental health services
- Active involvement in consumer groups/networks
- Knowledge of local, regional and national groups/networks for mental health consumers
- Commitment to improving mental health services
- Understanding of, and commitment to the principles of The Treaty of Waitangi
- Knowledge of legislation affecting mental health service consumers.

They also require consumer advisors to have the courage to speak out, good communication skills, the ability to work with others, the ability to manage time and resources, personal integrity, self motivation and initiative, the ability to identify personal limits, an established personal support system, and a sense of humour. They conclude:

This position is part of the Mental Health Service Management Team. The Consumer Advisor will advocate for, and support the development of, Mental Health Services that are responsive to the needs and ambitions of service users. The Consumer Advisor will provide a consumer perspective into the planning and monitoring processes of the Mental Health Service and will also provide advice to clinical and management staff on issues affecting client care. The position will also involve formalising and strengthening the relationships between consumers, Mental Health Service management and staff and other service providers.

This service's consumer advisors are expected to ensure the rights and needs of consumers are recognised in all policies and procedures. Advisors are expected to network and liaise with consumers, provide a consumer perspective in service planning and development, and to participate in the delivery of core training and orientation for MHS staff.

Service Provider 2 requires their consumer advisors to meet the same specifications as Service Provider 1, but in addition stress professionalism and creativity, and would prefer their employee to have a tertiary level qualification and Te Reo Māori. Service Provider 2 wishes their consumer advisors to bring a consumer perspective to policy development, planning, implementation, service development and monitoring at all levels of their Mental Health Division, as well as to help with consumer input in the recruitment, selection, education and training of MHS staff.

Service Provider 3, Christchurch CAFMHS, lists the following criteria for consumer representatives:

- A caregiver who has or has had a child or youth attending Christchurch CAFMHS
- A youth who is receiving or has received services from a Christchurch CAFMHS unit
- A present or past service user of the Eating Disorders or Mothers and Babies units
- A staff member from each unit or service area in CAFMHS
- Representation from Te Korowai Atawhai or
- Representation from the Migrant/Refugee programme at Family Mental Health Services.

The Christchurch 'CAFS Reps' Group terms of reference state the organisation wishes to promote, through an ongoing partnership between caregivers/service users and staff, service delivery that enhances the quality of care for client/patients of the CAFMHS and their families. Consumers and family/whānau should participate at every level of the mental health service.

Christchurch Mental Health Services' Consumer Advisory Council consists of Consumer Advisors who provide input into Adult Mental Health Services. They have a participatory role and are involved in all areas of service. In addition, the Christchurch CAFMHS have a "CAFS Representative Group", consisting of representatives from various areas, including family members, consumers, and service providers. The CAFS Representative Group contains at least: one youth representative from each CAFMHS unit/service (a past or present service user aged between 16 and mid-20s); one family member representative from each unit/service; and one

staff representative from each unit/service. This group meets once a month to discuss service issues and has a consultative role for service development documents, policies and procedures. Members also take part in planning days and sit on interview panels for new staff members. In addition, the youth representatives spend much time with current service users, to find out how they like the services, what they want from services and if they have problems or issues with services. The youth representatives speak at Child and Adolescent Mental Health Service (CAMHS) forums, and regularly attend the CAMHS youth day programme and inpatient unit to speak with current service users. They see their role as a partnership with service providers to ensure the best possible services.

Family Advisors Meeting

Essential attributes, qualifications and skills for Family Advisors are similar to those required by Service Providers 1 and 2. Personal experience of using mental health services is not mandatory but knowledge of mental illness is required. It was mentioned that Family Advisors might have relatives who experience ongoing mental health problems and this might prove a challenge. Additional competencies required by family advisors are: tertiary qualifications; public speaking ability; computer literacy; auditing abilities; and cultural knowledge.

Focus Group comments on this question

Most focus groups believed a consumer advisor must have personal experience of mental illness and of using a CAFMHS but should no longer be a service user and be relatively well on their way to recovery. Having a family member with a mental illness may be sufficient, but the advisor should be under 25 and a wise, supportive, outspoken and educated person with strong written and verbal communication skills. Empathy, a sense of humour, the ability to maintain confidentiality, patience, a 'team player', an understanding of recovery, and the ability to not take things personally were mentioned as important attributes by all focus groups.

