EVALUATION OF THE WHĀNAU CARERS TRAINING PROGRAMME DELIVERED BY LIFE UNLIMITED

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February 2004

ACKNOWLEDGEMENTS

The research team would like to thank LeAnne Kingi from LIFE Unlimited for her continual assistance throughout the evaluation process. Thanks also to Barbara Tane for her contribution to our research.

Our thanks to Bridgette Masters for her supervision and guidance throughout the entire research process, and to Neville Robertson and the Māori and Psychology Research Unit, who gave us the opportunity to participate in this evaluation.

Thanks also to Ruth Hungerford for her teaching, sharing of experiences, and ongoing advice throughout the year.

Finally, we would like to extend our appreciation to the whānau carers who took time out of their busy lives to provide us with their views of the whānau carers training programme. Thank you for your participation in our evaluation.

Me te mihi nui

Allanah, Sally and Keri

EXECUTIVE SUMMARY

In response to the needs of Māori informal carers, a training programme was developed for whānau carers in the Waikato region. It was delivered by LIFE Unlimited, an organisation which has informally delivered similar services to informal caregivers in the past. It is a unique training programme in that it is community driven and focuses on informal caregivers who are Māori. The overarching aim of the whānau carers training programme is to provide increased training and support of informal carers.

This evaluation of the whānau carers training programme involved the recording of events at workshops in Kāwhia and Te Kuiti, and is a part of a larger evaluation project being conducted by the Māori and Psychology Research Unit (MPRU) of the University of Waikato, for the Ministry of Health. The evaluators aimed to investigate the effectiveness of the whānau carers training programme, including: the unique nature of the programme, the critical success factors, the barriers to success if any, and suggested improvements.

Evaluative data was gathered through document analysis, a review of literature, stakeholder meetings, observation analysis, written questionnaires, and follow-up telephone interviews. The stakeholders for the evaluation were: The Ministry of Health; LIFE Unlimited; the whānau carers and their whānau members.

The unique nature of the programme

The whānau carers training programme delivered by LIFE Unlimited is unique and has been developed for a specific audience. One of the essential qualities of this programme is that it is community driven in terms of what is provided and where the programmes are held. The programme aimed to train and support informal caregivers that are Māori, and the 'by Māori for Māori' approach that was adopted by LIFE Unlimited has allowed the facilitators to specifically address the needs of Māori whānau carers.

Critical success factors

The research findings highlighted a variety of factors considered important to the success of the whānau carers training programme. These were:

- The impressive ability of the senior facilitator to create rapport with the whānau carers, and her ability and leadership in assisting and supporting the junior facilitators.

- The delivery format used within the workshops by facilitators was clear, supportive, positive and contributed to a proactive learning environment.

- Key contact people within the rural community were utilised to help publicise and recruit whānau carers in to the training programme.

- Whānau carers reported feelings of empowerment following the training programme, where information gained from the workshops proved useful and in their role as a whānau carer.

- Whānau carers reported the acquisition of new skills, knowledge, and confidence in dealing with relevant organisations or agencies.

Barriers to success

Whānau carers were generally very pleased with the training programme, and so reported few barriers to its success. However, the following areas of concern were identified by the senior facilitator:

- The inability to access a large number of whānau carers in the community.

- Publicity and advertising methods, using newspapers and radio had not been successful.

- Lack of key contacts in rural areas to set up further training workshops

While recognising that limited conclusions can be drawn from the relatively small number of participants who took part in the research, it is still obvious that the whānau carers training programme has had a positive and definite impact upon the whānau carers. The evaluation team has observed that the overall programme works very well and fulfils its stated obligations to the Ministry of Health. The programmes are delivered well, and are well received by the client group.

Recommendations

In light of the evaluation, we make the following recommendations:

i. *That LIFE Unlimited continue to utilise ongoing evaluations in order to continue the successful operation of this programme.*

ii. *That LIFE Unlimited ascertain which models of communication are the most effective, when planning future training programmes.*

iii. *That LIFE Unlimited support and encourage the programme facilitators to engage in ongoing training that will enhance the delivery of future training programmes.*

iv. *That the Ministry of Health continue funding the whānau carers training programme.*

ii. *That the Ministry of Health create and regularly maintain a database of key contact people, to assist in developing further whānau carer training programmes.*

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1.0 INTRODUCTION

1.1 Background

The Ministry of Health (MOH) contracted several service providers throughout New Zealand to deliver training programmes to informal caregivers. Informal caregivers are recognised as unpaid people, including family members and friends, who provide care for a person with a disability.

The common and overarching aim of these training programmes funded by the Ministry is to increase the support of informal carers. Specifically, these programmes aim to enable informal caregivers "to continue their role within the community with an increased sense of confidence and knowledge, accessing resources as appropriate and networking with others to gain support". (Hendry, 2001, p. 5).

In response to the needs of Māori carers, a training programme was developed for the use of whānau carers in the Waikato region. It was delivered by LIFE Unlimited, which is based in Hamilton. LIFE Unlimited is an organisation which has informally delivered similar services to caregivers in the past (LeAnne Kingi, personal communication, May 2003). However, the current whānau carers training programme, is the service provider's first formal project funded by the Ministry of Health. It is a unique training programme in that it focuses on informal caregivers who are Māori. That is, the programme will be delivered *'by Māori for Māori.'*

It was noted in discussions with Trish Davis, Locality Manager for the MOH, that several service providers submitted proposals for the funding of various training programmes for informal carers, but very few of those targeted Māori. The Ministry identified that by Māori for Māori training workshops, such as those that would be provided by LIFE Unlimited, were necessary in increasing the support of Māori informal caregivers. This was a key rationale in accepting the proposal by LIFE Unlimited to develop a whānau carers' training programme, and to approve its funding (Trish Davis, personal communication, 8th May 2003).

1.2 The whānau carers training programme

The whānau carers training programme was delivered in various rural areas throughout the Waikato region by LIFE Unlimited. It consisted of a series of workshops, each focussed on different areas of training and coping strategies for caregivers. The specific content of each workshop was determined at preliminary hui between the programme facilitators and representatives from the communities involved. Hence, each workshop within the training programme was tailored to meet the specific needs of the whānau carers who would be attending. Training included (but was not limited to) basic first aid training, relaxation strategies and information on accessing relevant services. In terms of delivery, the programme facilitators called on a number of guest speakers to present information to the whānau carers, as well as utilising different staff members from LIFE Unlimited.

The main objectives of the whānau carers' training programme were to:

- Develop more confidence within whānau carers and their ability to care for their whānau member
- Develop the confidence of the whānau carer to access all services available for their whānau member
- Develop strategies for whānau carers to maintain their own wellness and safety
- Ensure whānau carers have a better understanding of the Needs Assessment and Service Coordination Services (NASC) process and support available to them
- Ensure whānau carers have the ability to develop new networks of support

1.3 Evaluation

This evaluation of the whānau carers training programme involved the recording of events at workshops in Kāwhia and Te Kuiti and is a part of a larger evaluation project being conducted by the Māori and Psychology Research Unit (MPRU) of the University of Waikato, for the Ministry of Health.

Evaluation Purpose

The evaluation that was undertaken was formative in nature. The rationale for this was that the whānau carers training programme is in its early stages of development, and an evaluation could assist in the programme planning and development. We aimed to investigate the effectiveness of the whānau carers training programme, with a focus on the carers' perspective. The objectives of the evaluation were to:

- Describe the unique nature of the programme
- Identify the critical success factors of the programme
- Identify any significant barriers to the success of the programme
- Make recommendations for improvements to the programme
- Address any other relevant issues

The Evaluation Team

The evaluation was undertaken by three graduate students from the Psychology Department at the University of Waikato, as part of a course requirement for the paper Evaluation Research. The three students were Allanah Ashwell, Sally Ridley and Keri Thompson. The evaluation project was supervised by Bridgette Masters, who is one of the primary evaluators in the Māori and Psychology Research Unit (MPRU) project, contracted by the MOH.

The MPRU is a catalyst for Māori focussed research, and is located within the Psychology Department at the University of Waikato. To date, the MPRU has completed over 50 projects, including written publications, presentations, commissioned reports and student research.

2.0 LITERATURE REVIEW

This literature review supplements the evaluation of the Whanau Carers Support Training Programme delivered by community based service provider LIFE Unlimited, and funded by the MOH. The aim of this literature review is to document information related to informal care for people with disabilities, and to ultimately focus on Māori needs and Māori-focussed approaches to service delivery for informal carers. Key areas of discussion here include defining disability, understanding the dynamics of Māori whānau, Māori and disability, informal caregiving, profiles of caregivers, caregiver needs, barriers to accessing services, valuing and supporting caregivers in their role, and creating accessible services for Māori.

