

Mental Health Consumer Participation: A Technical Action Research Project

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Attestation of Authorship

I hereby declare that this is my own work and that to the best of my knowledge and belief, it contains no material previously published or written by another person or material which to a substantial extent has been accepted for the qualification of any other degree or diploma of a university or other institution of higher learning, except where due acknowledgement is made in the acknowledgements.

Signed: _____

Dated: _____

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Thank you.

Abstract

Located in a context of dynamic evolving change, this research project specifically targeted mental health social, recreational and prevocational services established to support people with mental health issues living in the community. Mental health stakeholders including consumers and their families and whānau, District Health Board (DHB) funding and planning managers, DHB service providers, Non-governmental organisations (NGOs), and Māori and Pacific Island service providers were recruited to engage in focus group discussions with the researcher. Data was gathered by interviews, a questionnaire and observations in community settings over five years. Participants engaged in data analysis and knowledge production.

Technical action research (TAR), underpinned by critical theory, was the methodology used to facilitate knowledge production. The research had three stages each of which was informed by Elliot's (1991) cyclic process of action for example reconnaissance, planning, implementation and evaluation. Thus each action cycle was grounded in and evaluated by the overall research goal.

The first stage was to gather data, historical and current, that would put the research into context. The second stage informed the selection of a consumer questionnaire which was then completed by mental health consumers in the final stage. Consumer feedback on mental health service performance was instrumental in service monitoring. The findings revealed a tension between service providers' understanding and consumers' expectations. Of significance is the connection between valuing and embracing the unique lived experience of the consumer, inclusion and recovery. Implications for service providers highlight the need to engage consumers and encourage participation, to improve relationships and address power imbalances.

Chapter One

Introduction

This research project explores consumer participation and service performance, in mental health social, recreational and prevocational services in the northern region of New Zealand. A Technical Action Research (TAR) methodology was used to engage consumers and other service stakeholders in action cycles, with a view towards developing knowledge in response to the research question: **How can consumer participation contribute to the monitoring of mental health service performance?**

Impetus

During the late 1990s in New Zealand, following the closure of psychiatric hospitals as part of the process of deinstitutionalisation of mental health services, social, recreational and prevocational services were established for mental health consumers (Gifford, 2004). At the time there was concern that mental health consumers who had been living in an institutional setting and who had engaged in structured activities during the daytime were now living in the community without structured daily activities. The goal of establishing social, recreational and prevocational services was to occupy consumers during the daytime in activities (Ministry of Health, 2001c).

The provision of services to occupy consumers in funded activity programmes continued for several years with little interference from government health officials (Gifford, 2004). Generally, it seemed that there was a lack of interest in further service development for this field of practice when other more acute areas of mental health service delivery had priority. A research project undertaken by Gifford (2004), and sponsored by the Northern District Health Board Shared Agency (NDSA) investigated the services delivered in one region. The findings highlighted some areas in need of attention. For example:

- The service definitions and specifications within the service contracts did not match the services being delivered;

- The staff and skill mix employed to deliver the services did not correspond to those documented in the contract;
- The volumes of people receiving contracted services varied and often there were no target numbers specified in the contract;
- Service outcomes were not being captured (Gifford, 2004).

In summary, the services being funded and delivered were not as expected by the District Health Boards. In order to address the identified issues, a second project was recommended (Gifford, 2004). I was invited to undertake this second project which had the potential to affect mental health service contracts, categorised under service specifications and purchase unit codes. These contracts were worth \$5.1 million annually.

Initially I enrolled as a part time doctoral student at the University of Technology (UTS) in Sydney. My application for ethics approval was received and approved by UTS (26/07/2005), by the Ministry of Health Northern X Ethics Committee in New Zealand (8/08/2005), and by Waitemata District Health Board (2/09/2005). See appendices A, B & C. UTS had appeal because it offered me potential opportunities of exposure to international perspectives and shared learning amongst a much wider collegial network. Unfortunately the isolation experienced by distance learning and lack of supervision proved too challenging. In 2009, I transferred to Auckland University of Technology (AUT) and welcomed the benefits of face to face local supervision on a more frequent basis and collegial support by those familiar with the New Zealand context.

At that time, I was completing two significant regional mental health projects while on secondment to the District Health Board (DHB) Shared Agency¹. I was due to return to the DHB, initially as a project manager and later, as a funding manager. This change in role within the DHB was believed to be an opportunity to minimise a potential conflict of interest by clearly defining the tasks and activities inherent to the research project for the Shared Agency and those aligned to my employment with the DHB. I also wanted to grasp any potential for conflict that might arise from meeting both the Shared Agency and my own research requirements.

¹ District Health Board (DHB) Shared Agency is an entity established to support DHB function with an emphasis on activity undertaken at regional or sub regional level.

To achieve this goal I needed a robust methodology that could be applied in a collaborative way. I had previously applied Technical Action Research (TAR) techniques to two regional mental health and addiction projects and had been impressed with the level of engagement I had achieved with service providers and consumers. This had added value to the outcomes of the projects as the participants had been part of the process and were very supportive (Sorensen, 2005a; Sorensen, 2005b). Consumer engagement was a critical aspect in developmental work in the mental health sector in order to capture the lived mental health experience (Mental Health Commission, 1998).

Framing the research process

Guba and Lincoln (1990) argued that to inform and guide qualitative inquiry the researcher should be clear about the paradigm underpinning the selected approach. Equally, Brockopp and Hastings-Tolsma, (2003) stressed the importance of the researcher choosing a method that was appropriate for the information being sought or the theoretical position being tested. Consequently when considering the information I was seeking and mindful of my desire to engage my participants, I ascertained some specific contexts that needed to be explored in order to frame the research. Stringer (2007) described the exploratory activities that must be undertaken before embarking on research as building a picture of how things are. I needed to create that picture to understand the contexts in which the mental health consumer of social, recreational and prevocational services was situated.

As already discussed these services were established to meet a specific purpose in a process of service evolution, from institution to community based care (Ministry of Health, 2001c). To achieve the research goal, I felt it important to know more about the purpose of social, recreational and prevocational services, in the mental health service continuum, particularly from a consumer perspective. I also wanted to know more about the current services and how they compared with best practice and consumer expectations. By drawing these areas of investigation together I narrowed down what I needed to know and in doing so I refined my research question.

I consequently drafted an outline consistent with Guba and Lincoln's (1990) recommendations of what would be essential for the chosen methodological approach. Given the parameters of both the project and my doctoral research, I then assessed a range of methodologies against the chosen criteria. Critical theory was my preferred

paradigm as it aims for critique and transformation through dialogue (Reason & Bradbury, 2006). TAR, which is a derivation of Action Research (AR) is grounded in critical theory. It incorporates the cyclic interactive participative elements typical of AR but with the addition of technical and facilitatory functions undertaken by the researcher (Grundy, 1987). Therefore TAR became the methodology applied in this research.

I reflected on the risks and challenges of using TAR. A calculated risk included the project outcomes being suitable for application in the funding and planning environment, while the challenge would be to complete the project within the expected timeframe. Funding managers had indicated that the revision of contract arrangements for the next financial year for mental health social, recreational, and prevocational services would be informed by the results of this project.

Faithful execution of the method as it is intended enables the researcher to sit outside the research project and take a more dominant role in facilitation (Kemmis, 2006). Similarly, careful management make it easier to achieve the project sponsor's expectations regarding timeframes and outcomes. When scoping the project, I knew it was important to keep in mind the requirements of my doctoral study (practice informing research and research informing practice) while meeting the requirements of the DHB funding and planning managers and the DHB Shared Agency.

The context

It soon became apparent that a far greater understanding of the historical, political and social context was necessary. I also thought it important to improve my knowledge of current trends in mental health service development in New Zealand as well as internationally. Therefore I undertook a thorough review of the literature. Additionally, the DHB Shared Agency, arranged a two week study tour in England for me to investigate and scope out similar mental health services. The evidence from the literature, coupled with my first-hand experience of reconfigured services in England, highlighted positive changes that could be implemented in social, recreational, and prevocational services here in New Zealand (Office of the Deputy Prime Minister, 2004). Service providers and service users such as the mental health consumers' groups have been influential in advocating for change in mental health service provision (Brunton, 2001). In the 1990s, a strong consumer movement increased service user participation in New Zealand however, it was limited to certain specific roles and

activities such as hospital based consumer advisors (Mental Health Commission, 1998; Ministry of Health, 1995, 2005). I was keen to extend consumer participation to other roles and functions including service monitoring within mental health service planning and funding. TAR provided an opportunity to design a project that would explore this idea.

Research project design

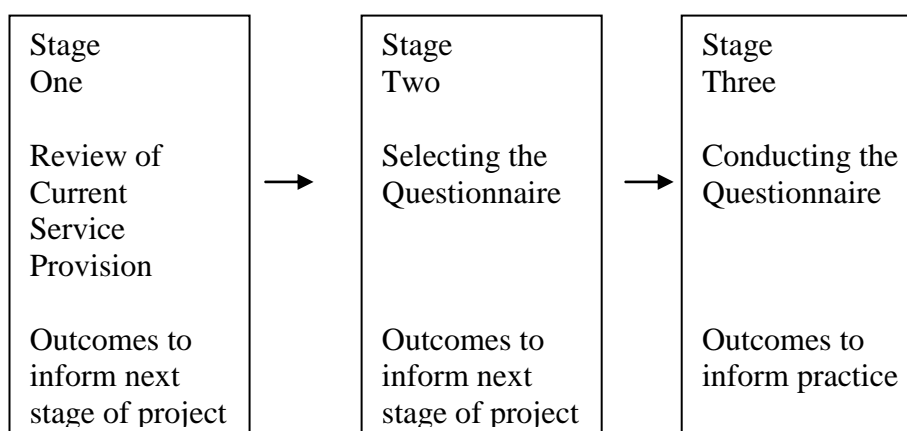
Given my research question, and the likely information required to improve and enhance services through consumer participation I focused on the project design. I decided to group my project into three stages each with its own setting, subjects or participants, and method. The outcomes of each stage informed the next stage.

1) Review of current service provision: Relevant information about the mental health social, recreational and prevocational service providers was collected and considered using a comparative analysis and data envelopment analysis (DEA) which is a quantitative method.

2) Selecting the questionnaire: Based on the principles of TAR which advocate inclusion a stakeholder reference group including consumers, selected a consumer questionnaire to elicit information; and,

3) Conducting the questionnaire: The questionnaire was to be undertaken by consumers of mental health social, recreational and prevocational services, Consumers through their responses provided feedback on service performance. These three stages are conceptualised in the following Figure 1.

Figure 1: The Three Stages



Stage One: Review of current service provision

The first stage of this project focused on the 32 provider organisations of mental health social recreational and pre-vocational services in the Northern region of New Zealand. However once the exclusions due to ethics committee requirements were taken into consideration, only 24 provider organisations were found to be suitable to engage in this project. The Northern X Regional Ethics committee requested that a number of service providers be excluded given the specific adult and mainstream focus of the project. This included Kaupapa Maori providers and child health providers. Data about the participating providers and the services they delivered, that had been collected by Gifford (2003) in an earlier project about the social, recreational and prevocational services was analysed with the providers consent. The same data was also used to conduct a comparative analysis based on a social inclusion model implemented in England (NIMHE, 2003).

A statistical analysis was then prepared on data submitted by these 24 provider organisations as part of their routine Ministry of Health reporting requirements. The goal was to use a data envelopment analysis (DEA) methodology to determine which providers were more efficient than others in providing mental health social, recreational and prevocational services. There was widespread acceptance of DEA as a management tool (Emrouznejad, 2001), and over the past two decades, it had emerged as an important tool in the field of efficiency measurement (Maani, Putterill & Sluti, 1994). DEA is used to compare Decision Making Units (DMUs) such as individuals or groups of individuals using one or more inputs to secure one or more outputs. DMUs use the same inputs and secure the same outputs but generally at varying levels. Consequently, it was proposed that the revenue funded for social, recreational and prevocational services would be compared with the service outputs. In other words, the workforce resource that was necessary to provide the service compared with service delivery achieved. However the data collection from provider monitoring reports by the Ministry of Health proved unreliable. When providers were contacted to validate the data, the majority believed the data to be incorrect. On this basis, it was decided not to undertake further analysis using this data given the uncertainty of its validity. The Ministry of Health was notified of the data problems and indicated an awareness of this and stating that a national project on reporting was being considered.