Interview comments on this question

Being at ease with and in one's own culture and recognising the impact it can have on people, both within one's culture and in other cultures are seen as helpful. A high degree of self-awareness, especially about personal boundaries, is also seen as important. Although it is advantageous to have an understanding of mental illness through personal experience or that of family members, individual experience is limited and varies widely from person to person. Interviewees believed it was therefore important to be able to be empathetic toward other people with mental illness.

Question 6: *How do you train your advisors/advocates?*

All CAFMHS who work with consumer advisors reported they provided some form of training. CAFMHS advisors receive training in:

- Systems and role
- Leadership, project planning, specific topics of relevance to team members
- Mental health disorder workshops
- Bachelor of Applied Science
- Orientation to DHB, MHS, advocacy, networking and empowerment
- Strengths assessment
- Understanding policies and procedures.

Although in-service training was the preferable, one unit was unable to specify what form the training took and another had not yet established training facilities. It is evident there is no standardised system of training for consumer advisors in New Zealand.

Focus Group comments on this question

The focus groups talked about what form of training they believed is necessary. While they generally agreed with the skills listed by the CAFMHS, tertiary level training was not universally regarded as important. One group suggested post-graduate papers in recovery and community work would be useful, while another group preferred ongoing professional development that 'is not too academic'. Other training areas mentioned by the groups and not covered by the CAFMHS list are:

- Legislation that relates to mental health issues
- 'Like Minds' training (a national anti-discrimination programme)
- Cultural issues
- Relaxation techniques and stress management
- Youth culture
- Mentoring
- Interviewing, presentation and public speaking
- Computer skills
- Critical analysis of documents
- Training around the boundaries of the role
- Professionalism
- Youth-oriented training (in particular covering problems associated with power, status and ageism)
- Advocacy
- Peer support
- Human Rights
- Clinical processes

- Knowledge of the ways in which mental health services work with families and individuals.

Support for consumer advisors in the form of regular supervision and mentoring was considered essential, especially if the advisors were young people and therefore more vulnerable. Good relationships with key staff in the service are also essential. The direct employment of the advisor by the service was considered unsafe; contracting services from an outside agency could provide more protection as advisors could have support from a team or network. Peer support and mentoring, as well as local, regional and national forums, were all mentioned as helpful. Wellness plans need to be in place, and if the advisor is working in an inpatient unit, 'time out' from advising is seen as important.

Interview comments on this question

Negotiation skills and diplomacy are needed, assertiveness training is useful, and rather than training in specific clinical issues, it is best to look at the clinical process in terms of referral, treatment and discharge planning. It was also pointed out that it would be better if the employed advisor were based in an outside agency contracted by the service. To allow for a less clinical and more critical view, it was advisable for the advisor to be 'outside' the CAFMHS structure; there would be more safety for the advisor if their support lay outside the service. An understanding of one's own place in society and culture is important, as is an understanding of different cultural styles of coping with mental illness. An appreciation of the interaction between mental and physical wellbeing is valuable.

Question 7: *Please comment on any barriers and difficulties your service encounters in having consumer advisors.*

Comments are recorded below:

- There is no specific funding to pay consumer advisors
- It is problematic keeping young people and families/whānau involved in CAFMHS once they are well
- It is difficult to get a consumer group together and to maintain it
- There is not always staff commitment to support young consumer advisors
- Staff are not comfortable working with young clients
- It is difficult to create new structures that would fit alongside and support the existing feedback, monitoring and evaluation systems built into current processes
- The issue of employing consumer advisors is complicated, and it is unclear whether the consumer is the young client or their parent/caregiver

- Boundaries are a problem for both consumer advisors and staff; some guidelines would be useful
- A single consumer advisor cannot represent the wide range of ages and needs of clients in CAFMHS
- Young people who are/have been service users of CAFMHS are vulnerable
- Issues of confidentiality
- Difficulties in recruiting appropriate consumer advisors for young age groups
- Most CAFS representative groups appear to have a more consultative than participatory role. In other words, they are asked to provide feedback on documents that already exist, rather than being involved in the conception of the document. However, there is no monitoring system to ensure their feedback is incorporated
- Combining the role of consumer advisors for CAFMHS with the pressures of school or university, homework, family events, sport, music can be stressful.