2.1 Disability Defined

Regardless of age, culture, religious beliefs, economic circumstances, or family situation, we can all expect to require care, provide care, or have close relationships with others in caring roles at some point during our lives (Case, 2000; Gibson, 1997; Lewis & Meredith, 1988; NHC, 1998; Qureshi & Walker, 1989; Singer & Powers, 1993; SPRU, 2001; Weaver, 1999).

Whilst the words disability, handicap and impairment are often used interchangeably, they are three distinctly defined terms. Livneh and Antonak (1997, p. 70) have given some useful definitions of these terms, which were adapted from the World Health Organisation. These are given below:

Impairment: "any loss or abnormality of the psychological, physiological, or anatomic structure or functions", which are seen as disturbances at[?] the body organ or systems level.

Disability: "any restriction or lack of ability to perform an activity in the manner or in the range considered normal for a human being", or disturbances at the person level or self-system.

Handicap: "a disadvantage for a given individual, resulting from an impairment or disability that limits or prevents the fulfilment of a role that is normal" (dependent on age, sex and social and cultural factors).

The MOH deems that a person with a disability will have at least a physical, sensory, psychiatric, intellectual and/or age related impairment (Ratima, Durie, Allan, Morrison, Gillies, & Waldon, 1995). Physical impairment is the most common disability. Nearly 43% of the population of New Zealand has a sensory disability which includes seeing and/or hearing impairments (NHC, 1998).

The proportion of most populations, whose disability prevents them from functioning to a significant degree, is commonly agreed to be about one in five people (NHC, 1998; NZDS, 2001). More than 674,000 adults and children living in New Zealand households report at least one disability; this is approximately 19% of New Zealand's total household population (i.e., not including those in institutional care) (NHC, 1998). This is not to say however that all disabled people require full time care.

Many people are unable to reach their potential or participate fully in their community because of barriers they face doing things that most New Zealanders take for granted (Barnes, 1994; Kingi & Bray, 2000; NHC, 1998). These barriers range from the purely physical, such as the inability to feed or dress oneself or the difficulty of accessing facilities designed primarily for non-disabled people, to the attitudinal, caused by ignorance and poor awareness of disability issues by others (NZDS, 2001).

Nearly one third of all adults and children in New Zealand report a lack in service provision and accessibility (NHC, 1998). It can be seen that the disability itself is often access to 'things' that most of society take for granted, rather than the impairment that an individual may have (Ballard, 1994; Marinelli & Dell Orto, 1999; NZDS, 2001). These figures and difficulties not only represent the barriers facing many disabled people, but also those of whānau carers.

2.2 Māori concept of whānau

A variety of attempts have been made throughout the literature to define the Māori concept of whānau. The most basic of these would define whānau as the extended family. Durie (1994 cited in Ministry of Health, 1998) goes further to describe whānau as "a diffuse unit, based on a common whakapapa…and within which certain responsibilities and obligations are maintained." (p. 2). Such obligations include protecting, nurturing, guarding, sharing, enabling and more. All of which typify the role of a family/informal caregiver.

In relation to the Māori concept of whānau, Mirin-Veitch et al (1997) found in their study that extended family contact was an integral component of the general functioning of a family with a disabled child. Similarly, Aranda and Knight (1997) alluded to the 'cultural value' of familism, a value present in family caregivers which was defined as; "a strong identification and attachment of individuals with their families (nuclear and extended), and strong feelings of loyalty, reciprocity and solidarity among members of the same family" (Sabogal, Marin, Otero-Sabogal, Marin, & Perez-Stable, 1987, pp. 397-398, cited in Aranda & Knight, 1997, p. 349).

Within a New Zealand context, the role of whānau in Māori health has been acknowledged as important, and has hence been incorporated within service policies and strategies.

> Given the central role that whānau play in the wellbeing of Māori individually and collectively, public health policy directed at improving the health status of Māori might best be directed at whānau. (Public Health Commission, 1995, cited in Ministry of Health, 1998, p. 1).

2.3 Māori and disability

In Māori culture, health and wellbeing are viewed holistically and should be approached that way (Ministry of Health, 1998). Mason Durie's Te Whare Tapa Whä model of Māori health provides a helpful framework from which Māori support services could be modelled. It takes into account spiritual wellbeing, mental wellbeing, physical wellbeing and whānau wellbeing. Hand (1999) also reported that good care of an individual would require a holistic approach. In doing so, attention should be given to the whole person, to his or her family, and to the social environments in which they live.

Statistics New Zealand (1998, cited in CDP, 2003) show that more Māori spend time caring for family/whanau members than do non Māori, and that overall Māori women spend the most time caring for family members. However, a welfare report presented by CDP (2003) shows that Māori are less likely to get special welfare benefits than European New Zealanders. This type of disparity has been noted in other Government departments including the Health and Education sectors (Ballard, 1994; Kingi & Bray, 2000). These issues combined mean that Māori women, already disadvantaged in many respects, are further underprivileged.

2.4 Who are informal carers?

Informal carers in the context of this literature review are unpaid caregivers; people who have some sort of relationship with the disabled person as opposed to paid, official, residential, or medical caregivers. According to the NZDS (2001) unpaid and informal carers are those who care for a relative or friend without payment other than a pension or benefit. The definition does not include paid care workers or volunteers arranged by formal care services. More often than not, informal carers are family or whānau members, who become essential components in the support network of the individual needing care. This enables people with disabilities to live in their own homes and communities (CDP, 2003; NHC, 1998).

According to Ballard and Brown (1997, cited in NHC, 1998), caring for people with disabilities in their own home is up to 30% cheaper than keeping them in a rest home, hospital or institution. The NHC (2000) reported that if informal carers were to stop providing care for their whānau members with disabilities, the average cost to the taxpayer would be much higher, as people with disabilities would then have to be shifted into formal care.

2.5 Profiles of caregivers

Two New Zealand studies, which looked into the profiles of informal caregivers, found similar results. The key points to emerge were that caregivers were most likely to be women (75% in the first study, and 80% percent in the second study), were most likely to be over the age of 40, and were most likely to be caring for their parents, spouse or partner (Abbott and Koopman-Boyden, 1994 cited in NHC, 1998; Belgrave and Brown, 1997 cited in NHC, 1998). In another study, Hirst and Arksey (2000 cited in SPRU, 2001) reported that between 2.8% and 1.5% of the adult population provide 20 hours or more of informal care per week. Their findings also show that care is most often provided for a person's spouse or parent (66% of all cases), and that caregivers within their sample were predominantly women.

The findings of these three studies have a number of commonalities. Overwhelmingly, women are positioned as carers. Many people are also providing high levels of care with little or no outside support. The high numbers of women found to be in caring roles combined with the findings of Belgrave and Brown (1997), that nearly sixty percent of people in caring roles are between the ages of 40 and 60 supports the 'sandwich generation' hypothesis, which speaks of people, predominantly women who are caring for children and parents at the same time. The age distribution of carers is significant also. One study revealed that 20% of carers were over 80 years old. In New Zealand, most carers are within the ages of 65 – 74. This is consistent with the notion that New Zealand has an ageing population.

One could speculate that the New Zealand study was aimed at collating data concerning older people as it does not appear to reflect the population of parents caring for disabled children, but the overall results do represent a large proportion of care being undertaken by older people whose vulnerability to health-related problems is increased by virtue of their age.

Yet another study within New Zealand investigated caregiving in a sample of women who were mothers of children born in Dunedin Hospital between 1972 and 1973. The findings revealed that 47% of carers cared for parents (including in-laws), and 16.5% for sons/daughters, as opposed to aunts, uncles, nieces, nephews, friends, grandparents, spouses and siblings. Thirty-four percent of carers in this sample where caring for more than one person at a time (Knight, Williams, McGee & Olaman, 1998).

2.6 Costs and stressors of caregiving

Although positive and rewarding aspects of providing care for a family member were identified in the literature, studies into the stressful and burdensome aspects of informal care-giving were more common (Aranda & Knight, 1997; Cousins, Davies, Turnball & Playfer, 2002; Hand, 1999; Knight, Williams, McGee & Olaman, 1998; Lefley, 1997; McCallion, Janicki, & Grant-Griffin, 1997).

It was stated that when the work required exceeds the resources of the caregiver (when the demands of the role become excessive and unremitting), it results in strain and stress. Some studies reported that caregiver strain was cumulative, and was directly related to the level of need by the person being looked after (Cousins et al, 2002; Knight, Williams, McGee & Olaman, 1998; Lefley, 1997).

The literature commonly reported a wide range of stressors associated with caregiving. These included social impact and personal cost, mental stress, and financial strain.

Social impact

Lefley (1997) discussed how relationship distress could be a result of the stressors of caregiving. To illustrate, it was stated that a dependent disabled child can often be upsetting to marital relationships, which may result in conflict and resentment between partners. In terms of the social impact in a more open arena, the literature stated that there are few social rewards in care-giving, and that stigma from professionals is rife. (Lefley, 1997). To explain, many family caregivers have suffered greatly from family-blaming theories. One example included reference to when a child is born with a disability. Blaming some element in the family, usually the mother, for the disability is common, and often based on such things as activities she undertook, foods she did or didn't eat or carelessness on her part. This type of treatment from relatives and others often results in parents tending to keep to themselves (Hand, 1999; Lefley, 1997).