Stage 2: Selecting the consumer questionnaire

The second stage focused on the established stakeholder reference group and the application of cycles of TAR. The goal was to review a range of standardised consumer self-assessed measurement tools or questionnaires by the selected stakeholder group. A number of documents aligned with the Mental Health Research and Development Strategy that had been published by The Health Research Council (2003; 2004) were assessed. The participants selected two questionnaires for application in the third stage of the research, but only one was available for use.

Stage 3: Conducting the consumer questionnaire

The third stage focused on using the selected questionnaire with fifty consumers who were all current users of the contracted social, recreational and prevocational services. They agreed to participate by completing the questionnaire which would assess the performance and outcomes of the services they were currently using.

Understanding the context

To situate this project in its New Zealand context it is important to explain the influential changes that took place in the late 1980s and early 1990s, as they are related to broader society and to the provision of mental health care in the twentieth century. Deinstitutionalisation was at the centre of these changes. Its impact on social inclusion triggered the establishment of social, recreational and prevocational services in the Northern region of New Zealand (Ministry of Health, 2001c).

Deinstitutionalisation

Deinstitutionalisation in New Zealand, the process by which the traditional psychiatric institutions were closed and much smaller psychiatric units were commissioned on the sites of general hospitals, commenced in the early 1990s. People requiring acute care were transferred to the general hospitals while those requiring non acute care or support were discharged from the institutions to community-based facilities (Brimblecombe, 2006; Brooks & Thomson, 2001; Brunton, 2001).

The closure of psychiatric institutions originally began in the British mental health services in the 1970s before reaching New Zealand. The change in philosophy and model of service delivery was supported by evidence (Brunton, 2001). Philosophically underpinning deinstitutionalisation was the belief that all people, including those who

experienced mental illness were entitled to a normal life. The institutions had exerted dominance, power and control over vulnerable people and thereby reinforced stigma and discrimination against those with mental illness. This approach to care needed to change (Brunton, 2001; Wilson, 1999); but the required changes were major and it had been suggested that the impacts were significantly under-estimated (Brunton, 2001). Some consumers, although unhappy with institutional life, had assumed a home for life where all their needs would be met. A move into community care created new anxieties and fear of the unknown for both consumers and their families and whānau² (Hobbs, Newton, Tennant, Rosen & Tribe, 2002). For the workforce, within these facilities deinstitutionalisation meant a change in location and work environment. Psychiatric nurses were relocated to general hospital sites alongside general nurses. Prebble and Bryder (2008) described some of the tensions that existed between these specific nursing professionals, at that time. Tensions were related to power and position and which professional was higher up the hospital's hierarchal scale.

Deinstitutionalisation had a significant role in New Zealand's history of mental health services and today its perceived negative results may be viewed as a driving force for greater remedial change. Discourse about what actions should or should not have been taken and by who prevails to this day. This debate today can only be helpful if the emphasis is about service improvement and better, more socially inclusive outcomes for mental health consumers rather than the attribution of blame. After all, deinstitutionalisation was about increasing social inclusion of people with mental illness.

Social inclusion

Social inclusion, in New Zealand's mental health context, implies that mental health consumers are included with other people within a community, and are able to access the same raft of options when choosing where to live and what to do. These options include subsidized appropriate housing, education, employment and social activities (Commins, 1993; Humberstone, 2002).

Social inclusion is also about access to, and participation in, social situations. People who experience mental illness want, and need to have, access to social situations that

2. The use of the term in this document recognises the wide diversity of families represented within Māori communities.

are valued in communities, and to receive the necessary support to participate in a way that others do (Deegan, 1993). Social inclusion is also important for recovery, in terms of an individual leading a fulfilled life despite having a mental illness. Recovery is both process and outcome (Deegan, 1998). It requires support and partnership and cannot occur in isolation (Ridgway, 2001). For people with mental illness to recover engaging in work or education is often a goal (Sullivan, 1994). A recovery pathway includes goals, dreams and aspirations, enabling outcomes such as a quality of life, empowerment, and life satisfaction (Rapp & Goscha, 2006). Morris (2005) suggested that people with mental illness aspired to belong and participate fully in their communities; however, despite community based care such an aspiration was difficult to realise.

Commins (1993) described social inclusion from a systems perspective suggesting that social inclusion be defined in terms of systems of integration. The legal system promotes civic integration; the labour market promotes economic integration; the welfare state system promotes social integration and the family and community system promotes interpersonal integration (Commins, 1993). This implies that to enhance social inclusion, action must be taken at many different levels and is not limited to the actions of one system, one organisation or one person.

Once an individual is in a social situation such as employment, education or a social network, there is a lack of on-going support by agencies to help people remain in that situation. There are other barriers that prevent people from engaging in the community besides having a mental illness. These barriers include being of an ethnic minority, language barriers, having parents who have mental health problems and/or having other complex needs such as co-existing disorders³ (Ministry of Health, 2005).

The benefits of strategies which make use of naturally occurring community activities and resources that are more integrated, accessible and accommodating for people with a mental illness are thought to be far reaching for both the individuals and the community (Rapp & Goscha, 2006). It is suggested that being included socially within a community and across a range of domains improves physical, mental and social wellbeing. The National Social Inclusion Programme (NSIP) at the National Institute of Mental Health

³ Co-existing disorders is the term used when substance misuse co-exists with mental health problems.

England (NIMHE) has been established in the United Kingdom (UK) for this purpose. It was designed to bring together agencies to enable people to fulfil their aspirations and improve their lives (NIMHE, 2005). Aspirations for people who experience mental illness are just like the aspirations of those without a mental illness and include: being socially accepted, having a real job, having friends, having somewhere stable to live, and learning new skills (Morris, 2005) .

Social, recreational and prevocational services

To respond to this need for social inclusion, the first social, recreational and prevocational services were established in the Northern region of New Zealand in the late 1990s. Investing in this sector, in this way, was seen as desirable. *The Blueprint for Mental Health Services in New Zealand, How things need to be* (Mental Health Commission, 1998) stated that there was a need for services that enhanced social inclusion. The new social, recreational and prevocational services therefore were consistent with that *Blueprint* requirement and were provided under contract to DHBs by Non-Government Organisations (NGOs). These services were also consistent with the mental health strategic vision, as described in *Looking Forward* (Ministry of Health, 1994), and included an improvement in health status, a reduction in the impact mental illness had on everyone within a community and a decrease in the prevalence of mental illness. These services formed part of the continuum of mental health and addiction services provided by DHBs to people in their communities. Predominantly day programme services focused on the development of living skills, arts and crafts, and entry skills for employment and mainstream education in a socially inclusive way. Programmes were delivered from a range of local and regional drop-in centres and other facilities throughout the Northern region. In some cases, mental health consumers were collected from their homes by mini bus and taken to a mental health specific facility for a day of activities (Gifford, 2004).

By 2003, service provision had grown and considerable funding had been committed to their on-going sustainability. However, Funding and Planning Managers in the region had become unclear about what programmes these social, recreational and prevocational services were actually delivering and to whom. They wanted to know if the services were really achieving greater social inclusion for their participants. They questioned the benefits and value for money of the current service contracts and consequently wanted more information. As a result, a project was commissioned by Funding and Planning

Managers to answer these questions. A project manager was contracted by a DHB Support Agency⁴ in 2003 to undertake the project. In action, the project undertook a stock take of contracted services and it was reported that approximately \$5.1 million was being paid for service delivery in the Northern region alone. Within those contractual arrangements however, it was found that the numbers of mental health consumers receiving services varied across DHBs (variable service volumes) and often the service described in the contract did not match the service being delivered (Gifford, 2004).

Apparently many services had developed according to local or regional demands. Despite sharing a common title, a common service specification within their contracts and a purchase unit code (the mechanism for contract payments), the services bore little resemblance to each other. Furthermore, many of these services had moved away from the initial staffing that had been agreed, and the contracted levels of staff did not match the actual staff employed. This staffing issue may have been due to services receiving funds from various funding streams and then finding it difficult to distinguish the staff specifically recruited for these social, recreational and prevocational service contracts.

Gifford (2004) also noted that service information and feedback was poorly collated and service providers used inconsistent methods to collect and record data. Therefore it was recommended that a further project focusing on the collection of appropriate reporting information and the measurement of outcomes be undertaken. This project would contribute to a programme of service improvement in the region by the DHB Shared Agency on behalf of the DHBs (Gifford, 2004).

Conclusion

This chapter has introduced the rationale for this research which focuses on mental health social, recreational and prevocational services in New Zealand. It has described the historical and political context in which these specific mental health services were established, with a particular focus on deinstitutionalisation and social inclusion. It also refers to an initial project undertaken by Gifford (2004) and the baseline information this provided.

⁴ District Health Board (DHB) Shared Agency is an entity established to support DHB function with an emphasis on activity undertaken at regional or sub regional level.

TAR is the chosen research methodology underpinned by critical theory. The three stages that make up this project and the tasks related to each one have been introduced. The first stage forms the basis of the second stage which then influences the third and final stage. The outcomes from the project are expected to bring about new knowledge and a change in practice in mental health social, recreational and prevocational services in New Zealand.

The following chapters explore the nature of consumer participation in the mental health sector and more specifically in the area of mental health service funding and planning. The research question is intended to investigate whether consumer participation can contribute to the monitoring of mental health service performance in social, recreational and prevocational services. Chapter two describes the historical, political, social and strategic contexts from which the research is set. Chapter three reviews the literature pertinent to the evolutionary development of the consumer movement and consumer participation in service development and delivery. Chapter four further explicates the methods used in each stage of the research and explores the methodology, and the ontological and epistemological positioning of TAR. Chapters five, six and seven describe the three stages of the research project in detail before the discussion is drawn together with conclusions and recommendations in chapter eight.

Chapter Two

From Institution to Community Care

The purpose of this chapter is to introduce the political and socio-historical context which predated the establishment of mental health services in New Zealand. Therefore the evolution of services in England between the 16th and the 20th century will be discussed before addressing service provision in New Zealand. This will include the impact of the Mason Report (1996) and the establishment of the Mental Health Commission, as well as the rise of the mental health consumer movement and its flow-on effect.

The movement towards deinstitutionalisation of mental health services to community based care was already occurring internationally before it began in New Zealand in the 1970s. Prior to that time there had been a number of reforms, both internationally and nationally, in approaches toward caring for, and treating, people with a mental illness. The more recent changes, supported by a philosophical intent of community integration, consumer participation and social inclusion, were challenging. Those changes, and the factors and outcomes which framed them, including the establishment of New Zealand's Mental Health Commission and the development of the *Blueprint* document are also explored in this chapter.

Historical context

Pre- asylum: 16th century

One of the earliest documented approaches to mental health care is that of the pre-asylum era in 16th century England (Kosky, 1986). The pre-asylum era was a community based approach where families cared for family members with mental health problems at home with limited support from medical practitioners in the local villages (Pelling & Webster, 1979). Taxes levied by the local parishes assisted with the costs of care, indicating overall community support and a shared community responsibility for those with a mental illness. Furthermore, at that time, there was a degree of tolerance toward the mentally ill based on an “attitude which accepted mental disorder as part of the rich fabric of life” (Kosky, 1986, p. 181). Despite this suggested

tolerance, behaviours toward the mentally ill appeared to vary with reports of imprisonment, whipping, and containment in stocks (Kosky, 1986). It would seem that individuals who lacked wealth, substance and family, received a lesser level of tolerance, support and care, with containment being considered a more appropriate and necessary course of action (Kosky, 1986).

First institutions: 17th to 18th century

Individuals who in many cases were destitute, homeless and/or ill became the first residents of institutions or work houses. These institutions were established in England in 1697 based on an underlying belief that 'hard work' was good for people with mental illness, or those whom they termed mad (Foucault, 1967). There is no evidence of cures for mental illness and despite the initial best intentions of good works and charitable acts toward those in need, these English work houses soon gained a reputation for abuse, great hardship and violence (Scull, 1981). By the end of the 18th century atrocities against the workhouse inhabitants, with or without a mental illness, were well known and calls for reform led to the establishment of asylums (Kosky, 1986).