Focus Group comments on this question

Groups asserted that there is never equality between staff members and consumers. This is partly because of the youth of advisors, but it can also be compounded by the stigma of being a past service user. It can be particularly difficult managing a different type of relationship with staff from the one established when the advisor was a service user. Service management can show prejudice and a lack of openness.

There are problems with money: Koha is not appropriate, and the role of consumer advisor needs to be funded and resourced adequately; for example, 25 hours per week is not enough time to do the job properly. This is particularly problematic if the advisor is also juggling school or university, meetings and family matters.

CAFMHS are not always willing to use the advice given by consumer advisors, who sometimes feel like political pawns. In some services, consumer advisors and representatives are used like 'window dressing' and only involved when it looks good to use them. It is very difficult to hear children's voices, especially since many parents do not want their children to talk about their experiences.

Difficulties ensuring the safety and confidentiality of young advisors were raised by management as reasons for not proceeding with peer support schemes. The Pacific Island focus group was concerned about issues of confidentiality in small Pacific communities. Being a consumer advisor would involve exposure to the high level of stigma associated with mental

illness, as some in the Pacific community believe mental illness comes from turning your back on God. The Māori focus group believed access to tamariki who are mental health consumers is a sensitive issue for Māori, and anyone taking on this role should be vetted by the police for safety reasons.

Interview comments on this question

CAFMHS may not be willing to make use of advice from consumer advisors, and the process is dependent on individual services having a strong leader who genuinely believes in consumer involvement. Authentic relationships between CAFMHS and consumer advisors can only be built where there are openness and willingness on the part of the service. For example, for those specialist services treating consumers with autism, it would be very difficult to find a person with an ASD who could work as a consumer advisor as these persons have difficulties forming relationships.

Question 8: *Are there other significant issues regarding consumer involvement in services that we should know about?*

Responses indicate:

- Child advocacy services need to be age-appropriate and take account of developmental stages
- CAFMHS are concerned there is insufficient time in clinical services to support the ongoing networking and relationship building required to keep consumer involvement an integral part of the service
- In some cases, youth representatives cannot join the organisation's adult representatives, as meetings are set when the young people are at school
- Services are concerned about issues of cultural safety, stigma, and the public perception that links crime and mental illness
- It is difficult for consumer advisors to communicate with clinicians who have another language and a different culture
- Some CAFMHS would prefer not to have a dedicated consumer advisor, instead preferring to consult an outside advisor as required.

Focus Group comments on this question

Groups stress that cultural perspectives are essential for recovery and wellness, and consumers must have the choice of 'Māori for Māori' services. The position of consumer advisor must not be voluntary for either the youth advisor or the family advisor.

Discussion

Due to the small number of survey responses received insufficient quantitative data are available to assess accurately the extent of consumer and family representation within CAFMHS in New Zealand. It cannot be assumed services that did not respond have no CAFMHS nor can it be assumed that if they do provide services, that they do not involve consumers as advisors. A telephone survey of DHBs and NGOs who did not respond to the survey could give a more accurate picture.

However, it would be useful analyse the qualitative data gathered from the surveys, focus groups and individual interviews as they contain the opinions and expertise of representatives from all stakeholder groups. Predominant themes emerging from the qualitative data are summarised below and provide the basis for recommendations.

Consumer advisors and representatives currently employed by CAFMHS fulfil a range of roles:

- A conduit of information between consumers and service providers and a means to connect with young consumers, enabling their voices to be heard (representative role)
- Using insights gained from personal experience to advise service providers on policy, planning, service development and implementation and participation on staff recruitment panels (advisory role)
- Role-modelling recovery, empowerment and inspiring hope (peer support role)
- Assisting resolution of complaints (advocacy role)
- Education and orientation programmes for staff and consumers (training/education role).