Emotional burdens, such as guilt and shame, were also identified and discussed as stressors in the literature (Hand, 1999; Hilsgen, 2002; Lefley, 1997).

Mental Stress

Findings in the United Kingdom (SPRU, 2001) attest to the adverse affects to carers' mental health when they take on a caring role. Specifically, this refers to the following concerns:

- The risk of anxiety and depression rises progressively with the numbers of hours devoted to caring each week;
- Distress levels in the carer population increase during the first year of care-giving and do not return to former levels as caring continues;
- Among those taking on full time or continuous care, women are almost twice as likely as men to report increased distress.

According to Gibson (1997), Norris (1988) and Qureshi and Walker (1989), women have traditionally taken on more informal caring roles than men. These findings can help explain the higher proportion of women carers reporting increased distress in comparison to men. Put simply, whilst there may be twice as many women reporting distress, there are four times as many female carers than male carers.

New Zealand based literature shows similar concern on the mental health of informal carers. Specifically, if carers continue to provide care beyond their coping ability, carers risk their own health and well being, as well as that of the person they care for (NHC, 1988). For example, Belgrave and Brown (1997, cited in NHC, 1998) warn that "the amount of personal stress and hardship can affect the quality of care given…the potential is real for the informal care situation to deteriorate."

Financial stress

Financially speaking, carers are generally worse off than non-carers. The various commitments involved in informal caregiving often prevent carers from engaging in paid work, volunteer work or recreation. As a result of this, accessing and paying for formal services and professional help is often very difficult. In addition, carers are left uncertain about their financial future, which they have not been able to adequately prepare for (Gibson, 1997; Hand, 1999; Lefley, 1997; NHC, 1998; Qureshi & Walker, 1989; Singer & Powers, 1993; SPRU, 2001). This illustrates a need of caregivers for not only emotional and physical support, but for financial support and greater opportunities as well – such as compensations for lost job opportunities, reimbursements, subsidies and the like (Hand, 1999).

2.7 Caregiver needs

In recent years, awareness of both the importance of carers in the community, and of their needs, has increased (Moore & Tennant, 1997; NHC, 1998; NZDS, 2001).

Every caregiving situation is unique, and carers face many challenges, (Ballard, 1994; Case, 2000; Gibson, 1997; Kingi & Bray, 2000; Lewis & Meredith, 1988; NHC, 1998; Qureshi & Walker, 1989; Singer & Powers, 1993; Weaver, 1999). Providing support for carers is necessary in order for carers to provide optimal care for their family/whanau members as well as themselves. Hirst and Arksey (2000, cited in SPRU, 2001) recorded the following as carer-defined needs:

- Being kept fully informed about the diagnosis, specific needs, and services available for their family members.
- Being fully supported in their role.
- Having their own needs, well being and health taken into consideration.
- Having access to quality health services for themselves and their family member.
- Having access to respite services.
- Having a voice in service development.
- Being listened to and having their opinion valued by health service providers.

Furthermore, and in support of the NHC findings, lack of knowledge of services, lack of access to services, poorly designed or non-user-friendly services, culturally inappropriate services, difficulty obtaining funding for needs, and lack of suitable support from helping agencies, exhaustion, stress, resentment and feelings of loneliness and desperation, and lack of recognition for the importance and difficulty of the job have all been identified as areas of concern to carers (Ballard, 1994; Barnes, 1994; CDP, 2003; Harrison, 1995;Hilsgen, 2002; Katzenellenbogen, Jakob-Hoff & Millard,1997; Kingi & Bray, 2000; Moore & Tennant, 1997; Qureshi & Walker, 1989; Singer & Powers, 1993; Taylor, Bogdan & Racino, 1991; Weaver, 1999).

2.8 Barriers to the utilisation of services

Despite the need for help, McCallion, Janicki, & Grant-Griffin (1997) reported that many care-giving families actively avoid contact with service systems. This was associated with the following barriers:

- A rejection of service systems because of poor experiences in the past
- A belief that siblings will take responsibility for the person if they eventually can't
- A fear that planning will result in the immediate removal of the family member
- A lack of knowledge about service alternatives
- A belief that no one else can provide the same level of care that they provide
- An unwillingness to acknowledge that through their own death or illness, that they will be unable to provide the family member with lifetime care

A number of different studies (cited in McCallion et al., 1997) have attempted to explain why there is a greater tendency of under-utilisation of services by cultural minorities. It was found that this was sometimes due to a greater availability of extended family supports, suspicion of formal structures, cultural beliefs that one should take care of one's own, ethnic families' preference for family caregiving and not discussing their problems with strangers and low expectations of "White-culture" institutions.

It has been recorded by several sources that Māori under-utilise primary health services (Malcolm 1995 cited in Ministry of Health, 1998; Marwick & Crampton, 2003; Pomare, Keefe-Ormsby & Ormsby, 1995, cited in Ministry of Health, 1998). It was reported that this is due primarily to perceived cost barriers, location barriers, cultural barriers and structural barriers (Marwick & Crampton, 2003).

2.9 Valuing Carers

Generally speaking, informal carers are under-valued. They are unpaid and often ignored or devalued by health professionals and by a system that expects them to be unpaid carers but does not acknowledge them as performing a valuable and necessary task. They rarely or with much difficulty gain funding for their requirements which in turn creates difficulties for both them and the person./people they care for. "Persons providing informal care for a frail or impaired relative or friend in the community are a health service resource seldom acknowledged in any tangible manner." (Knight, Williams, McGee & Olaman, 1998, p. 616). In addition to this, the literature repeatedly reports that there is currently inadequate support and respite for caregivers which further elevates the stressors of care-giving (Hand, 1999; Cousins, Davies, Turnball & Playfer, 2002; Lefley, 1997;).

Areas identified by NHC (1998) which need to be addressed for optimal carer support are;

- Recognition for the job they do

- Competent proactive needs assessment for the carer at the same time as the cared for
- Availability of suitable information
- Financial concerns
- Provision of adequate services
- Recognition and reduction of isolation
- Proactive support from health services
- Culturally appropriate services

2.10 Carers' support networks

The literature has variously documented the importance of social support as a resource for caregivers who must cope with stress. This particularly refers to the support received by the extended family. For example, throughout the literature grandparents have been identified as vital sources of support for families with disabled children (Mirin-Veitch, Bray and Watson, 1996; Mirin-Veitch, Bray & Watson, 1997; Findler, 2000). This typifies the concept of manaakitanga by the whānau, and could be identified as an integral aspect of the informal support network of the Māori caregiver. In their paper on intergenerational relationships in families including children with disabilities, Mirin-Veitch et al. (1997) challenged professionals to encourage a level of involvement by grandparents (or other extended family members) in the care of high-need or disabled children. References are made to workshops, which have been designed to educate and inform grandparents as supporters of parent caregivers. They went on to state: "Workshops of this kind are reported to have had significant success in helping grandparents come to terms with their grandchild's disability, and as a result, become less of a burden and more of a support to the child's parents" (Gabel & Kotsch, 1981; George, 1988; Meyer and Vadasy, 1986; ?? & Turnball & Turnball, 1990, cited in Mirin-Veitch et al, 1997, p. 305). Mirin-Veitch et al (1997) suggested that interventions and strategies could be based on relationship counselling in families, as this would contribute to more effective networks of informal support within families. In contradiction to the majority of the literature reviewed however, Lefley (1997) advised that although large family networks can provide extra support, such networks can also be a source of intrusiveness, bad advice and conflict.

At present in New Zealand a national network of carer support groups is evolving, which focus solely on the needs of carers. Support has also been set up via the Internet, including websites such as carer.org.nz. Furthermore, carer support programmes are crucial. This comes through clearly in all the relevant literature (Ballard, 1994; Barnes, 1994; CDP, 2003; Harrison, 1995;Hilsgen, 2002; Katzenellenbogen, Jakob-Hoff & Millard,1997; Kingi & Bray, 2000; Moore & Tennant, 1997; Qureshi & Walker, 1989; Singer & Powers, 1993; Taylor, Bogdan & Racino, 1991; Weaver, 1999). Programmes which are specifically designed to meet the needs of Māori are needed even more in New Zealand (Ballard, 1994; Barnes, 1994; Broughton, 1999; Durie, 1994, 2001; Katzenellenbogen et al, 1997; Kingi & Bray, 2000; Moore & Tennant, 1997; NHC, 1998; NZDS, 2000, 2001; Ratima et al, 1995).

2.11 Support for Māori carers

The Treaty of Waitangi provides a platform for providing culturally relevant health and social services for Māori. From this assumption, Māori have the right to be able to access culturally appropriate support when caring for a whānau member with a disability. Despite this, service interventions and programmes have not always been relevant to Māori, and may therefore be ineffective.