Asylum era: 18th to 19th century

Designed using the knowledge of the time and enthusiastic optimism to promote mental health recovery, and eventual return to the community (Grob, 1994), asylums were a demonstration of concern by governments and the wider public (Ellis, 1984). In England asylums were built between 1750 and 1850 and people who had previously been housed in workhouses were transferred to the new facilities. However, both adults and children, who were sick, poor, without family, disabled and/or had a mental illness, were also housed in these asylums (Kosky, 1986).

In Scotland there were no asylums, so people with mental illnesses were often contained in what was known as Bedlam madhouse, a celled area attached to the Edinburgh Charity Workhouse. The experience of influential Scottish poet Robert Fergusson provides an example of the treatment a person with mental illness received at that time. Fergusson, who suffered from depression, was admitted to Bedlam against his will. He endured horrific conditions, confined to a small cell with stone walls and straw for a bed. A head injury, led to his most untimely death at age 24. His doctor, Andrew

Duncan, who had been responsible for his admission to Bedlam, felt so moved by his tragic death that he campaigned and fundraised for a new asylum (Veitch, 2006).

Asylums in the colonies

As colonies were established throughout the world, asylums became part of the community infrastructure. Asylums in America, Australia and New Zealand were modelled on English designs. Australia's first lunatic asylum, Castle Hill, opened in 1811. It was part of the convict era and was established in former convict barracks. Furthermore, the first asylum keepers to be employed at Castle Hill were convicts themselves. Conflict amongst the patients sometimes resulted in murder and demanded government intervention and tight controls (Parkinson, 1981).

New Zealand asylums

Early in the 20th century the New Zealand government introduced the Mental Defectives Act, and lunatic asylums consequently became known as a mental hospital; lunatics became inmates and attendants became nurses (Williams, 1987). Treatment was limited to containment of patients in locked single rooms. Patients received little contact from staff and could be heard screaming and yelling night and day. It would seem that patients were kept clean, but there were few treatments and disappointing results (Williams, 1987). Patients were deemed incurable and therefore often became residents for life (Brunton, 1996).

Asylum resident status

Factors that impacted asylum treatment were class gender and culture. Class status and the determination of public versus private patients in the asylum, impacted the treatment received and inevitably the outcome (Walsh, 2004). Treatments appeared to vary, as did the level of containment for rich and poor. There were policies and practices associated with the management of individuals known as lunatics who were also paupers. Pathways for individuals governed by legislation were determined by magistrates with further distinction related to the gender of the individual (Forsythe, Melling, & Adair, 1996).

Gender seems to have been a huge influence not only in the diagnosis of mental illness but the treatment and actual period of confinement in an asylum. Many mental illnesses were thought to be caused by domestic circumstances, for example domestic abuse and

violence, relationship conflict, and unresolved grief due to family bereavement (Shepherd, 2004). Some even suggested that pleading insanity was a desperate response to escape domestic dysfunction (Levine-Clark, 2000). Furthermore, cultural issues prevailed. A research study looking at the treatment of Māori in the Auckland Asylum in 1860s-1890s revealed that colonial attitudes toward indigenous people with mental illnesses impacted on the way they were managed in the asylum including committal, containment and treatment (Burke, 2006).

Asylum nursing

Nursing in an asylum environment was challenging. Conditions were poor, the hours were long, and the work was very hard and requiring much discipline (Brimblecombe, 2005). Many nurses came from unskilled or semi-skilled backgrounds, were young, and from rural towns. They would often live on the premises with board and lodgings provided, in addition to their wages. An increasing number of male workers joined the asylum workforce, many of whom became known as attendants. In some areas attendants were identified as keepers and undertook a custodial role, which in some cases, resulted in an unhealthy power relationship between attendant and patient. Mechanical restraint and punitive measures were reportedly used by attendants in patient treatment. The reputations of those working in the asylums, nurses and attendants alike, were tarnished by allegations of brutality and subsequently this workforce was perceived negatively by the public (Brimblecombe, 2005, 2006).

Asylum growth

Despite negative public perception there was a growth in publicly funded asylums and their resident populations. Tashiro, et al. (1992) suggested that it was medical imperialism and industrialisation that had triggered the growth in asylums and not a burgeoning increase in mental illness. Conversely, Wright (1997) did not support the medical orientated diagnosis and treatment view but did agree that the impact of industrialisation had been detrimental to households and the family unit. Regardless of the cause of the asylum growth and the corresponding increase in associated expenditure, by the 1970s stakeholder groups such as consumers and their families were demanding further mental health reform. This reform was a move away from institutional care to a community based approach known as deinstitutionalisation. Some believe that it was Deutsch's (1948) book, *The Shame of the States*, which contributed to the deinstitutionalisation movement. Published in United States of America this book

vividly portrayed the abuse occurring in the asylums. The overcrowding, residents inadequately fed and clothed, patients being over worked and/or unnecessarily restrained. All this abuse led to avoidable accidents and premature death. Deutsch's book called for change (Mowbray, & Grazier, 2002).

Deinstitutionalisation: 20th century

Deinstitutionalisation was a policy intended to improve the management and treatment of people with mental illness by moving their care into smaller community based facilities where they would be supported by community based services. The General Accounting Office Report (1997) defined deinstitutionalisation as:

the process of preventing both unnecessary admission to and retention in institutions; finding and developing appropriate alternatives in the community for housing, treatment, training, education and rehabilitation of the mentally disabled who do not need to be in institutions; and improving conditions, care and treatment for those who need institutional care (Mowbray & Grazier, 2002, p. 4).

Other factors contributing to deinstitutionalisation included the long history of public dissatisfaction with the care of the mentally ill, the rise of consumerism in the 1950s and 1960s, and increased awareness of people's rights. In addition, there was popular support for social science research and ideologies that challenged traditional beliefs about mental illness. It was suggested that mental illness was fabricated to marginalise people who may be a little different to the main stream (Mowbray & Grazier, 2002). There were also increasing liberalistic and humanistic views that were anti-psychiatry, believing asylum's to be medically dominated (Wilson, 1999).

New approaches

Improved treatments along with the introduction of new medications such as Clozapine are thought to have contributed to the potential for community based care (Brunton, 2001). Psychotic conditions appeared to respond well to new medications. Pharmaceutical companies were quick to promote this positive response, and adopted strategies to persuade governments to increase drug funding. It was suggested that this increased drug usage would surely lead to a reduction in institutional utilisation and thereby reduce institutional costs in the future (Mowbray & Grazier, 2002). Community medication based treatments seemed attractive and a financially efficient option; given

that health budgets were carrying the costs of operating psychiatric institutions and those costs had escalated to a significant portion of the health services budget (Mowbray & Grazier, 2002).

Move to community care

In light of the English view that institutions did not benefit staff or the patients; their closure and the development of community services was deemed to be beneficial to all. Both staff and patients had become institutionalised in isolated mental hospitals and those with the most severe problems did not receive the care they needed (White et al., 1997) so deinstitutionalisation was thought to be the future direction for mental health.

Establishment

Health policy and processes were needed to facilitate deinstitutionalisation and to move people into community based options (Brunton, 1986). Acute mental health units were established on local hospital sites for those with acute mental health needs while a range of accommodation options were established for those with chronic mental health needs. In addition, specific community based facilities were set up for people with high support needs who required a place of safety as a result of a severe, yet chronic condition. Those who had been housed inappropriately in institutions were identified and more suitable, individual housing solutions found. Some of these people were intellectually disabled, physically disabled, epileptic, experienced drug or alcohol problems or had been wrongfully placed (Brunton, 2001; Hall, 1988). For these people, deinstitutionalisation was a new beginning and a new life.

Whereas deinstitutionalisation commenced in New Zealand in the 1970s, it escalated in the late 1980s and by the early 1990s the total number of psychiatric inpatient beds had halved (Brunton, 2001). This was a significant transition for the sector given that 80% of the mental health funding in Auckland had been allocated to sustaining the institutions (Brunton, 2001). Now in the absence of the institutions, but with an entire cohort of people with mental health needs, appropriate care was required in a range of community based settings. Although community integration and inclusion was internationally recognised as the most cost-effective way of providing care (Ministry of Health, 1994) the major changes were not welcomed by local service providers. The workforce was unprepared and without the necessary rehabilitation skills (Cripps,

1998). The accommodation required to house people moving into the community put pressure on a limited housing stock (Smith, Kearns & Abbott, 1992).

From a policy development perspective, the response to change was “shaped by international trends, cultural legacies, social attitudes, management and fiscal pressures and by the decisions, actions and interactions of various interest groups” (Brunton, 2001, p. 183). Many assumptions were made in applying an international trend to the New Zealand environment. One frequent assumption was that when an approach is implemented in a city of similar demographic status as New Zealand then the outcomes will be similar. According to Brunton (2001), this was not necessarily the case and furthermore the issues that arose were affected by other influencing factors.

Influencing factors

Factors such as the lack of policy to support the changes that occurred, and coupled with a lack of adequate resources undermined the success of the change process. The same level of funding on which institutions operated, was transferred to hospital boards at deinstitutionalisation but at least two unforeseen aspects affected the allocation of funding. One, the absorption of the mental health funding into hospital budgets by hospital boards occurred without a financial ring fence. It would seem that hospital personnel did not fully understand the associated mental health costs. Two, the lack of robust financial planning of mental health service provision led to the underestimation of the increased costs of establishing and sustaining mental health care in the community. Inadequate resources impacted service outcomes and were ultimately detrimental to the consumer (Mason, Johnston & Crowe, 1996).

Overtime the number of incidents escalated, and subsequent inquiries conducted by District Inspectors and other agencies (Mason, Johnston, & Crowe, 1996) were perceived by many to be evidence of the inadequacy of the new model. Inability to respond to the needs of mental health consumers was seen as a failure to protect the community. Incidents and inquiries were not isolated events, for example, in 1991 there were two inquiries into the standard of care provided to mental health consumers. One patient had experienced adverse effects from treatment and another patient had died. This prompted a Ministry of Health review of mental health services.

The review, and the aforementioned inquiries and reported incidents, indicated an urgent need for direction and support for mental health service providers. In response to identified needs, the Ministry of Health developed and later launched its 1994 National Mental Health strategy: *Looking Forward, Strategic Directions for Mental Health Services*, referred to as *Looking Forward* (Ministry of Health, 1994).

The government, by their actions and the development of *Looking Forward*, was setting an agenda for mental health, led by expert and technical advisors. It was hoped that this strategy would be a springboard for change, a change from mental health services dominated by psychiatric hospitals to mental health services delivered in the community by teams. It was anticipated that *Looking Forward* would be instrumental in future decision and policy making. Its two key goals were: to decrease the prevalence of mental illness and mental health problems within the community, and to increase health status by reducing the impact of mental disorders on consumers, their families, caregivers and the general community (Ministry of Health, 1994).

In order to support and implement this new strategy for mental health, the government needed to provide additional funding, but exactly how that funding could be fairly allocated across the country was in question. For example, was it to be on a population share basis or according to the level of unmet mental health need within a district?

Social inclusion

Looking Forward also reinforced the notion of social inclusion within local communities for people who experience mental illness. Social inclusion is about being included in ordinary life, doing ordinary things like other people, and being respected citizens who can participate in social situations (Commins, 1993). Social inclusion is important for an individual's recovery, to ensure the individual is able to lead a fulfilled and meaningful life of their choosing. Yet social isolation remained an issue for many people experiencing mental illness (Bates, 2002; Becker & Drake, 1994).

Ministry of Health checks investment

In 1995, the Ministry of Health wanted to check the progress made with the additional investments in mental health services and communicate them to the public (Ministry of

Health, 1996). A stock take of current service provision showed that indeed there were more services, particularly more community based mental health teams and community based residential services, but it was unclear as to whether the services being provided were better or more accessible. Many of the community based residential and day services were being managed by NGOs. Subsequent to this the government tagged a further \$70 million for mental health expenditure, but the issues of poor access to mental health services and enough quality services continued (Mental Health Commission, 1998). Poor access to mental health services and supports was thought to contribute negatively to the wellbeing of mental health consumers. Without access to appropriate services and supports such as housing mental health consumers were more unwell, and some more likely to be homeless (Humberstone, 2002). Access difficulties also were thought to be a cause of distress for families and carers, and on occasions the poor access was blamed for what was deemed to be the inappropriate behaviour of mental health consumers. This situation further heightened the public levels of stigma and discrimination (Brunton, 2001).