The major barriers to achieving adequate consumer representation in CAFMHS are:

- Services do not budget adequate funding to reimburse consumer advisors appropriately for their services, or to provide training or ongoing support
- Some mental health workers are uncomfortable working with young consumer advisors
- Problems for consumer representatives with boundary definition and balancing the dual roles of being an advisor to a service in which they have previously been, or currently are, a service user
- Lack of clarity on who is the consumer – the young client, the parent/caregiver, or both
- Inadequate recognition of the need to structure advisory services in a way that acknowledges the distinct needs and values of three

- developmental stages (children under 12, adolescents aged 13–15, youth aged 16–20), plus the needs of family/whānau and caregivers
- Advice not being listened to or acted on. In some instances consumer advisors feel they are used simply as 'political pawns' and 'window dressing' for certification
 - No standardized national strategy
 - Difficulties in recruiting young consumer advisors owing to other demands on their time and energy such as education, socialising. Arguably, young people's recovery is not supported by making a 'career' of their experience of mental illness
 - Isolation and lack of support compromises the successful use of advisors working alone in a CAFMHS
 - Inadequate representation for young Pacific people. This poses a particular challenge as there is concern about confidentiality in small Pacific communities, both for clients and for consumer advisors, given the stigma attached to mental illness in some areas of the Pacific community
 - The ratio of Maori advisors does not fully reflect service use by young Maori, and it is not always possible for Maori advisors to work in a manner consistent with Kaupapa Maori
 - Young people of other ethnicities use mental health services, for example Asian, Iraqi, Somali and Bangladeshi. Currently they have no representation in CAFMHS.

The CAFS representative structure used in Christchurch is a good system for involving young consumers for a number of reasons:

- Young consumers are involved and visible
- All staff members know who they are and what they do, and, it would appear, support them in this
- The support systems provided for them are well established and robust. A mentor provides support, guidance and encouragement for new members in the group, when a specific task is taken on
- If a CAFS representative becomes unwell there are guidelines for their protection, and the person affected can take leave of absence and receive support from a non-staff group member
- Each advisor is part of a group of representatives rather than working alone across all units
- Each new member of the group is provided with a comprehensive orientation package, including the group's terms of reference and minutes from the previous 6 months' meetings.

Recommendations

- **Review Blueprint requirements for consumer involvement in CAFMHS**

New Zealand's mental health policy, as articulated in the National Mental Health Standards, promotes involvement of consumers in mental health service at the levels of policy, planning, service delivery and evaluation. However, there are regional variations in the way this is implemented as reported in the *Update on the Blueprint*, (2003) and confirmed by this research.

It is therefore appropriate to review policies and standards related to consumer involvement in CAFMHS and in particular ask: Are Blueprint recommendations appropriate in the light of research that shows children and young people are able to articulate what they want from services? (*Blueprint recommends that the resource for consumer and family input in the 15–19 age group be 0.4 FTE per 100,000 of the population. It does not recommend any resource for consumer and family input in the 0–14 age group.*)

- **Review the application of Standard Nine of the National Mental Health Sector Standards**

Ensure auditors appropriately assess the level of involvement of consumer advisors in CAFMHS to ensure they are fully used and not merely “on show” in an effort to satisfy the Standards.

- **Require all CAFMHS to budget for a consumer advisory service**

Auckland District Health Board is an example of a DHB that is well resourced in terms of consumer involvement. With a workforce of approximately 700 staff, ADHB contracts the services of 4.8 FTE equivalents of consumer advisors. This represents approximately 0.5% of its workforce budget. A legal requirement for all CAFMHS to ring-fence a similar proportion of their workforce budget may overcome current barriers to providing an optimum service. An appropriate level of funding would assist in:

- increasing the number of advisors per service so young advisors no longer have to work alone with inadequate support
- reducing the number of units and service users each advisor are expected to cover. This would allow for appropriate involvement in different age groups, giving advisors time to fulfil all requirements of their job descriptions

- providing adequate training, supervision and mentoring.
- **Form a national association that supports CAFMHS consumer advisors to work effectively**

The National Association of Mental Health Services Consumer Advisors (NAMHSCA) is a body of forty-two potential members, the leading mainstream and tangata whaiora advisors from each of the twenty-one DHBs. As such, few, if any, CAFMHS advisor would qualify for membership. However NAMHSCA does provide a useful model for an association for CAFMHS advisor as well as the possibility of a mutually beneficial collegial relationship between the memberships.