Lack of access for Māori has been identified as an issue insofar as Māori whanau carers are concerned (Ballard, 1994; Barnes, 1994; Broughton, 1999; Durie, 1994, 2001; Kingi & Bray, 2000; Moore & Tennant, 1997; NZDS, 2000, 2001; Ratima et al, 1995). Ballard (1994) states that Māori people live surrounded by their own culture, but also as that of the Päkehä people. He highlights how disabled Māori have a double struggle in terms of their disability and the lack of recognition of their culture. The best possible scenario when it comes to meeting Māori whānau needs, in the most optimal way, seems to be Māori for Māori services. This has been born out by many different studies in the literature (Ballard, 1994; Barnes, 1994; Broughton, 1999; Durie, 1994, 2001; Katzenellenbogen, Jakob-Hoff & Millard, 1997; Kingi & Bray, 2000; Moore & Tennant, 1997; NHC, 1998; NZDS, 2000, 2001; Ratima et al, 1995).

Durie (1996) stated that direct participation is probably a prerequisite for improved Māori health, at least in terms of the Ottawa Charter with its emphasis on community empowerment as a critical factor in health promotion. He goes further to acknowledge that the provision of health services by Māori providers over the years has achieved positive and measurable outcomes. The suggestion is that this positive trend can continue and improve with the development and continuation of Māori services.

The evaluation conducted by Barnes in 1994 for the Alcohol and Public Health Research Unit, provides many examples of interviews with Māori that stress the importance and essentiality of by Māori for Māori services, with input from Māori from the planning stages through to the delivery. Broughton (1999), Kingi and Bray (2000), Moore and Tennant (1997), NZDS, (2000, 2001), Ratima et al, (1995), and Ballard (1994) all concur with these sentiments.

For informal caregiving to continue, proactive support of carers is important (Ballard, 1994; Hilsgen, 2002; NHC, 1998; Solomon, Pistrang & Barker, 2001). The literature also suggested that much could be accomplished in the education or training of caregivers: "Good family education can also be of immeasurable help in clarifying and alleviating a basic element of caregiver burden" (Lefley, 1997, p. 445).

2.12 Conclusion

Overall, there is a dearth of literature surrounding issues of informal care-giving within Māori whānau. Because of this, the scope of this literature review was broadened quite significantly to include 'general' information on informal caregiving as a vital role in the health of the family, the stressors of such a role, and the possible coping strategies required. The limitation of this literature review lies in the fact that few studies were found which looked at evaluating training programmes for caregivers in general, let alone Māori caregivers. However, a number of important points have been made in this review.

While caring can be a positive experience for many carers, the role of caring can involve substantial personal costs, both in terms of mental and physical stress and in lost opportunities for work, the earning of income and leisure (CDP, 2003; Hilsgen, 2002; Kingi & Bray, 2000; N.H.C, 1998; Weaver, 1999). Informal carers undertake a tremendously difficult, but essential job, and the literature suggests that the role of caregiving is one that many people will carry out at some point in their lives. Several studies also state that women are far more likely that men to become carers and often the task will fall on them when they are past middle age. It has also been recognised that the acquisition of the caregiving role by many leads to financial and personal hardship and stress.

There needs to be official and tangible recognition of the burden carers have taken on in order to support their disabled family members to remain at home. Making generous provision for caregiver needs, along with an emphasis on quality service provision are areas the Government, through the Ministry of Health and various satellite agencies needs to address. In relation to whānau caregiving, there is evidence to show that Māori needs are best met by Māori designed, developed and delivered programmes. This should be taken into account when developing training programmes for Māori carers.

3.0 METHOD

In this section we provide an overview of the methods that were used to collect information for the evaluation. This was a formative evaluation of the whānau carers training programme delivered by LIFE Unlimited, hence the information gathered was intended for use in refining and improving the programme. The methods used are outlined below:

3.1 Literature review

Although undertaking a literature review did not relate specifically to the evaluation aims, it was useful in providing the evaluators with insight into the issues surrounding informal caregiving, such as the needs of caregivers, the stressors involved in caregiving and further general information on Māori and disability. In addition, the literature revealed a number of methods which have been successfully utilised elsewhere in the support of informal caregivers. Overall, the aim of the literature review was to document information related to informal care for people with disabilities, and to ultimately focus on Māori needs and Māori-focussed approaches to service delivery for informal carers. Key areas of discussion here include defining disability, understanding the dynamics of Māori whānau, Māori and disability, informal caregiving, profiles of caregivers, caregiver needs, barriers to accessing services, valuing and supporting caregivers in their role, and creating accessible services for Māori.

3.2 Participant observation

Participant observation combined with low key participation in programme activities provided the evaluation team with useful information about the everyday realities of the workshops. The intention of this method of data collection was simply to experience the workshops for ourselves. Participatory observation was achieved without intruding unduly on the delivery of the programme. We were available to attend the training workshops which were delivered in Kāwhia and Te Kuiti. All of us attended the initial workshop in Kāwhia. Following this, at least one of us was present at each of the remaining three workshops in Kāwhia, and the one-day workshop in Te Kuiti. Informed consent was sought from the facilitators, prior to attending the workshops. We again introduced our research to the facilitators and whānau carers as part of the introduction process on the day of each workshop (the carers were informed of our role as evaluating researchers). As each workshop proceeded, each evaluator recorded their observations, which were later filed as site reports. An analysis of each site report has been incorporated into the results section of the current report.

3.3 Stakeholder meetings

We maintained regular contact with the training programme manager, facilitators, and other relevant staff from LIFE Unlimited. This allowed for a reciprocal relationship to occur with informal progress reports shared and any relevant information and documents made available to us within these meetings. Examples of this included the sharing of workshop registration forms, discussions about planned guest speakers, and references to other whānau carer training programmes which were held in Melville and at Kirikiriroa Marae. All of this information served to be useful in the write-up stages of the final report.

3.4 Written questionnaires

We distributed a structured written questionnaire at each training workshop which was formulated to gain the overall perspective of the whānau carers training programme in relation to its effectiveness. These questionnaires allowed whānau carers to express their views privately and anonymously about the training programme. The questionnaires looked at four major areas utilising a series of likert-type as well as open-ended questions. The areas covered included; the programmes' usefulness; aspects which were not so useful; general ratings of the different aspects of the programme (such as the facilitators and content); and suggested improvements for future workshops (Refer to Appendix 3). The carers were given the opportunity to take the questionnaire away, fill it out and return it by freepost mail. Completion and return of this questionnaire was taken as consent.

3.5 Follow-up telephone interviews

Follow-up telephone interviews with whānau/carers who attended the workshops were conducted at least three months after the last training workshop. The questions that were used in the follow-up interviews were developed after the workshops had been completed. The follow-up calls were a practical way of accessing information from the participants as they would have had some time to reflect on the long-term impact of the programme for themselves and their whānau. The follow-up telephone interview questions specifically sought to identify if the workshops had made a difference in the lives of the whānau carers.

Written consent for the follow-up telephone interviews was obtained via consent forms which were included in the participants' information packs (refer to Appendix 4, p. 44). Whānau carers were asked to record their contact details on the consent form and mail it in to the evaluators. At the onset of the telephone interviews, participants had the opportunity to confirm their consent, or decline to being interviewed (refer to Section 3.5 Ethical issues, p. 21). Comments provided in the telephone interviews were recorded, and later analysed for the results section of the report (For an outline of the interview schedule, refer to Appendix 5).

3.5 Ethical Issues

The evaluators have been committed to upholding high ethical standards. All methods used in the data collection phases of this project were first reviewed and approved by the research committee of the Department of Psychology at the University of Waikato. This ensured that the research met the ethical standards of the New Zealand Psychological Society.

All whānau carers were presented with an information sheet about the evaluation (refer to Appendix 2, p. 40) and the research was again explained verbally at the start of each workshop. The whānau carers, as well as facilitators, were also given an opportunity to ask questions about the research and our role as evaluators. In regards to the written questionnaires, returned questionnaires were taken as consent. Secondly, all whānau carers who participated in the telephone follow-up interviews had completed consent forms prior to our contacting them. Verbal consent was also sought at the beginning of each telephone interview. Participants were reassured that they could pull out of the research at any time, and that their anonymity would be guaranteed at all times.

4.0 RESULTS

4.1 Demographics of the WCTP trainees:

LIFE Unlimited requested that each trainee (the whānau carers) fill in registration forms at the workshops. The evaluators were supplied with copies of these registration forms and were able to gain insight into the demographic profile of the whānau carers. It was noted however, that many of the forms were incompletely filled out with details such as relationship, name, disability type and date of birth missing.

Registration forms were analysed (37 in total) from workshops at 4 different locations: Kāwhia (15), Te Kuiti (14), Kirikiriroa (5) and Melville (3). Neither the Kirikiriroa nor the Melville programmes were attended by the evaluators.