Even though there was continued public criticism, the question of whether the Ministry of Health had done the right thing by deinstitutionalising mental health services was not reviewed. It was deemed to be philosophically the right thing to do and from their perspective the most cost effective way of providing services (Ministry of Health, 1994). The cost savings may have been difficult to understand, and even argued, given the millions of health dollars tagged for mental health services. Nonetheless, mental health services delivered in community settings cost less overtime when an inclusive environment aids an individual's recovery. Hence, the individual would require a reduced level of service (NIMHE, 2003).

Legislation

The shift from institutional care to the community could not have happened without the support of legislation. The Mental Health Compulsory Assessment and Treatment Act (1992) was instrumental in validating the move from containment in an institution, for often a lengthy period of time, to a community setting with support. The Act allowed people with serious mental illness to be compulsorily treated in the community and for those who required treatment in psychiatric inpatient settings, care was provided;

however, it was considered to be for short stay acute care only. The Act brought new policies and procedures that mental health professionals had to become familiar with. The Act also required inter-sector collaboration with Ministry of Justice, Department of Corrections, the police, the district courts, judges, legal representatives, district inspectors, patient advocates, and family advocates to enforce the Act (The Mental Health Compulsory Assessment and Treatment Act, 1992).

However despite strategies and updated legislation there were further incidents raising concern with mental health services and this resulted in the 1996 Mason inquiry (Mason, 1996). Previous inquiries had focused on specific incidences or services, but this inquiry was to be a comprehensive investigation covering both the availability and the delivery of mental health services. The inquiry generated huge interest. A total of 720 submissions were received from individuals, and key stakeholder groups. This was a considerably higher response level to previous inquiries, and it demonstrated the growth and strength of interested groups including the mental health consumer movement in New Zealand (Brunton, 2001). It was suggested that the response was a “powerful testimony to the growing impact of mental health services upon the community, the widespread frustration with systemic failure and a great longing to see this inquiry finally solve the problems of the system” (Brunton, 2001, p. 183-184).

The Mason Report

The Mason Report (Mason, 1996) brought together the perspectives of the many drivers for change and was itself a catalyst for change. The drivers of change were consumers, family members and carers of consumers, advocates for Māori people, advocates for Pacific people, multiple interest groups, and non-government sector organisations. The media also played a part in capturing the attention of the public with events that may not have been directly related to mental health yet they were given a mental health spin. Reports from the media often trigger the actions of others, and at times fuel negative opinion. The Mason Report highlighted recommended corrective actions in response to the inquiry findings. Those major findings concluded that the sector was under-funded, despite the additional funding overtime. In addition, there was a lack of coordination between, and across services, a lack of services for children and youth, and a poor service to Māori. This was further impacted by major workforce issues including recruitment and retention difficulties, stigma, and discrimination, warranting a public

awareness campaign (Ministry of Health, 2001a). As a consequence of the Mason Report, the Mental Health Commission was established in 1996 and the *Blueprint* document developed. The Mental Health Commission was initially established for a five year period and this period was subsequently extended. Concerns were raised over how mental health services would function with three separate governing bodies each with separate funding streams demanding separate reporting. The three bodies included: The Ministry of Health, The Mental Health Commission and The Health Funding Authority.

Reporting directly to the Minister of Health, The Mental Health Commission had three key responsibilities. First, to monitor the implementation of the national mental health strategy, *Looking Forward*; second, to reduce discrimination against people with mental illness; and third, to ensure the mental health workforce was strengthened. While some considered these measures to be a political band aid, the introduction of the Mental Health Commission brought some robustness in accountability systems, ensuring mental health funding was not diverted for other purposes and promised outcomes were delivered (Brunton, 2001). Furthermore, the Mental Health Commission was a watch dog ensuring the mental health sector remained a priority for the government, Ministry of Health and health boards (Mental Health Commission, 1998).

Although mental health had been prioritised and given additional funding, the Mason Report stated that services were barely adequate due to the level of funding (Mason, 1996). That meant that funding streams in mental health, to be successful, needed to incorporate two dimensions; one stream of funding to increase the services to the appropriate level and a second stream to ensure the new services were sustainable. New funds labelled 'Mason funding' were allocated for new and additional services as recommended in the Mason Report. The total amount allocated was an additional \$142 million per annum for five years. The funding streams were confirmed and passed on to local mental health services to invest in the development of new services, improvements, and enhancements to the current services. This was to be done according to service requirements. However, even with the significant additional funding, there were still many challenges ahead. One of which the Mason Report identified, the need for greater mental health leadership.

Strategic context

A number of significant political drivers set the scene strategically for further developments in mental health in New Zealand. While the additional Mason funding, described earlier in this chapter, was welcome there were some concerns over whether the funding could make the difference that was needed. Therefore the newly established Mental Health Commission (1996) formed a working party to support the implementation of the mental health priorities and goals. The working party was not limited to experts from past regimes; it also involved Māori and Pacific people, consumers, families of consumers and NGO representatives (Ministry of Health, 2001a).

Setting the scene

In the early 1990s, there had been considerable interest, in understanding the complex facets of an adequate mental health service. By 1993, some benchmarking of mental health services for adults had been carried out. The benchmarking was based on information collected from several sources including British epidemiological studies, and Australian studies. This information, documented in the Tolkein Report, (Andrews, 2006), was considered instrumental to the development of New Zealand benchmarks. These sources were then used in a New Zealand study, to estimate the prevalence of mental illness in New Zealand.

The New Zealand study revealed that around 20% of the adult population had a diagnosable mental illness at any one time. Of those, 3% had high support needs due to the severity of their illness (Wells, Bushnell, Hornblow, Joyce, & Oakley-Browne, 1989). The research which informed the benchmarking work led by the Ministry was used in conjunction with two reports outlining proposals for an adequate mental health service in New Zealand. The two reports, which were critical to the formation of the *Blueprint* document, included Chris Harris's (1997) Rehabilitation/Recovery report, which focused on recovery intent and resource guidelines for support services; and Derek Wright's (1997) draft *Blueprint* document which developed guidelines for clinical services (Mental Health Commission, 1997).

The working *Blueprint* document addressing both the support and clinical needs of those experiencing mental illness was then developed. Whereas in the past New Zealand

had tended to replicate approaches from international studies, this was the first time that such comprehensive detail of specific mental health service needs and resource requirements in New Zealand had been documented. The working document was circulated widely for public consultation and amendments were made before the final document titled: *Blueprint for Mental Health Services in New Zealand. How things need to be* (1998) was released by the Mental Health Commission.

Moving Forward

During, 1997 the focus on mental health services within the Ministry of Health was intense, with the release of a document titled *Moving Forward* (Ministry of Health, 1997), which was a sequel, to *Looking Forward*. As a national mental health plan, *Moving Forward* built on the strategic directions of *Looking Forward* (Ministry of Health, 1994) and included two more strategic directions. With a focus on promotion and prevention, and service infrastructure development, *Moving Forward* introduced mental health benchmarking models thereby indicating the need for more and better services. The *Blueprint* document provided a service development framework on how to achieve the *Looking Forward* and *Moving Forward* strategies (Mental Health Commission, 1998). Implementation of the strategies was assisted by funding specifically allocated for the implementation of the *Blueprint* recommendations.

Blueprint funding

Blueprint funding was tagged or ‘ring fenced’ for mental health use only following the Mason Report (1996) funding. Concerns over how to allocate the new funding sources fairly were addressed within the *Blueprint* framework. Distribution of funds was based on the level of mental health need within a district according to the *Blueprint* benchmarking. Evaluation and review of progress made with the level of funding were scheduled on a regular basis and the findings were published nationally in the *Review of Progress 1994-1999* (Mental Health Commission, 1999) and *Report on Progress 1998-2000* (Mental Health Commission, 2000). The Mental Health Commission offered advice to mental health service providers on how best to implement the *Blueprint*. Their vision statement, which is reiterated in the *Blueprint*, is:

To ensure that people with a mental illness live in an environment which respects their rights, provides fair and equal opportunities and have access to a fully developed range of mental health services which is provided by the right

combination of people responding appropriately to people's needs in order to achieve the best possible outcomes and recovery (Mental Health Commission, 1998, p. 2).

Ringfence project

The Mental Health Commission led a project jointly with the Ministry of Health reviewing DHB mental health funding application for the financial year 2001/02 and planning for 2002/03. Terms such as protecting the mental health ring fence were used as they investigated six DHBs. The ring fence is a complex administrative mechanism to protect or provide an incentive for development in particular service areas or particular initiatives in line with the *Blueprint*. The Ministry of Health's investigation found that DHBs' were applying funding to mental health services as required but that there were systems and process issues that needed to be addressed. Recommendations were made in a project report to those participating DHBs (Mental Health Commission & Ministry of Health, 2003).

Translating the Blueprint

In 2003 a project titled *Translating the Blueprint* (Mental Health Commission, 2003b) was undertaken in two DHB organisations. To maintain stakeholder communication throughout the project processes, the Mental Health Commission established a stakeholder reference group from around the country. The project sought to understand how the *Blueprint* was translated at DHB operational level. While the Mental Health Commission reviewed translation of the Blueprint the Ministry of Health embarked on further planning.

New plan and action plan

Having a solid foundation of strategic and operational context with *Looking Forward* (Ministry of Health, 1994), *Moving Forward* (Ministry of Health, 1997), and the *Blueprint* (Mental Health Commission, 1998), the Ministry of Health then developed a new national 10 year plan called *Te Tahuhu Improving Mental Health*, (2005). This plan was quickly followed by *Te Kokiri* (2006) a more detailed action plan for the implementation of *Te Tahuhu Improving Mental Health* (2005).

Despite these very comprehensive and inclusive new documents the impacts of the implementation of the *Blueprint*, both positive and negative, had not been forgotten. That is to say, DHBs had more clarity with regards to funding paths and a greater understanding of the cost implications of establishing new and additional services (Ministry of Health, 2006). Similarly DHBs were very aware of the performance outcomes that both Ministry of Health and Mental Health Commission expected from them for the funding provided.

Financial implications

Sound financial management is critical in the funding of health services as there is a limited amount of money available. Mental Health funding is channelled from the New Zealand government via Vote Health to the Ministry of Health and on to DHBs where contracting processes occur with providers of mental health services (Ministry of Health, 2006). The Ministry of Health is responsible for decisions made as to how funding is allocated. The first decision determines the amount of money given to the mental health sector. A second decision is made regarding how much to give to each DHB throughout New Zealand. Similar decisions must be made at DHB level where the funding is then tagged to new services or core services through a contracting process (Ministry of Health, 2006). As discussed in chapter one services for mental health were better delivered from a recovery paradigm.

Recovery Model

The *Blueprint* as a piece of instrumental mental health policy, had insisted on a change in practice, and demanded that initiatives be put in place to ensure those changes occurred, for example the recovery philosophy in practice, community integration and family participation. Expectations of services were to provide environments that supported recovery not just treat illness (Mental Health Commission, 1998).

For some health professionals, particularly those who had practiced clinically using the medical model, they found this *Blueprint* approach, challenging. The more traditional medical model focuses on diagnosis of illness or problem followed by treatment which is expected to reduce symptoms and decrease levels of required acute care (Rapp & Goscha, 2006). Within this approach, the power resided with the health professional. Consumers many of whom identified more readily with the goals of the recovery model

felt empowered by the notion of recovery and gained greater understanding of what to expect from mental health service providers and how they could participate (Davidson, Tondora, Lawless, O'Connell & Rowe, 2009).

Resources were developed describing how consumers could get the most out of mental health services (Mental Health Commission, 2003a). For some consumers, and those who wanted to participate in their care, the *Blueprint* gave greater autonomy and control in their treatment options and life decisions. Furthermore, the *Blueprint* framework defined recovery, promoted social inclusion and encouraged participation in ordinary everyday activities (Mental Health Commission, 1998).