A national body of young consumers involved in CAFMHS could promote:

- The development of standardised training, job descriptions or terms of reference for consumer advisors
- Mentoring and the opportunity to meet with peers
- The development of tangata whai ora consumer advisory services for young Maori using kaupapa Maori services
- The inclusion of Pacific Island and other ethnic groups as consumer advisors
- Standardisation of service specifications for all CAFMHS, whether DHB or NGO based
- Professionalisation of the consumer advisory role by developing codes of practice. This may go some way to countering the stigmatisation encountered by some advisors when working with staff who have not yet recognised the value of service user participation

The above recommendations require changes at a national level and will consequently take time to implement. The recommendations that follow can be readily implemented through CAFMHS' commitment to developing effective and comprehensive consumer participation:

- Appropriately reimburse consumer advisors for the services they currently provide
- Provide support by means of supervision, mentoring and facilitating connections with peers
- Provide training for new advisors and in-service training for existing advisors
- Assess staff attitudes towards young consumer advisors and provide in-service training to minimise stigmatisation, disempowerment and ageism where necessary

- Train staff in health care ethics and the law as it relates to minors to clarify who is the service user – the child, the family or both
- Structure young peoples' advisory services in a way that acknowledges the distinct needs and values of the three developmental stages (children under 12, adolescents aged 13–15, youth aged 16–20) plus the needs of family/whānau and caregivers
- Ensure policy and planning meetings include consumer participation and give consumer advisors opportunity to examine carefully drafts and revisions of all documents
- Schedule meetings at times that do not conflict with the consumer advisors' other obligations, for example, hold meetings outside school hours
- Employ designated tangata whaiora advisors and acknowledge the need to support kaupapa Maori protocols
- Employ designated advisors to work with young Pacific people where necessary and seek ways to use the advice of young people from other ethnic groups as appropriate.

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APPENDIX A

CAMHS Services Questionnaire

1. Are you a specialist provider of child and adolescent services?

Yes No

(if no please do not complete, but email us to remove you from the list)

If yes, can you tell us please:

a. The age range of your clients:

To

b. Approximate number of clients using your service at any one time:

c. The ethnic groups using your service in significant numbers:

d. The people using your service are:

Mainly female
 Mainly male
 About 50/50

2. Do you have consumers working in an advocacy, representative or advisory role?

Yes No

(if no please go directly to question 7)

If yes:

How many are voluntary?

How many who are employed / contracted?

Total FTE

a. Are these consumers:

i. Current services users of your service?

ii. Past service users?

iii. Users of adult services

b. What age are the consumer advisors? (enter number if more than one)

- Under 12
- 13–15
- 16–18
- 19–25
- over 25

c. What ethnicity are the consumer advisors? (enter number if more than one)

- Maori
 - European
 - Pacific
 - Asian
 - Other (please specify)
-

3. Do you have family members involved in advocacy/advisory role?

Yes No

4. What areas of your service are your consumer advisors involved in? Please mark all those that apply.

- Consumer surveys
- Quality improvement
- Service development
- Policy development/review

<input type="checkbox"/>	1:1 peer support
<input type="checkbox"/>	Group peer support
<input type="checkbox"/>	Advocacy for individuals
<input type="checkbox"/>	Staff recruitment panels
<input type="checkbox"/>	Staff education
<input type="checkbox"/>	Consumer education
<input type="checkbox"/>	Others (please specify)
<input type="text"/>	

5. Do you have terms of reference or job descriptions for consumer advisors?

Yes No

Will you allow us to have a copy of the relevant documents?

Yes No

If yes, please attach a copy.

How do you train your advisors/advocates?

<input type="checkbox"/>	In-service training
<input type="checkbox"/>	External training
<input type="checkbox"/>	University
<input type="checkbox"/>	Polytechnic
<input type="checkbox"/>	Other (please specify)
<input type="text"/>	

What skills do your advisors receive training in?

In what additional skills would you like to see training available?

6. Please comment on any barriers and difficulties your service encounters in having consumer advisors?

7. Are there other significant issues regarding consumer involvement in services that we should know about?

**IF YOU WOULD LIKE A SUMMARY OF THIS RESEARCH AT THE
CONCLUSION OF THE PROJECT PLEASE TICK HERE**

THANK YOU FOR YOUR TIME

APPENDIX B

Focus Group Interview Questions

1. The role of the consumer advisor:
 - a) What needs to be achieved?
 - b) How is this achieved?
2. What are the training needs for the role of consumer advisor?
3. What personal qualities are needed?
4. What are the support needs for someone in the role of consumer advisor?
5. What are the barriers for consumer advisors?
6. Are there any other comments you would like to make?