The ethnicity of the carers was not required on the registration forms. However, from the site reports and personal knowledge of the evaluators the participant whānau carers were predominantly Māori women (36 females and 1 male completed the registration form).

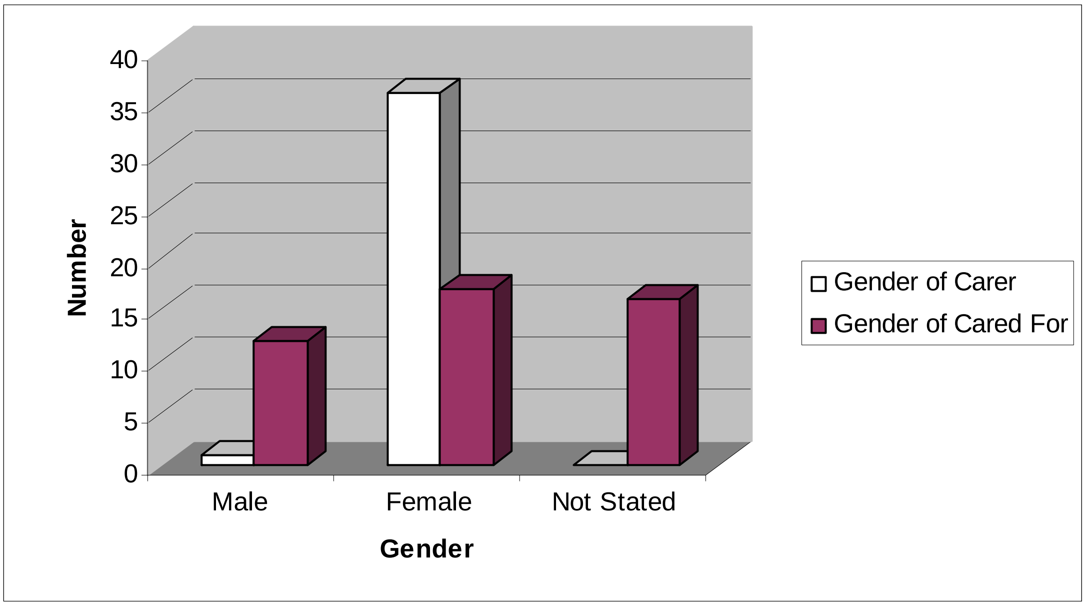

Figure 1. Gender of whānau carers, and the whānau members being cared for.

Of the 44 cared for people, 23 were listed as Māori and 5 as Päkehä. A further 5 were listed as other, comprising of 2 Dutch Kiwis, and three New Zealanders. The ethnicity of 11 others was not stated.

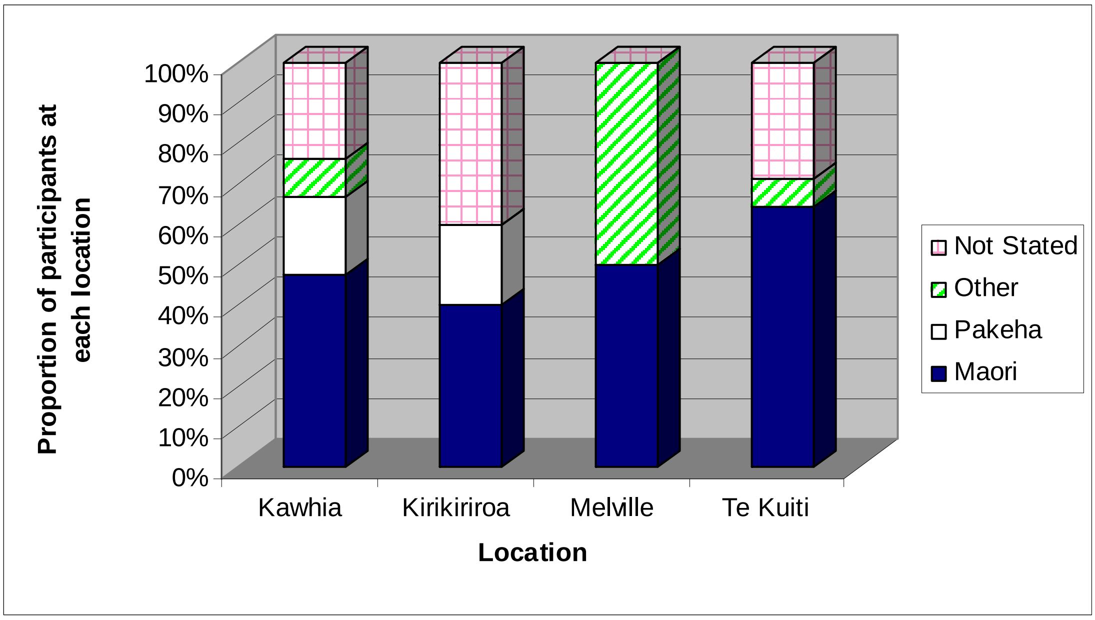

Figure 2. Ethnicity of whānau carers across location

The data showed that the majority of the whānau carers were in the 31 to 70 age group, and that the highest proportion of whānau-based care was for young children or adults over 60 years of age.

Of the 14 people attending the Te Kuiti programme, four cited the newspaper as their first source of information regarding the training programmes. Seven cited a personal contact, and of that seven, four were contacted by the co-ordinator and three by friends. Other sources cited were a disability coordinator/social worker, a notice on the Te Kuiti community house notice board, and 'found out by accident'. In Kāwhia, of 14 responses, three did not specify where they had heard about the training. All the others reported hearing about the programme from personal contacts, such as the coordinator, friends, or health workers. None of the attendees at the Kāwhia workshops had seen the notices, newspapers or radio advertising. Melville attendance was also as a result of personal contact or recommendation by friends or the co-ordinator of the programme. The Kirikiriroa people attended the training programme as a result of an IHC forwarded flyer, a Community living Trust Co-ordinator and personal contacts.

4.2 Site Observation Analysis

The training programme consisted of four workshops at Kāwhia, which ran from 9.00am to 12.00pm, and one workshop at Te Kuiti from 9.00pm to 3.00pm.

Overall, we found that the atmosphere throughout the training programme was positive, although at Kāwhia, the location could have perhaps been changed to provide more comfortable facilities for those attending the workshops. Areas of concern included warmth, accessibility, space, bathroom and kitchen facilities.

The location at Te Kuiti, however, seemed to incorporate all of these aspects well.

It was noted that key contact people, such as iwi support people and local personnel, were significant to the recruitment of whānau carers to the workshops. This was particularly evident in Kāwhia.

Each workshop started with a karakia by either one of the facilitators or the whānau carers themselves. This served well to start off each workshop. Comprehensive information packs were given out by LIFE Unlimited to the whānau carers, but the contents of these packs did not seem to be utilised by the participants nor facilitators. The packs comprised a number of resources for the whānau carers. These included a workbook from LIFE Unlimited, which contained introductory information on Te Whare Tapa Whā and Te Wheke models of health, a pen and pad, and a selection of pamphlets outlining the services of participating agencies such as Disability Service Link (DSL). The evaluators observed that the information packs were not referred to throughout the course of the workshops by the facilitators, which was perhaps the reason why the whānau carers did not utilise the packs.

Various guest speakers were utilised throughout the training programme, each of whom presented a range of topics relevant to the whānau carers. Overall, the presentations were of high quality with good use of visual aids and equipment. They were delivered in an accessible manner and were well received by the whānau carers.

At the Te Kuiti workshop, it was observed that a number of whānau carers left the workshop during the midday break. This could have been due to the cancellation of a key guest speaker, or simply the length of the workshop, but we were not able to identify the specific cause. Cancellations by key speakers also occurred at the Kāwhia workshops, however, this did not result in people leaving. This suggests that the length of each workshop is an important issue, with half day workshops being seen as more favourable than full day workshops.

There were few aspects within the training programme which needed attending to. However, two areas which stood out were punctuality, and the presence of children. Specifically, this relates to casual adherence to specified starting times by some facilitators, and the lack of suitable childcare facilities for parents who attended.

Finally, it was apparent that these workshops were well received by the whānau carers, the majority of whom expressed a desire for further and ongoing training to be provided.

4.3 Findings from the written questionnaires

The written questionnaires utilised in this evaluation looked at four major themes: programmes' usefulness, aspects which were not so useful, an overall rating, and suggested improvements. Only 8 participants (just 22% of those who attended the training programme) returned the questionnaires. It was found through an analysis of the returned questionnaires that trainees were generally pleased with the whānau carers training programme (WCPT).

Usefulness of the WCTP

Overall, trainees reported positive comments in regards to the usefulness of the training programme. In particular, trainees felt that the information provided was very useful, that they felt more informed about disability services, and that the presenters were good.