Consumer participation

The *Blueprint* reinforced consumer participation and inclusion by stating the number of consumer led initiatives a DHB was expected to fund for a population. It was expected for DHBs to contract a mix of consumer run initiatives and, in addition to this, some DHBs established consumer advisory roles within their services (Mental Health Commission, 1998).

Some professionals found consumer advocates and advisors disconcerting and at times challenging. Health professionals used to the traditional medical model had previously been in a position of power and control and they were uncomfortable with legislation and standards governing their actions. Resistant to change, some tried to tighten up local procedures by using legislation such as the Privacy Act, as a barrier to conversing with consumers and their families (Wallace, 2003). Local DHB health information policies have since been introduced, accompanied by education and training to support staff information sharing as advocated in the *Blueprint*.

Mental health consumers and their families established groups of supporters, advocates, special interest groups, rights groups, and lobbyists (Brunton, 2001). The Mental Health Commission and the Ministry of Health also acted as drivers of change. Some groups of health professionals resisted the changes because they feared the impact change would have on their own practices, careers and personal livelihoods.

This tussle between drivers and resisters resulted in rigorous public debate. Although the final outcome did not necessarily reach a compromising agreement, each of the players' stances on the issues arising were communicated and therefore contributed to the overall body of knowledge in the mental health sector at the time. When implementing the new policies, stakeholder perspectives were taken into consideration and the Ministry of Health put strategies in place in order to gain greater acceptance or buy in. For example, the Ministry of Health made a significant investment in raising awareness and understanding of mental illness in an attempt to de-stigmatise the issue (Ministry of Health, 2006). Acceptance of the services by Māori was poor in terms of recognising what benefits the services could offer people experiencing mental illness (Cunningham & Kiro, 2001).

Tāngata Whenua

A stakeholder of significance in this sector is Māori. In New Zealand the Treaty of Waitangi (Cunningham & Kiro, 2001) signifies a partnership between Māori and Pakeha. Māori are known as tāngata whenua or the people of the land. The Treaty mandates the Crown to act in the interests of Maori as outlined in the articles of the treaty. The Treaty stresses protection, partnership and participation (Cunningham & Kiro, 2001). Many of the established health services did not take Māori and their cultural paradigms into consideration. Subsequently, many Māori failed to engage with traditional health services and it would seem, developed a disproportionate increase in incidence and level of disability due to mental illness. As drivers of change, Māori people wanted a move from traditional approaches to a more participative and inclusive approach. Above all, they wanted to improve the rates of mental health service access and thereby reduce the rates of mental illness amongst Māori (Durie, 2001).

Overseas frameworks

Other countries have developed similar frameworks to assist with the development of performance indicators and standards that services should achieve (Tansella & Thornicroft, 1998). In England much work has been done establishing frameworks of strategies, policies and more recently, guidelines. Their National Service Framework for Mental Health is highly regarded as a blueprint for UK mental health services (Becker, 2001; Department of Health, 1999).

In Ontario, Canada, a similar framework was also developed specifically for mental health services which sought to establish an accountability framework with set outcome measures included. Those measures extended to wellness not just illness reduction (Ontario Ministry of Health and Long-Term Care, 1999). Their established mechanisms would examine the effectiveness of each mental health programme according to its contribution to a coordinated continuum of services, in addition to its individual programme merits. Specifically developed evaluation tools assisted programme examination.

Leadership in change

It was suggested that charismatic leadership was needed to drive change (Bolman & Deal, 1997). Hussey (2000) described a leader in times of change as needing to be “envisioning, activating, supporting, implementing, ensuring and recognising” (p. 72). The leader created the vision and sold it to the team or organisation. That is a vision which addressed the needs of its followers; their challenges, aspirations and values (Bolman & Deal, 1997). Leadership was required at every level for changes to be implemented effectively. A response to mental health issues at a national level required the government to show leadership in the political arena (Brunton, 2001). Leadership, which supported positive change in service delivery, and campaigned for anti-discrimination.

Summary

This chapter has described the socio-historical and political context framing the development of mental health services in New Zealand. Following international imperatives in the provision of community based care for people with a mental illness, New Zealand embarked on major service change. It was fraught with challenges and so the mental health social, recreational and prevocational services were established to try and support consumers adapting to the changes in service provision and transitioning to community based care. At a political governmental level, the need for strategic leadership was recognised. This chapter has considered the political drivers that contributed strategically to developments in mental health. The leadership provided to the mental health sector by the Ministry of Health and the Mental Health Commission has been outlined. More specifically the influence of policy documents such as the *Blueprint* which was considered to be radical in its approach. Furthermore, discussion

includes the challenges that arose when DHBs applied their own interpretation to the *Blueprint* as they embarked on the change process. Mental health consumers and family members lobbied for services that would meet their needs in a socially inclusive way. Despite growing support, barriers such as societal attitudes and stigma persisted (Dew & Kirkman, 2002). Meanwhile the Ministry of Health and the Mental Health Commission continued to stress the importance of consumer participation. A review of the literature regarding consumer participation is described in the next chapter.

Chapter Three

Review of the Literature

This literature review was undertaken to inform my research and to contextualise the study by considering that which is already known. The notion of the consumer being the lay expert participating in a health care partnership has been difficult for some health professionals to comprehend (Griffiths et al., 2004). In this literature review, I explore the theoretical frameworks that support consumer participation and consider the historical developments that have occurred, including the positive and negative influences that have impacted on consumer participation. Furthermore, I will review the strategies and service models which have been developed to embed consumer participation in mental health services despite opposition.

Consumer participation

Consumer participation in mental health services is defined as people who use mental health services participating in the services that they access (Mental Health Commission, 1998). This is in keeping with the guidelines set out in the *Blueprint* (1998) and which called for consumers to participate in services at every level including planning, decision making and evaluation (Mental Health Commission, 1998). Participation in mental health services can be at different levels: societal, community, organisational, and/or as an independent individual (Sang, 2004). Family and whānau may also participate in mental health services as they support a family member who is a consumer (Mental Health Commission, 1998). Consumer participation is based on theories and beliefs about the consumer's role or function within a health care system (Deegan, 1992).

Theoretical frameworks

The theoretical basis for involving consumers in their own health care is a matter of social justice and equality (Cowan, 2008). From a democratic perspective, individuals should be able to participate equally and without bias in society. Citizenship is a fundamental right of individuals within a society, including those with a mental illness

(Mental Health Commission, 2002). Denying citizenship on grounds of mental illness, or due to stigma or discrimination, is a violation of human rights (United Nations, 1948) and therefore a social justice issue.

According to Kidd et al., (2007) the consumer perspective should be valued. Indeed, it has been suggested that consumer participation is about socialisation and that potential barriers to the idea are due to the influence of patriarchy (Dew & Kirkman, 2002). Furthermore, it has been reported that patronising attitudes and behaviours toward those with a mental illness are compounded by traditional beliefs about roles and functions within society, for example traditional patient and doctor roles (Dew & Kirkman, 2002).

Developments over time

Consumers objecting to traditional beliefs, and exerting their right to participate in decisions regarding their own health care and treatment is recognised as consumerism (Dew & Kirkman, 2002). Since the 1980s, consumer participation in New Zealand has developed from a place where consumers and their families lacked confidence in the health services provided (Brunton, 2001). National inquiries into health care resulted in greater exposure of faults and errors in service delivery (Brunton, 2005) and so consumers became more determined to be heard.

One of the most significant events to shape consumerism in New Zealand was the Cartwright report. The report, which was published in 1988, was a response to an inquiry led by Dame Silvia Cartwright. The investigation found unethical research practices involving women were being undertaken in a reputable city hospital. This report gained huge media attention; raising public concern and revealing a lack of confidence in the medical profession (Cartwright, 1988). This ultimately led to considerable reform in ethical practices at a national level followed by a thorough scrutiny of the processes for engaging consumers in research activities. This course of action included reviewing informed consent procedures and establishing a Health and Disability Commissioner.

The Commissioner's role is to independently investigate any consumer complaints regarding the provision of health care services including the actions of health practitioners. Furthermore, researchers seeking consumers to participate in any research

project are required to direct them to the Health and Disability Commissioner or an Advocate should they have concerns (Davis & Ashton, 2001).

Legislation and policy

In recent years, consumer participation has been written into legislation and policy, thereby making it a compliance issue which enforced action and subsequent change for health care providers (Griffiths et al., 2004). Here in New Zealand it was decreed in standards that, by 1998, consumers would participate in policy development and planning at a national level (Ministry of Health, 1997). The expectation of participation was reinforced in the *Blueprint* (Mental Health Commission, 1998), and the Health and Disability Service Standards (Ministry of Health & Standards New Zealand, 2007) as well as in mental health strategic documents such as *Te Tahuhu: Improving mental health 2005-2015*; *The second New Zealand mental health and addiction plan*. These documents provided direction on how to implement consumer participation in services (Ministry of Health, 2005). An independent investigation into how consumer perspectives could be obtained and integrated into policy and legislation found that there were three critical components. Effective relationships, dialogue and action were deemed to be a prerequisite to achieving positive benefits (Kites Trust, 2005).

Positive benefits

According to the Mental Health Commission (2002) there are many positive reasons why consumers should participate in services. For instance, participation is an effective component of a consumer's recovery; since improved services are in the interests of the consumer. This stance is endorsed by Stringfellow and Muscari (2003) who argued that mental health consumer participation, while beneficial to shaping mental health services and policy, can also strengthen an individual's self-determination. Research undertaken overseas supports this stance.

Overseas trends

According to Sang (2004) legislation in the UK, outlined in the Health and Social Care Act (2008), recognised the right of the health care consumers to be involved in decisions made about their care and to work in partnership with providers. Moreover, Sang (2004) discussed the notion of consumers of health services as citizens, seeking an

equal partnership in the way services were shaped and delivered. This partnership was enforced by legislation.

Similarly, in West Virginia, USA, consumers were offered formal leadership training and engagement in a network for mental health advocacy. Those engaged in the leadership training began as students and progressed through to the role of tutor and coach. This was empowering for participants and when observed by other professionals, consumer performance went beyond expectations. Graduates of the leadership programmes served on boards and committees, and attended conferences. Through this programme individual consumers were able to participate equally, like other citizens, undertaking civic duties and integrating within their communities (Stringfellow & Muscari, 2003).

Strategies and service models

There is a shift in thinking, both locally and internationally from the ‘doctor knows best’ culture to one of greater inclusion and partnership between health professionals and consumers (Sang, 2004). The goal of participation is to improve the decision making, quality and shape of services by empowering the consumer to contribute to services (Kites Trust, 2005). It has been suggested that before commencing an intervention or treatment there should be partnership between the doctor or clinician and consumer (Sang, 2004) that is participatory and collaborative (Draper & Hill, 1995). Such a shift in paradigm would require strategies such as improving service delivery, delivering compliance measures, shaping policy and enhancing research (Epstein & Shaw, 1997).

Compliance measures

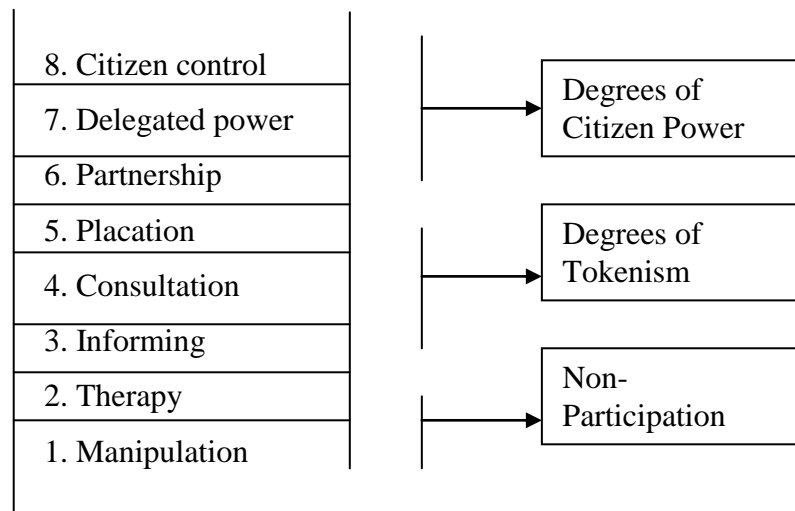
Mental health services are audited to ensure compliance with the Code of Health and Disability Services Consumers’ Rights. These rights include:

The right to be treated with respect; the right to freedom from discrimination, coercion, harassment, and exploitation; the right to dignity and independence; the right to services of an appropriate standard; the right to effective communication; the right to be fully informed, the right to make an informed choice and give informed consent; the right to support, rights in respect of teaching or research; and the right to complain (Health & Disability Commissioner’s Office, n.d., p. 1).