Table 1. Phrases listed by trainees in regards to the programme's usefulness[1]

Response	**Frequency***
Very useful information	6
I feel more informed about disability services	5
The presenters were good	5
I would recommend it to others	4
Friendly and relaxed	3
Good information	1
Layman's terms used	1
Learnt how to develop my abilities	1
It was just what I needed	1
Very good done in half days	1
Very good things going around	1

When asked how the training programme might impact on their role as a whānau carer, trainees commented positively. Examples included:

> *"The workshop gave me an insight on what is available out there in the community."*
>
> *"I believe it empowered me. I have the information to access the agencies I need, and that power gives me choice and support."*
>
> *"[It] Reinforces that there is help out there, that the carer is not on its own. As it is, I feel that a basic caregiver's course to those of the whānau carer would benefit the carer and those to whom they are caring for."*
>
> *"More informed. Do not have to feel alone."*

Aspects of the training programme which whānau carers felt needed more development:

In the questionnaires, trainees were asked "What did you find least useful in this workshop?" Only two responses were made in regards to least useful aspects. The

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[1] Participants could list multiple responses

first commented on the issue of not enough group discussion, while the second comment suggested that there were too many guest speakers, and that one or two guest speakers would be more appropriate. Other trainees simply reiterated that they found the training programme useful, and that there no aspects within the training programme which were not useful.

In another section of the questionnaire, trainees were asked if they felt like they were encouraged to share their ideas and experiences during the workshops. This was answered by selecting a number on a scale of 1 to 5. One corresponded to 'Always', whereas 5 corresponded to 'Never'. Only two trainees reported that they 'always' felt encouraged to share their ideas, while the other trainees reported that they 'usually' or 'sometimes' were encouraged. It was noted however that two trainees who misread the questionnaire, both circling 5 (Never), but it was made evident through the rest of their responses that they intended to circle the most positive option on the scale.

Overall rating of the WCTP:

Trainees were asked to provide an overall rating of the WCTP on a scale of 1 to 5. One being poor, and 5 being excellent. The median response from the trainees was 4, which corresponded to a rating of "Very good." See Figure 1 below.

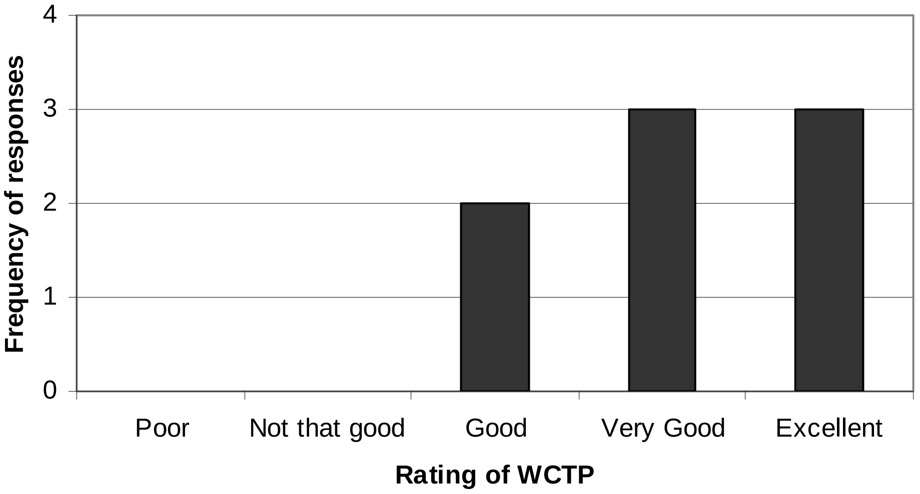

Figure 3. Trainees' overall rating of the WCTP

In general, comments were positive regarding the overall presentation of the WCTP, relating to both its content, and the programme facilitators. Views on the performance of the programme facilitators were made evident in other sections of the questionnaire, where nearly half of the trainees referred to the facilitators as being friendly and interesting. Others commented though, that there was room for improvement (although they did not provide any specific suggestions), and that they were not always encouraged to share their ideas and experiences.

When asked why they had rated the WCTP the way they did, trainees who rated the WCTP as good (a rating of 3) reported that:

> *"The group (providers) were willing to share ideas."*
>
> *"The presenters were interesting, always room for improvement."*

Trainees who rated the WCTP as very good (a rating of 4), reported that:

> *"The information was very useful and that it related to the information I was seeking."*
>
> *"Informed me on a lot of the services around our rohe."*
>
> *"I was pleased with new information from different avenues."*

Trainees who rated the WCTP as excellent (a rating of 5), reported that:

> *"The presenters, and topics they spoke about, were very pertinent. I feel everything was covered and I recommend to any person in a caring situation to attend these hui."*
>
> *"Because it gave me confidence to show me how to improve my sickness and showed me how to do other people when they are sick."*
>
> *"It was excellent because I did not know a thing about it at all."*

Suggested improvements by the trainees

Only two of the trainees suggested any specific ways to improve the WCTP. Both suggested that trainees should be offered a place where they can leave their children, while attending the course, or children should not be permitted at all. The rationale for this was that attending to the children was very distracting, and that it seemed the mothers really wanted to be a part of the workshop. The other suggestion was that the training programmes should start promptly at the time specified. In relation to this, the trainee noted that one workshop started half-an-hour late.

Trainees were also asked if there were any other areas that they would have liked the facilitators to cover. A number of requests were made. These included;

- Follow-up workshops on services in rural areas;
- Information on dementia;
- Information on developing communication skills;
- Information on how to access other agencies;
- Information on physical injuries;

- Information on seizures;
- Discussions on intellectual issues (specifically, children's transitions from special needs schools to employment);
- and further information on WINZ funding.

Awareness of the WCTP

In the last section of the questionnaire, trainees were asked how they first heard about the workshop. The majority of trainees had heard about the training programme through notices in newsletters, fliers and by word of mouth (from health workers, iwi workers, friends and programme facilitators).

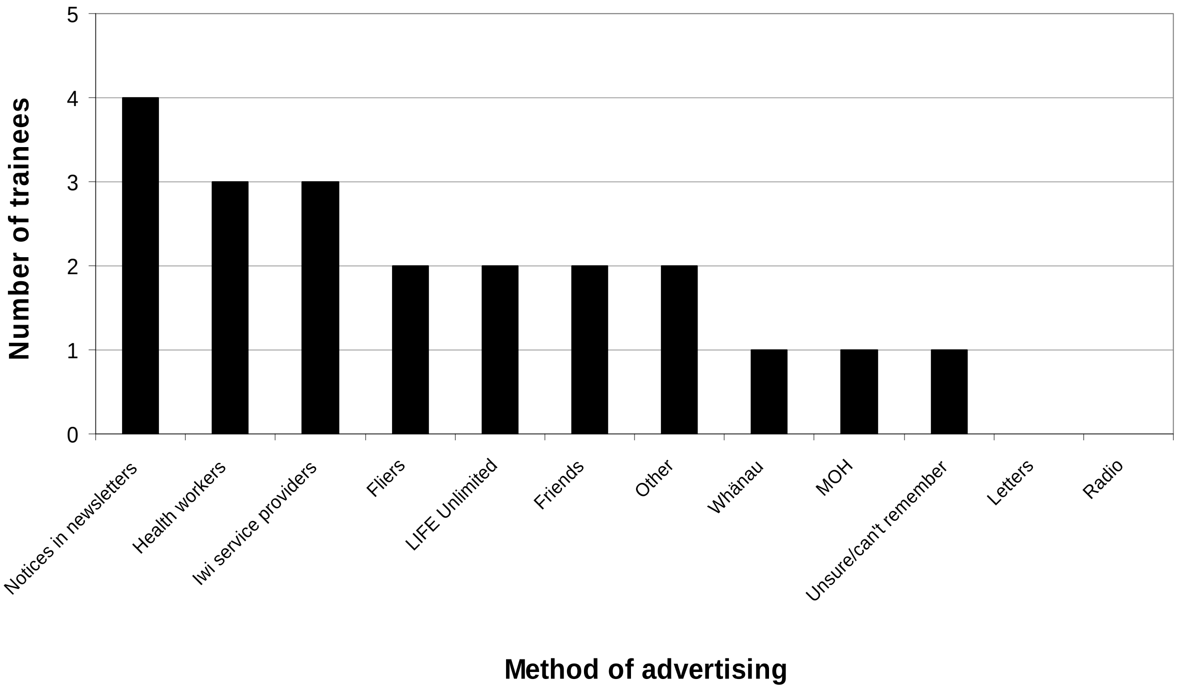

Figure 4. Method of finding out about the WCTP[2]

4.4 *Follow-up phone interviews*

To find out whether or not the training programme had a lasting impact on the whānau carers, we conducted follow-up phone interviews with the carers three months after the final workshops to discuss what was learnt. However, only five trainees gave consent to be contacted out of 37. What's more, of the five trainees who gave consent, we were only able to contact three for the interviews.