Shaping policy

Arnstein (1969) created a framework titled ‘A ladder of citizen participation’. The ladder focused on power and control, and included the right to make decisions as shown in figure 2.

Figure 2: Arnstein's Ladder of Citizen Engagement



(Adapted from Tritter & McCullum, 2005).

Others have attempted to revise Arnstein’s ladder (Tritter & McCullum, 2005). For instance, Wilcox (1994) suggested that within the ladder framework, the consumer should be working in conjunction with others, deciding, acting and supporting independence. Further, Tritter and McCullum (2005) found that the environment had changed and the application of Arnstein’s model was limiting. They proposed a new model to replace Arnstein’s ladder one that engages consumers in transformational processes that will require new learning for both health professionals and consumers.

Broner, Franczak, Dye, and McAllister (2001), suggested using a consensus model to develop policy and services in mental health. In the application of such a model they found that consumer representation and advocacy was essential, particularly with respect to progressing developments and communicating with stakeholders. It would seem that more research is required to further show the effectiveness of consumer participation within different models.

Shaping research

The benefits of consumer participation in research have been recognised by several researchers. For example, the consumer brings a unique perspective, expertise, and relevancy to the research (Peterson, 1999). Furthermore, Griffiths et al., (2004) argued that the consumer increases the ethical nature of the research and the researcher accountability by their presence since: “Their input can direct research where it is needed, rather than where researchers may want it” (p. 40). Involving consumers in research from the very beginning means the process is more likely to be consumer centred and consumer relevant. Consumer participants have a right to engage in research that is about their health issues, in fact, they are more likely to want to engage (Peterson, 1999).

Health professionals participating in a workshop in Australia were surveyed about consumer participation in research. Advantages of consumer participation were considered significant and specific to the research project, to public health, and to the consumer (Griffiths et al., 2004). What is more, Griffiths et al., (2004) found that consumer participation in research “empowers mental health consumers by not treating them as victims or passive recipients, [it] shows respect for the knowledge and skills they possess” (p. 44). The consumer has a sense of ownership, a voice, an opportunity to contribute, without stigma and discrimination, when participating in research (Peterson, 1999). However it has been stated that consumer participation may not always be valid. According to Griffiths et al. (2004) “just because somebody says they involve consumers, it doesn’t mean that they really do involve consumers” (p. 23). Claims are sometimes made that consumers are involved; yet the consumers do not really feel involved and so they need to know that they have been listened to in a participative process and that actions have occurred as a result.

Challenges in research

There are challenges to consumer participation in research. Peterson (1999) indicated that as well as increasing the cost of the research, objectivity may be lost. Similarly, research can be jeopardized by a consumer’s illness, and/or individual agendas may surface rather than the representational one that is sought. Training is necessary to mitigate these challenges and ensure the research is rigorous. Equally, informed consumers have greater understanding of how to participate and to enhance the value of research (Griffiths et al., 2004)

Improving the delivery of services

Consumers in New Zealand are moving beyond the provision of advice and advocacy to become service providers thereby improving service delivery (Orwin & Burdett, 2009). Furthermore, consumers now assume roles and functions within DHBs or NGOs. These include peer support workers, network members, consumer consultants, and consumer advisors (Ministry of Health, 2006). In addition, consumers have engaged with mental health professionals in training environments, and by sharing information about their recovery journey (Mental Health Commission, 2001). They may also provide information and advocacy services to more acute services.

Consultancy, advocacy and advice

According to Stockdale et al., (2006), community participation and partnership positively addresses a mental health problem within a community by providing mental health consumers with an opportunity to share information about issues that were relevant to them. The researchers in this project saw the capability of the community group to maintain equitable levels of participation, as a measure of success. Another community partnership model was explored by Wells, Miranda, Bruce, Algeria & Wallerstein, (2004). The findings showed that managing multiple stakeholders in a partnership model, in a complex environment, was challenging from initiation to implementation and evaluation. Stigmatisation of mental health consumers was an issue that needed to be taken into consideration. However drawing consumers together in formal arrangements such as networks was advantageous.

Consumer networks

As more organisations and communities seek to include a consumer voice, consumer networks are becoming more established (Miller & Moore, 2009). Different organisational models are being used from the more formal, which promote financial and management accountability, to those less formal which have been likened to a club (Doughty & Tse, 2005). Formal models often have a leadership emphasis with a board made up of consumer members. Successful networks usually demonstrate transparency, and a sense of shared purpose. They also conduct strategic planning and mentoring, establishing a foundation for growth and visionary leadership (Miller & Moore, 2009).

Peer led services

Peer led services are those where consumers intentionally participate in the leadership, planning, management, operational activity and evaluation of an organisation in an employment capacity. Service provision is based on the understanding that those who have experienced and overcome an illness have expertise that can benefit others (Davidson, Chinman, Sells, & Rowe, 2010). Research from these service types has shown positive outcomes for consumers as both provider and receiver (Doughty & Tse, 2005). However, the authors identified the fact that limited research has been done with regards to peer led services in New Zealand. This is despite evidence which shows that it is an effective model of mental health service delivery.

Peer support

Peer support is provided by one consumer to another with similar experiences (Mead & MacNeil, 2004; Orwin & Burdett, 2009). Based on the Strengths Model (Rapp & Goscha, 2006), the goal of a peer support worker is to build on the strengths of the individual consumer, and to assist them to achieve their goals. Peer support is delivered independent of other services (Orwin & Burdett, 2009); yet is linked to the range of care and supports provided for an individual.

Cleary, Glenn, Malins, Matheson, and Escott (2009) advocated for adequate training in alcohol and substance misuse, for mental health peer support workers. Given that this is an issue that they will likely encounter when supporting other mental health consumers, it was argued that they need to be prepared. Additionally, the role of peer support workers may be extended to other associated tasks.

Peer evaluation

Consumers have an increasing role to play in the evaluation of services. Nationally administered consumer satisfaction surveys are more commonly used by the Ministry of Health with a focused effort occurring at a local service level (Zwier, 2009). One DHB gave a consumer evaluation team responsibility for assessing the DHB services from a consumer perspective (Te Pou, 2008). A mental health workforce organisation also facilitated the use of consumer measurement tools. Titled Taku Reo, Taku Mauri Ora- My Voice, My life- a Tāngata Whaiora/service user self-assessed outcome measure (Gordon et al., 2009). The tools were developed for consumers by consumers.

Overcoming barriers and navigating obstacles

The barriers and obstacles to consumer participation that are often linked to relationship difficulties between the consumer and an organisation can be overcome. Each party just needs to recognise the benefits of participation and to enter the relationship with respect for the other (Kites Trust, 2005). The benefits of consumer participation are well known but this is not always reflected at the clinical practice level. Borg, Karlsson & Kim (2009) referred to it as the rhetoric rather than reality of consumer participation. They identified some key challenges which must be overcome if consumer involvement in community mental health practice is to become reality.

Consumer participation exposes a tension between service providers focused on maintaining quality, improving safety and reducing risk, and consumers' notions of increasing choice, obtaining informed consent and partnerships (Sang, 2004). Power imbalances still affect the way these groups interact and work together (Chinn, 2004). To be successful, any group seeking to change the way service is provided, including those with consumers participating, need to have shared values and to reflect those values in order to see transformation with a view towards avoiding alienation of group members. With regards to group work, Chinn (2004) also described group or gathering 'meeting closure processes' as important. Three parts were essential to bring a meeting to a positive conclusion: appreciation, critical reflection and affirmation. In addition, there needs to be a commitment to moving forward.

Attitudes

Research has shown that attitudes can also be a barrier to engaging with consumers. Other people's attitudes were captured in a project that sought to establish mental health supported accommodation in a neighbourhood. Potential neighbours raised issues of public concern about having people with a mental illness living in their neighbourhood; they felt that they should have been consulted at different stages of the project (Cowan, 2003). Such fears and assumptions about mental illness are often detrimental to recovery (Stringfellow & Muscari, 2003).

Similarly McCann et al. (2006) investigated attitudes of mental health professionals about consumer participation. They found that generally the mental health professionals supported consumer consultants' participation; however they were less supportive of them participating in activities staff thought were their domain. This perspective was

evident with nurses, who did not support the notion of consumer participation that may impinge on nursing tasks.

Attitudes of mental health professionals were often found to be limiting in terms of inclusion (Happell, Pinikahana, & Roper 2002). Researchers measured attitudes of nursing students about consumer participation and although there was a high acceptance of consumer participation, this acceptance was directed at specific planning and delivery functions. There was a reluctance to accept the need of a consumer academic role.

Public attitudes about mental illness also influenced opportunities for consumers in a volunteer work scheme. Young and Passmore (2007) described barriers that consumers experienced when taking part in volunteer work schemes. Despite the barriers the study found that volunteering, as part of their individual recovery, had a positive effect on consumers.

Conclusion

This literature review reveals that over time there have been significant developments related to consumer participation within the mental health sector in New Zealand. However, there is a dearth of research designed to evaluate the progress of consumer participation in a range of roles including planning, funding and evaluation.

The research on consumer participation revealed in the literature tends to be based on other people's ideas. In order to increase understanding of the benefits of consumer participation, it is imperative to 'hear' the voices of people who live with mental illness. Capturing their experiences, views and opinions frames them as potential contributors to wider debates, including policy debate.

Chapter Four

Methodology and Methods

This research provided an opportunity to give voice to consumers who had previously been marginalised by their communities and the services that they accessed (Stringer, 2007). My role as researcher was to dialectically engage selected consumer participants along with other stakeholders, in facilitated activities; to build their capacity through collaboration and knowledge sharing to bring about organisational change. Action research processes aim to change, develop, improve and innovate (Zuber-Skerritt, 1996). By applying action research which is: “a disciplined approach to discovery and understanding, with a commitment to share what is learnt” (Senge & Scharmer, 2006, p.197), the goals of my research would be achieved.

Action research is different to other research methods, in that it is flexible, responsive and reflective. Other research methods utilise statistics and numerical data with controls and standardisation (Dick, 2002). Action Research is conducted with a foundation of moral and social values and inquiry that is democratic, equitable, liberating and life enhancing (Stringer, 2007).

Technical Action Research (TAR) a type of Action Research was chosen more specifically for this research because of its fit with the topic, and the community mental health based context, with the expectation of fostering growth and learning in the researcher and the research participants (Kemmis, 2006). Dick (1996) demonstrated the practical application of TAR in a study which highlighted the processes of participation leading to organisational change. This research sought to achieve a similar route to organisational change.

This chapter will describe the features of TAR its similarity and differences with other forms of AR, and its positioning within the frameworks of critical theory. Some AR is driven by the participants, while other action research is more driven by the researcher’s agenda, such as TAR. Further to this, TAR seeks to achieve a specific goal (Coghlan & Brannick, 2005; Reason & Bradbury, 2006). In addition, the research methods underpinning this research are discussed.

Critical paradigm

TAR, as with other AR approaches is situated within the critical theory paradigm. The assumptions within this paradigm suggest that reality is understood by the historical contexts that shape it and overtime it becomes embedded in taken- for- granted understandings (Stringer, 2007). Since critical theory is dialogic and dialectical, a relationship of inquiry is required between the researcher and the research participants (Guba & Lincoln, 2000) in this way knowledge can be uncovered and rationalised. It is transformed and grows as a result of dialectical processes. Knowledge urges change with a call to action (Reason & Bradbury, 2006).

The ontological position of AR is grounded on the assumptions that reality itself is shaped by socio-economic, cultural, ethnic, and political contexts and an individual's values (Guba & Lincoln, 2000). "Action research is value laden and morally committed" (McNiff & Whitehead, 2006, p. 26). This means that as an approach it respects and values the contribution of others. The research findings are viewed through the values lens, or described as "value mediated" (Guba & Lincoln, 2000, p. 110). From an epistemological position AR knowledge is uncertain and so the creation of knowledge is a collaborative process. Knowledge is generated by the interaction of the participants within the action cycle. From a methodological perspective, Dick (1997a) argued that AR is a research paradigm that is useful in situations where other methodological approaches may not easily fit, with a group of methods based on principles and a unique flavour. AR is undertaken by practitioners in the field, it is about development and social change (McNiff & Whitehead, 2006). Furthermore, opportunity is created through transformational inquiry to achieve transformational leadership (Burns, 1978).