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[2] Trainees could list multiple responses

Each interview was transcribed and later analysed. The transcripts revealed two main themes in relation to the success of the training programme. These were; higher utilisation of skills by whānau carers, and increased confidence in accessing services for their whānau member.

Knowledge and practical skills gained

All of the carers who were interviewed reported that the information and skills acquired at the training workshops were valuable and useful in the period following the programme. Specifically, carers reported feelings of appreciation for gaining knowledge on resources for whānau carers, disability equipment, networking, first aid, advocacy, WINZ and accessing other services.

> *"The information that was given by the facilitators was really good; resources that you can access for your whānau, disability equipment, how to network with agencies and how to get the benefits of their services." (Whānau carer, Te Kuiti).*
>
> *"I know more now than I did before... know more about what is available in the community." (Whānau carer, Kāwhia).*
>
> *"The First Aid was really good... It was really good, all the information. [e.g,]All the information about the hospitals, and things, advocacy and how to access services." (Whānau carer, Te Kuiti).*

Accessing services

'Access' was a key word reported by whānau carers throughout the interviews. Hence, the ability to access relevant services for their whānau member is noted as a key issue for whānau carers. Overall, carers reported that their ability and confidence to access different services for their whānau member was enhanced as a result of the training programme:

> *"They made it sound really easy to access resources that you need and I followed some of the suggestions and places that were suggested. I also took on board some tips they gave me, and for me it has been really easy accessing services." (Whānau carer, Te Kuiti).*
>
> *"I am happier now to access services, and doing it is easier." (Whānau carer, Kāwhia).*
>
> *"...how to access services was the most important thing I learnt...The information about how to access services has made a difference in my life, and I am able to pass on information to others." (Whānau carer, Te Kuiti).*

Suggestions for improvements

Only two suggestions were made in the final stages of the interview, to improve the programme. These were: 1) punctuality of facilitators, and 2) offering childcare options for parents wishing to attend the workshops. This is consistent with the findings from the site reports and questionnaires.

Further comments

The most persistent finding to emerge from the interview transcripts was that carers were very pleased with the training programme, and its content. One whānau carer even went further to say that that programme had made a huge difference in her life, as well as the whānau member she was caring for. Lastly, all of the carers interviewed said that they would recommend the training programme to others.

5.0 DISCUSSION

5.1 The unique nature of the programme

The whānau carers training programme delivered by LIFE Unlimited is unique and has been developed for a specific audience. One of the essential qualities of this programme is that it is community driven in terms of what is provided and where the programmes are held. The programme aimed to train and support informal caregivers that are Māori, and the 'by Māori for Māori' approach that was adopted by LIFE Unlimited has allowed the facilitators to specifically address the needs of Māori whānau carers.

The outcomes of the preliminary hui between LIFE Unlimited and the Māori service providers in Te Kuiti and Kāwhia demonstrated the flexibility within the programme structure, as each programme was specifically tailored to meet the needs of the whānau carers in those settings. Initially, LIFE Unlimited had proposed that the training programmes would take place in a marae setting and would run over a two day period. However this changed to suit the communities involved. This resulted in the evaluation taking place, not within a marae setting, but at venues chosen to meet the needs of the whānau carers. The proposed two day training programme in Kāwhia evolved into four 3 hour workshops that occurred over four consecutive weeks. In Te Kuiti, the facilitators used a different approach, opting for one 6 hour programme. It was noted however in the results section that some whānau carers preferred the half day workshops (3 hours), as that provided time for just enough information to digest.

5.2 Critical Success Factors

Through participant observation, the evaluators believed that the training workshops were delivered with a high degree of professionalism and competency. In particular, the senior facilitator showed an impressive ability to create rapport with the whānau carers, and her leadership, in regards to assisting and supporting the junior facilitators, was clearly evident. In addition, the delivery format used within the workshops by facilitators was clear, supportive, positive and contributed to a proactive learning environment.

There was unanimous agreement amongst the whānau carers who participated in the research, that the whānau carer training programme was delivered in an efficient manner. During our meetings, and by witnessing the workshop dynamics, it became evident that a specific Māori liaison person within the rural community provided more enhanced outcomes for both the service users and the service providers. This key contact person was able to help publicise the training programme to several whānau carers in the community, as well as liaise with facilitators of the workshops to meet the needs of the carers. It was apparent, not only to the evaluators but also to the senior facilitator, that this was a successful method in recruiting whānau carers to the training workshops, where personal contacts were utilised in the networking process.

During the latter stages of the evaluation, the whānau carers who were contacted by telephone all spoke of the active changes that they have made in their lives as a result of what was learnt in the training programme. This was a key theme to emerge from the research findings, that is, the clear impact that the training programme had on the lives of the whānau carers, as well as that of the whānau member that they were providing care for.

Success factors, as reported by the whānau carers, involve the acquisition of new skills, knowledge, and confidence in dealing with relevant organisations or agencies. It is a testament to the success of the training programme that whānau carers report feelings of empowerment following the programme, by the development of networks with other carers and through the demystifying of agencies such as WINZ and DSL. Enhanced caring for their whānau member by accessing assistance, information and financial support has now been made achievable.

5.3 Significant Barriers

An estimated 10 % of most modern populations have a disability which prevents them from functioning to a significant degree. In New Zealand, within this 10%, there is a disproportionately large representation of Māori (Kingi & Bray, 2000). An issue that has been recognised is the high proportion of disabled Māori and their whānau carers who do not, or can not, access the information and assistance that is available to them.

A number of times during our stakeholder meetings the programme co-ordinator indicated that a significant, frustrating and consistent barrier that had arisen during the development of the programme was the inability to access a large number of whānau carers in the community. This was particularly true for Kāwhia, where only a small number of whānau carers attended each workshop. LIFE Unlimited's publicity and advertising methods, using newspapers and radio had not been as successful as they had hoped. One problem during the recruitment phase was that not all Māori service providers and iwi organisations were publicly known to LIFE Unlimited, and were therefore inaccessible to the coordinator.

5.4 Areas for Improvement

The issue of children being a distraction, both to mothers and other participants was raised. Some people commented that either onsite childcare or a no child policy should be put in place as mothers, as well as other attendees, found their attention distracted by their children. The opportunity was offered for participants to receive financial assistance towards employing a temporary caregiver for their whānau member while attending the workshops. However, this did not address general childcare issues or the scarcity of available caregivers in less populated rural settings.

Punctuality was noted as an area that some participants felt could be improved. It was noted by the evaluators, that delays in the start time of the workshops, were due to various factors. However, facilitators may need to allow more sufficient time, prior to workshops, to deal with unexpected delays.

Some whānau carers commented that they had specific issues relevant to their whānau member that they would have liked addressed further. This did not detract from their positive overview of the training programme, but carers expressed needs in other areas, in their pursuit of optimal care for their disabled whānau members. This included information about particular disabilities and impairments. Ensuring that facilitators find out and are aware of these needs prior to the programme should be a continuing priority.

Whilst acknowledging the finance, accessibility and availability issues that surround booking suitable venues it must be said that venue at Kāwhia, being extremely cold (in the Winter season) and lacking reasonable bathroom and kitchen facilities, was not an environment well-suited to the delivery or reception of a training programme. The Te Kuiti workshop, on the other hand, was held in an appropriate venue.

The importance of filling in the registration forms needs to be emphasised as the information gathered via these forms is important for statistical purposes. Assistance should be forthcoming and the forms checked on collection to ensure details have been entered correctly. Recommendations for improving the registration forms include:

- Stating date attending
- Stating place of training programme attended
- Stating gender age and ethnicity of carer
- Stating gender, age, ethnicity of and relationship to whanau member.

Overall, comments that the evaluators heard on site were generally positive, with very few made by the whānau carers in regards to areas for improvement. One participant though commented that they would have liked more group involvement. Yet others said they had felt very comfortable with the interaction between themselves and the facilitators. Observations made by evaluators on site showed people appeared confident to speak out and question the presenters.

5.5 Other Relevant Issues

The leadership qualities within the programme staff came through after an unfortunate accident which put the senior facilitator out of action for some weeks. With minimal experience and preparation time, the junior facilitators were able to take up the challenge and present professional and thorough training sessions.

Other key issues that emerged throughout the evaluation included the apparently high stress levels of whānau carers prior to the programme. A pattern of misunderstanding and mis-information concerning the availability and accessing of services, funding entitlements, respite care entitlements, and so forth was clearly present in the whānau carers. It was promising to see however that the training workshops went some way to put carers at ease about some of the issues they were unsure about, or the problems they were experiencing.

The programme coordinator is an experienced facilitator and has been responsible for providing onsite training for the whānau carer training programme to other staff members. She clearly is an essential person in the development and positive delivery of the training programme, and undertakes her role confidently and to a high standard.