As an inquiry process it seeks to achieve goals and bring about changes, " is informed by diverse streams of intellectual and political thought, which both inform practice and provide underpinnings in the philosophy of knowledge and social action" (Reason and Bradbury, 2006, p. xxviii).

Philosophical background

Several key philosophers informed this critical approach.

Kurt Lewin

Lewin followed the social scientific work of John Collier in the 1940s (Reason & Bradbury, 2006). Credit for AR is given to both men; yet each worked independently of the other (Lewin, 1951; Reason & Bradbury, 2006). Lewin explored racial issues, indeed the term AR is first mentioned in a paper titled “*Action Research and Minority Problems*” (Lewin, 1946) in which Lewin described AR as social action made up of planning, action and fact finding within spirals of steps (McNiff & Whitehead, 2006).

Lewin (1951) predominately worked within organisational environments and introduced a further AR three step model: unfreeze, move, and refreeze. This model demonstrated a problem solving capability that could be applied to a workforce. Lewin (1951) found that engaging workers in a cycle of fact finding, action and evaluation, meant that the workers solved work related issues leading to improved work production. When Lewin died, in 1947, AR was claimed by the organisational development movement and became a significant part of organisational research and development (Coghlan & Brannick, 2005).

John Dewey

Dewey, an American philosopher was responsible for the thinking behind using science to solve practical social problems. In order to do this he posed “five phases of reflective thinking: suggestion, intellectualisation, hypothesising, reasoning and testing hypotheses in action” (Passmore, 2006, p. 38). He introduced his theories to education, suggesting that students should learn to think rather than learning the information.

Jurgen Habermas

Habermas was a German philosopher with a focus on critical theory. He suggested that critical theory in the literature was a type of hermeneutics. He saw three categories of knowledge: that related to practical work (technical), that that arose between people in communicative action (practical), and then a final category which was the understanding of needing to emancipate people to create change (emancipator) (Kemmis, 2006).

Pierre Bourdieu

Bourdieu was a French philosopher, anthropologist and sociologist. His investigative studies revealed the power relationships in social life and the application of classification systems which determined the more dominant groups. His understanding of social systems and order he transformed based on a number of theories: social agent, fields, habitus and capital (Bourdieu, 1984). His structurationist view is referred to by Bradbury and Reason (2006) as providing a logical basis for commencing and achieving a system change as in action research.

The common theme between these philosophers is their focus on helping achieve change based on insights of what is underpinning current concerns. Some, such as Habermas, move to explore issues of hegemony (Habermas, 1984), the hidden powerbases that keep groups in society oppressed. This research is immersed in a social political context in which the researcher is already embedded. Therefore, close examination of issues of power and vested interest were left to emerge rather than specifically addressed. There is vulnerability for both the researcher and participants in a research project that directly seeks to overthrow power structures (Habermas, 1984).

Common features of action research

All types of AR including TAR share the following features including the position of the researcher within or outside the research which needs to be determined. According to Habermas, the researcher cannot do the learning for the research participants. The research participants will choose how to participate on their own terms. Habermas's perspective underpins emancipatory AR (Kemmis, 2006).

- *The Action Cycles:* Action is a key focus from initiation of research to completion, and concurrently within the research process. It can be described as spirals of action or action cycles. An example of an action cycle was a stakeholder reference group meeting. Each meeting from pre-meeting preparation to post meeting reflection and evaluation was an action cycle within action cycles. Carr and Kemmis (1986) described AR as a cycle of planning and reconnaissance, action, observation, reflections and re-planning. Critical reflection is an important part of the cycles before further action. The cycles also involve a deliberate and planned sequence of events (Carr &

Kemmis, 1986; Coghlan & Brannick, 2005; Reason & Bradbury, 2006; Stringer, 2007).

- *Emergent Nature:* As a methodology AR slowly develops through the growing body of knowledge shared by the research participants. It is responsive and flexible, adapting as circumstances change (Dick, 1996). “Action research is best seen as an emergent, evolutionary and educational process of engaging with self, persons and communities which needs to be sustained for a significant period of time” (Reason & Bradbury, 2006, p. 12).
- *Partnership with Participants:* The researcher working in partnership with the research participants is engaged democratically to achieve an outcome (Reason & Bradbury, 2006; Stringer, 2007). Dick (1997a) suggested that in AR there are 5 aspects of participation: the participants are informants, interpreters, planners and decision makers, and implementers.
- *Pathways of Practice:* The concept of first, second and third person research practice has evolved from AR. It is research which focuses on the individual and the researcher inquiries into their everyday life, asking why they do what they do is first person research. Seeking out others with shared concerns to achieve a solution is second person research. Third person research is about extending to the wider organisation or community such as that leading to organisational transformational change (Torbert, 2006).
- *Types of Knowing:* AR distinguishes four types of knowing: experiential, presentational, propositional and practical (Coghlan & Brannick, 2005; Reason & Bradbury, 2006). These 4 types of knowing can produce 4 types of evaluation based on that knowing (Herr & Anderson, 2005).
- *Practical Application:* AR is a methodology which has a theoretical basis that can be applied practically (Stringer, 1996). It provides researchers with the ability to improve their own practices through self-reflective enquiry (Kemmis & McTaggart, 1986). Critical analysis and interpretation can bring about improved understandings (Dick, 1997b). Reason and Bradbury (2006) suggested that action research brings practical knowledge that can be used in normal life.

Types of action research

AR has had some six decades of development and over time many methodologies have evolved (Reason & Bradbury, 2006). These methodologies have quite different interpretations compared with the traditional AR.

1. *Technical Action Research (TAR)*, the methodology selected for this research is described by Reason and Bradbury (2006) as a form of problem solving that is more constructed towards achieving a specific end goal.
2. *Participatory Action Research (PAR)* has a strong community focus and seeks to develop and change community organisations through empowering the people as research participants. Paulo Freire's work has influenced PAR (Reason & Bradbury, 2006; Stringer, 1997), "It involves a whole range of powerless groups of people: the exploited, the poor, the oppressed, the marginal" (Hall, 1979, p. 289).
3. *Collaborative Inquiry*, also known as co-operative inquiry, originated from John Heron in 1971. This approach involves at least two people researching the same topic but through their own world view in order to find out what should be changed to make things better (Coghlan & Brannick, 2005; Heron, 1996; Heron & Reason, 2006).
4. *Developmental Action Inquiry* as described by William Torbert involves the inquiry being part of a normal life. As things occur the individuals reflect on their behaviours and act and reflect again (Coghlan & Brannick, 2005).
5. *Living Theory Approach* as described by McNiff and Whitehead (2006) sees the researcher accountable for his or her own learning and influencing the learning of others.

6. *Practical Action Research* has been influenced by Donald Schon and seeks to promote practice improvement through practitioner reflection and a greater understanding of themselves (Reason & Bradbury, 2006).
7. *Emancipatory Action Research* was influenced by the theories of Habermas, and seeks to achieve a critical understanding of how groups of people and their environments are shaped by the historical, social and cultural contexts. This is particularly useful in considering the environmental impacts on marginalised groups (Kemmis, 2006).

Key features of Technical Action Research

TAR, is described as being of a technical or instrumental nature for “getting things done effectively” (Kemmis, 2006, p. 95). It is key to achieving an intended outcome or a means to an end interest. This is a popular approach in organisational contexts as it is orientated towards functional improvement. An investigation may be triggered with an increase or decrease in incidence of certain occurrences or outcomes. In this context, the researcher would not necessarily question the research goals or the context in which the research is set for example historical, political, social or cultural contexts. The success of TAR is measured by whether the intended outcome has been achieved such as the expected research outcomes meeting the aspirations (Kemmis, 2006).

How Technical Action Research is different

When compared to the more traditional AR there are a number of differences in TAR. First, the role of the researcher is outside the study rather than in the study. Secondly, in TAR the researcher prominently guides, directs and facilitates the study processes. In AR the processes are driven by the participants. Third, the evaluation of the outcome of the study is focused on the achievement of the set goals in place at the initiation of the study. In AR outcomes are achieved during the cyclic processes and may include outcomes that were not expected (Kemmis, 2006).

Technical Action Research in this study

Working from an established theoretical frame, the researcher, working with research participants, sought to improve practice, using open ended and developmental approaches (McNiff & Whitehead, 2006). The participative processes of TAR included

reviewing the service purpose (social, recreational and prevocational service type) and selecting a measurement tool or questionnaire for application. This was necessary within a set timeframe as funding and planning managers expected the study results to inform contractual decisions for the following financial year.

Methods

Defining the problem

The funding and planning managers of the mental health service where I was working were unsure of the effectiveness of mental health social, recreational and prevocational services. Furthermore, they wanted to know how best to monitor their performance. This provided the opportunity for me to develop this research project in collaboration with them and their needs. Probing questions were asked to further clarify the issues and to try and grasp the nature of the potential outcome measures (DePoy & Gitlin, 1994). It was agreed that the project would become my doctoral research and thereby address the problem within the parameters of a negotiated scope.

Process to review the literature

A literature search was undertaken using a range of data bases including Medline, Pub Med, and Cinahl, for the years 1999 to 2004. The following key words were used for the literature search: deinstitutionalisation, consumer participation, action research, technical action research, social inclusion. Other relevant literature was obtained using the reference lists from the articles found. A further literature search was undertaken later for the years 2005 to 2010. The same key words were used.

Chinn & Kramer (1995) argued that the researcher should explore the theoretical underpinning and other relevant research since literature reviews are essential to the research process. The first part of the review, described in chapter two, focused on the historical and political contexts that set the scene for devolution of services from institutions to community based settings. Little was found in the literature specifically on the evolution of social, recreational and prevocational services. The second part of the literature review, described in chapter three, engaged with the findings of *the Blueprint* document (Mental Health Commission, 1998) which saw the inclusion of social, recreational and prevocational services and confirmed these as a relevant approach to enhance a consumer's recovery. The role of consumers and the potential of

participating in the monitoring of services were evidenced. The research question was framed in light of this contextual background:

How can consumer participation contribute to the monitoring of mental health service performance?

Research project design

The research design included a three stage project and their connections. Each stage informed the next stage to achieve the overall research outcome. The stages included:

1) Review of current service provision: The relevant information about the mental health social, recreational and prevocational service providers was collected and considered using quantitative methods;

2) Selecting the questionnaire: A stakeholder reference group including consumer membership, using TAR, selected a consumer questionnaire for application; and,

3) Conducting the questionnaire: The questionnaire was undertaken by 50 consumers of mental health social, recreational and prevocational services.

A brief summary of the research methods is offered below in terms of the generic processes and as a brief introduction to the specific issues within each of the three action cycles.

Selection of participants

For the first stage there were twenty four participants. These were all current contracted mainstream adult mental health social, recreational and prevocational service providers. Their services were the key focus of concern for the funding and planning managers. For the second stage the participants formed a stakeholder reference group. The funding and planning managers had indicated the stakeholder perspectives that they wanted to be represented by the participants. This included Maori mental health service providers, Pacific mental health service providers, DHB mental health service providers, Non-government organisations (NGOs), consumers who accessed the services and their families, and the funding and planning managers also nominated one of their colleagues for inclusion. I approached the different organisations and the regional consumer network inviting representatives as discussed in chapter seven. Written communications about the research were provided for the stakeholder organisations and oral presentations introducing the research given at stakeholder network meetings.

An analysis of the stakeholders and their potential positive or negative impact on the research processes was also undertaken. Grundy (1997) described stakeholders as people who are influential and have the potential to impact decision making. It was important to ensure stakeholder participants and their positioning and expectations were understood and mitigating actions for any negative impacts could be planned (Murdock, 2004).

For the third stage, a flyer on communication boards at service locations invited consumer participation. This was supported by face to face visits where I the researcher explained the questionnaire process. Individuals wishing to participate either contacted me directly, indicated to the manager of the service or arrived at the facility on the nominated day for the questionnaire process stating their interest.