5.6 Limitations of the evaluation

It has been recognised that limited conclusions can be drawn from this research as only a small number of whānau carers took part in the evaluation process. Specifically, only a small number of the carers returned the written questionnaires and gave consent to participate in the follow-up telephone interviews.

The timeframe of the evaluation in general caused a number of minor limitations to the research. The start time of the evaluation process became an issue, as the training programme had already commenced before the research process began. As a result, the evaluators did not attend the preliminary hui between the programme facilitators and the whānau carers. In addition, the evaluators were only able to attend one series of the training workshops to collect data for the evaluation (these being at Kāwhia and Te Kuiti).

6.0 RECOMMENDATIONS

As this evaluation is of a formative nature and the whānau carer training programmes were in the early stages of development, our discussion and recommendations will surround the objectives of our evaluation.

We would like to commend LIFE Unlimited for their excellent work and delivery of the whānau carers training programme. Any issues we raise are intended to be of a positive nature and reflect ways to further improve the programme.

6.1 Recommendations for LIFE Unlimited

i. ***We recommend that ongoing evaluations are undertaken in order to continue the successful operation of this programme.***

Ongoing evaluations are essential in order to assist programme developers in creating more effective of training programmes for informal carers within New Zealand. These evaluations would also serve to keep the training workshops responsive to and tailored to the differing needs of Māori whānau carers. Incorporating process and outcome evaluation methods are necessary for understanding and supporting the developments and changes that evolve within the training programme.

ii. ***We recommend that LIFE Unlimited ascertain which models of communication are the most effective, when planning future training programmes.***

We note that an important area for future investigation (identified by the Family/Whānau Carer Support Project and the Carer NZ Information Network) is finding models of communication that can successfully enable service providers such as LIFE Unlimited to communicate, market, publicise and inform the Maori community about their services and training programmes.

iii. ***We recommend that LIFE Unlimited support and encourage the programme facilitators to engage in ongoing training that will enhance the delivery of future training programmes.***

Findings from the written questionnaires and site observation reports clearly showed concerns from whānau carers regarding punctuality, suitability of venue, clear registration forms and the issue of various distractions during the workshops. Ongoing facilitative training in different techniques to cater for these issues, and also to suit the learning preferences of the diverse audiences that may attend the programmes, would serve to further enhance programme delivery. For example, facilitators could have training to address different areas such as:

- Organising suitable venues
- Creating clear registration forms
- Facilitating childcare arrangements
- Utilising a variety of teaching mediums

6.2 Ministry of Health Recommendations

i. ***We recommend continued funding for whānau carers training programme delivered by LIFE Unlimited.***

The programmes are contracted to be run over a run over a fixed time period, however LIFE Unlimited are, by necessity, flexible in their delivery of the programmes. It should be acknowledged that a programme run for half a day such as those in Kāwhia still equates to a full days involvement for the staff when planning, travelling, and setting up, etc, are taken into account. Funding should therefore reflect this.

ii. ***We recommend that a database of key contact people is created and regularly maintained.***

It is our observation that key people in the communities are of significant importance to the programme delivery. The breakdown of how people heard about the training programme in the data analysis showed the importance of key contact people within rural communities. The reported difficulty of reaching whānau carers and the recognition of the importance of having key contact people available both for the dissemination of relevant information outwards and inwards highlights the need for the MOH to be proactive in the creation of a database of relevant key people within Māori service provider and iwi organisations. We suggest this could be accomplished by the creation of a funded 0.5 position in which a person is responsible for the establishing and maintenance of links between the various Rūnanga in New Zealand.

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8.0 APPENDICES

Appendix 1: Information Sheet

Contact:

Research Team:
Allanah Ashwell
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Project Supervisor:
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Email: bridge@waikato.ac.nz

The University of Waikato
Te Whare Wānanga o Waikato

Tēnā rawa atu koutou

He mihi mahana ki a koutou katoa i tēnei wā.
Ko Allanah, ko Sally, ā, ko Keri ā mātou ingoa. Nō Te Whare Wānanga o Waikato mātou.

Why are we here?

The Ministry of Health has contracted several different community-based service providers throughout New Zealand to deliver training programmes to whānau caregivers. We are here to evaluate the Whānau Carers Training Programme to be delivered by LIFE Unlimited. Our findings will contribute to a wider report, which is being compiled by the Māori and Psychology Research Unit (MPRU) at the University of Waikato for the Ministry of Health.

Evaluation Purpose:

What we plan to do is evaluate the effectiveness of the whānau carers training programme. The objectives of the evaluation are to:

- Describe the unique nature of the programme
- Identify the critical success factors of the programme
- Identify any significant barriers to the success of the programme
- Make recommendations for improvements to the programme
- Address any other relevant issues

Evaluation forms will be given to each of the whānau carers to gain your perspectives on the programme. Therefore we would be very appreciative of any input you might have.

Information collecting:

Attached to this information sheet is the evaluation form which will give us insight into your views in a confidential way. The anonymity of all whānau carers will be respected at all times. Follow-up telephone calls will be made to those who consent. Please note, you are free to withdraw from this research process at any time, and that there will be no penalty or loss of benefits that you would otherwise be entitled to, if you choose to withdraw.

Thank you all for your contributions.

Noho ora mai i raro i te manaakitanga o te Atua. Pai marire.

Nä Allanah Ashwell, Sally Ridley and Keri Thompson.

Appendix 2: Written questionnaire

Whānau Carers Support Training Programme

Evaluation Appraisal Questionnaire

The evaluation team would appreciate your feedback concerning all aspects of this *Whānau Carers Training Programme.* We value your views about the programme, the facilitation process and your own experiences and learning. The evaluation report will include a summary of your feedback for the purpose of maintaining and modifying aspects of the training programme. The evaluation research team will hold the questionnaires forms.

1. What did you find most useful in this workshop? (Please refer to the phrases at the bottom of the page for examples).

____

____

____

____

2. What did you find least useful in this workshop?

____

____

____

____

3. Please circle any of the following phrases that you believe apply to this workshop:

- Too much information
- Friendly and relaxed
- Not enough group discussion
- Very useful information
- It was just what I needed
- I found it difficult to understand
- I would recommend it to others
- The presenters were good
- Too much group discussion
- Too many complicated terms
- I feel more informed about disability services

Please continue over page…

4. On a scale of 1 to 5, how would you rate the workshop? (Please circle a number that best suits how you feel):

Poor	Not that good	Good	Very good	Excellent
1	2	3	4	5

4b. Please write down your reasons for the number you chose:

5. Did you feel like you were encouraged to share your ideas during the workshop?

Always	Usually	Sometimes	Seldom	Never
1	2	3	4	5

6. How would you change the workshop if you could?

7. What other areas would you have liked the facilitators to cover?

Please continue over page…

8. In what ways, if any, do you think attending this workshop might impact on the mahi that you do?

____

____

____

____

9. Which of the following are the ways that you heard about the workshop? Please circle one or more of the following:

- Letters
- Fliers
- Whānau
- Health workers
- Notices in newsletters
- Ministry of Health
- Iwi service providers
- Friends
- Radio
- Unsure/can’t remember
- Training programme provider
- Other (please specify) _________________________

10. Please write any other comments you would like to make:

____

____

____

____

Please detach this questionnaire and return it by mail in the self-addressed freepost envelope.

We would appreciate your feedback in a couple of month’s time regarding the usefulness of the training programme in your mahi. If you consent, we would contact you by phone with some simple questions regarding the way in which the training programme has or has not benefited you and your whānau. Should you consent to be part of this follow up interview, please provide your name and contact details on the separate piece of paper provided and return it by mail to us in the second freepost envelope provided.

Please continue over page…

TELEPHONE INTERVIEW CONSENT FORM

Evaluation of the whānau carers training programme:

NAME: ……………………………………………………………………………

CONTACT PHONE DETAILS: ……………………………………………………

Location of workshop: ………………………………………………………………

When would you prefer to be contacted? (Please circle)

Morning Lunch Afternoon Evening

Mon Tues Wed Thurs Friday Sat Sun

Please consider the following information:

We will contact you by phone with some simple questions regarding the way in which the training programme has or has not benefited you and your whānau. By filling out this form, your consent for participating in this follow-up process will be given. However, you have the right to withdraw from this process at any time. If you have any queries you can contact the project researchers through Allanah Ashwell at **07 838 4466 ext 8155.**

Alternatively, if you have any concerns regarding the follow up interviews, you can contact the project supervisor, Bridgette Masters, at **07 838 4466 ext 8298**.

Thank you for your contribution to this research project.

Allanah, Keri and Sally

Please detach this sheet and return in the self addressed envelope provided.

Appendix 4: Telephone interview schedule

Date:

Name:

Contact No:

Location of whānau training programme:

1) What knowledge, information or practical skills, do you feel you gained from attending the whānau carers training programme?

2) Has attending the programme made a difference to your situation? If so How and in what way?

3) Would you recommend the training programme to anyone and do you have any suggestions for further training programme?

4) Further comments