Informed consent

As previously discussed there were three separate groups of participants, for each of the three stages of the project, with each being selected specifically for the task required. Informed consent procedures were therefore tailored to the requirements of each group of participants within the ethics requirements of the local DHBs, the regionally based ethics committee and the affiliated university of the researcher (see Appendices). Group specific information sheets were developed to give to the potential participants prior to them providing written consent. Ethically, the rights of participants were protected through informed consent and by providing planned and structured processes that were communicated to all participants. All participants received both a verbal and written outline of the purpose of the research study, the associated processes and the researchers' contact details should they have any queries or concerns. They were also given the opportunity to leave the research study at any time without consequence. Confidentiality was maintained at all times. Participants who engaged in the questionnaire were invited to undertake the process in a quiet private room, with a support person in attendance. This is described in more detail in chapter eight.

Data sources

In the first stage of the project I undertook to gather contextual information about the social, recreational and prevocational services and prepare for the next phase of cyclic

action within action cycles. Data sources were identified from current collection points. DHBs and NGOs had been reporting to the Ministry of Health on a regular basis which meant this data had been captured. Further, an earlier project on social recreational and prevocational services that captured the current service provision had resulted in considerable data being collected about the services of interest (Gifford, 2003). This data was made available for this research.

Data collection

The service providers were contacted by telephone and their consent obtained to access the data they had submitted to the Ministry of Health in monitoring reports and notes from interviews that had been undertaken by Gifford (Gifford, 2004). The second stage data collection involved participant observation, diary recording, meeting minutes and participant communications, enabling a questionnaire to be selected by participants using action cycles in a series of meetings. The representative group established known as the stakeholder reference group (SRG), comprised representatives of: Maori mental health service providers, Pacific mental health service providers, DHB mental health service providers, Non-government organisations (NGOs), consumers who accessed the services and their families, and DHB funding and planning managers. The SRG considered the service purpose (social, recreational and prevocational services) and methods of measuring the performance of the service providers. They appraised standardised questionnaires, using TAR action cycles, as described by Carr and Kemmis (1986) and Stringer (2007). The appraisal included several cycles of planning and reconnaissance, action, observation, reflections and re-planning. Ultimately, the SRG selected and tested a questionnaire that they considered to best reflect the requirements of the services.

In the third stage 50 consumers were engaged in a questionnaire selected by the stakeholder reference group. I as the researcher joined the participants in local activities, usually a shared lunch or afternoon tea prior to conducting the questionnaire process. This time provided some informal engagement and the opportunity for consumers to feel more comfortable and safe with me as the researcher. I introduced the questionnaire to the selected participants individually and they commenced their responses which are described in chapter eight. Participant observation such as their level of engagement in the process, particular questions they chose not to answer and additional information

that they wished to share was recorded manually as handwritten field notes and analysed.

Bias

The risks of bias were taken into consideration during the research processes. A rationale was established to provide rigour to the selection process. In establishing the stakeholder reference group, the mix of individuals who came to be part of that group as representative of a wider group, influenced the nature of the discussion and decisions. Action research accepts the nature of such bias as being inevitable (Dick, 1997b).

In the original selection of participants in cycle three when consumers were recruited to complete the questionnaire, there was evidence of recruiter bias. Staff at some facilities attempted to encourage consumers to participate while holding others back. Recognising this, the researcher attempted to compensate by being overly inclusive and encouraged all consumers to participate. The questionnaire was conducted over a limited period of weeks to minimise disruption to facilities and maintain heightened awareness of the research study during that specific time.

Analysis of findings

Analysis in cycle one was drawn from the use of pre-established evaluative criteria devised by the researcher. In cycle two the group established its own criteria for assessing the questionnaire that would be given to the consumers in cycle three. In cycle three the questionnaires were analysed using colour coding and categories. Steps common to qualitative processes were followed and these are described in chapter seven (Field & Morse, 1985). The identified key themes are also described in chapter eight. The findings were presented to the consumers who participated in the development of a draft document, before being presented to a wider audience including the funding and planning managers. This was an opportunity for participants to challenge the findings and for the data to be withdrawn if necessary. A range of visual diagrams were used to demonstrate the findings, such as pie charts and bar graphs. Refer to appendices. Additionally there were face to face presentations provided for consumer participants at the facilities involved.

Interpreting research results

Research results were interpreted within the wider context of the research and the chosen methodology. This is described in chapter eight. These interpretations were subjected to member checking and their responses recorded. This is recognised as an important step to address errors in interpretation that may be due to research design or bias (Abdellah & Levine, 1986).

Summary

In summary, the methods applied in this research followed standard processes underpinned by a theoretical framework of critical theory with a technical action research methodology. TAR is an interpretation of the more traditional AR, (Lewin, 1951). Since its inception, AR has evolved over time offering many variations to the traditional action research, including TAR. It is emergent in nature and develops through a sequence of events in reoccurring cycles or spirals. It draws on several types of knowing, experiential, presentational, propositional and practical, and engages its participants in collaborative processes that lead to growth (Coghlan & Brannick, 2005; Kemmis, 2006).

This research was made up of a project in three stages each with its own set of participants and action research processes. Each stage composed of an investigation and findings in action cycles that informed the next stage to address the research question. The action cycles implicit in TAR are described in chapters five, six and seven.

Chapter Five

Setting the Scene

Specific contexts required exploring in order to frame the project and the research. Stringer (2007) described the exploratory activities that must be undertaken before embarking on research, as building a picture of how things are. I needed to build that picture to understand the contexts in which the mental health consumer of social, recreational and prevocational services was situated.

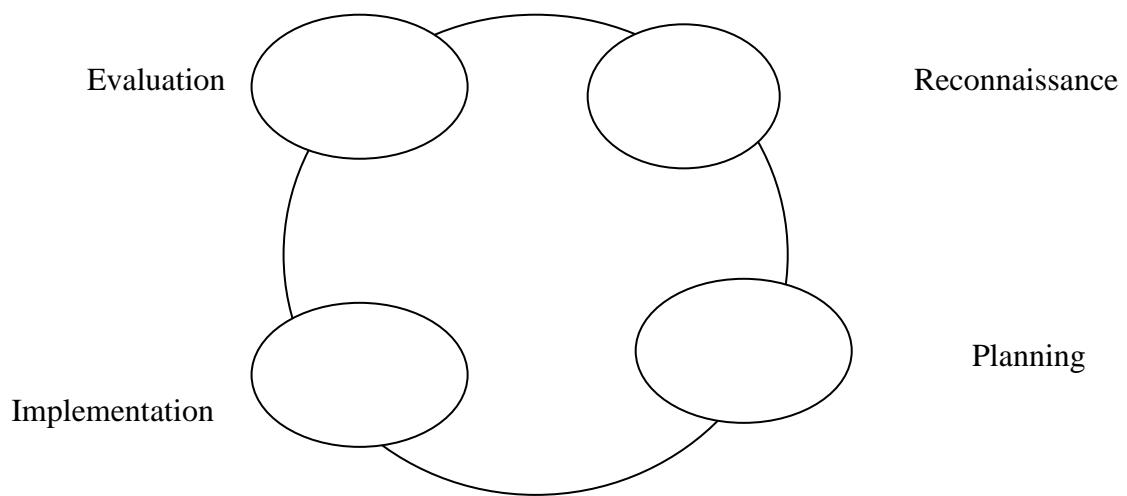
As already discussed these services were established to meet a specific purpose in a process of service evolution, from institution to community based care (Ministry of Health, 2001a). To achieve the research goal, I needed to know more about the purpose of social, recreational and prevocational services, in the mental health service continuum, particularly from a consumer perspective. I also wanted to know more about the current services and how they compared with best practice and consumer expectations. Furthermore, I wanted to know how to monitor and measure the contracted services, using consumer participants. By drawing these areas of investigation together, I narrowed down what I needed to know and in doing so I identified my research question:

How can consumer participation contribute to the monitoring of mental health service performance?

Stage one

I considered my research question, and the body of information that I was likely to require, and then scoped the research activities. My task was to collect data, using action cycles to explore how things occur, reflect on what has occurred, before planning to implement change (Reason & Bradbury, 2006). The activities were part of an action cycle, and each action cycle sat within an action cycle, as depicted in Figure 3. The steps in the action cycle include reconnaissance, planning, implementation and evaluation (Elliot, 1991).

Figure 3: The Action Process



Reconnaissance, as described in this chapter, is about considering the bigger picture and understanding the many contexts in which the specific services were being delivered, and for what purpose.

Reconnaissance

Reconnaissance is, described in AR methods, as the time taken to explore and gain a greater understanding of the problem or issues that need to be addressed (Elliott, 1991). This section will discuss the approach taken and the reconnaissance processes implemented. Initially I focused on the 32 provider organisations of social, recreational and prevocational services in this Northern region. However the scope was reduced to the 24 provider organisations all of which were providers of mainstream adult mental health services. This was the focus of my research.

Approach

I contacted the 24 provider organisations, (listed in the appendix) inviting their participation. Initial discussions of the research included the informed consent requirements. Letters of introduction were then forwarded on, along with the consent forms for their perusal and signatures. Both these documents had been prepared, submitted and approved by the Ministry of Health and UTS ethics committees. (See appendices A, B and C).

In the first instance, informed consent was required from the 24 organisations to use the documentation and the interview findings previously recorded by Gifford (2004). The

second step was to get informed consent for the 24 organisations to provide information about their service provision over a three month period, under the current funded contract. They were also required to attend a structured interview about their services and submit a monthly data sheet about their service performance.

Using the information from the Gifford report (2004) I manually mapped the identified service provision for each of the providers against the National Institute of Mental Health of England (NIMHE) (2003) social inclusion work stream. This document identified six life domains including:

- Employment
- Education
- Housing
- Leisure
- Community Activity
- Personal Finance

The reason these life domains were selected was because the literature review revealed that similar services, with a focus on life domains, were being delivered in England (NIMHE, 2003). This mapping process provided an opportunity to test whether the New Zealand social, recreational and prevocational services also had a focus on life domains. To assist with the mapping process and to accurately capture the results, I specifically designed and applied a set of tables.

Process

In doing this I wanted to gain a greater understanding of the social inclusion literature and more specifically to design a report which looked at the importance of social inclusion with regards to the wider determinants of mental wellbeing. The Office of the Deputy Prime Minister, (2004) emphasised the importance of meeting basic needs such as housing, transport, and financial security. This was regarded as ‘getting the basics right’. This caused me to reflect on how I could capture socially inclusive practices from the Gifford (2004) project documentation. To that end, I identified four key questions that I would ask providers. Consequently, the interview documentation included the following questions.

1. Who are the people for which the service is provided? I wanted to know whether services were provided for people with a mental illness alongside people with other health or social issues. More socially inclusive services would deliver services to those with mental illness within a mainstream construct with supports as needed.
2. What life domains does the funded programme address? I wanted to know the answers to this question based on the UK documented life domains.
3. How socially inclusive are the programmes mapped against red, amber and green Social Exclusion Unit (2004) criteria?
4. What strategies were in place to support individuals to participate in mainstream community activities like any other member of the public?

I then read each provider organisation's response as captured by Gifford (2004). I looked again at the tables that I had developed and made some adjustments. I reread each organisation's response to Gifford, mapping the content with the categories on the tables according to the four questions.

Findings

The findings revealed that the 24 organisations provided services for people with solely mental health needs. Some organisations provided services for people with other needs as well. Two organisations provided services for refugees, three organisations provided services for people with learning disabilities, and one organisation provided extended services such as budgeting to the local community. Providers that extended services to people who did not experience mental health problems used alternative funding streams to make this possible. Mental health funding was directed at services strictly for people with mental health problems.

Life Domains Addressed

The mapping process showed that the provider organisations offered services to support and assist people across life domains. The domains that were covered varied as demonstrated below:

- One service offered personal finance budgeting
- 25% of the services offered supported employment

- 30% of the services offered life skills
- 50% of the services offered educational programmes or access to education
- 50% of the services offered leisure programmes
- 62% of the services offered community activities

With regards to budget and financial services, these were mainly provided by organisations such as the Salvation Army and the James Family. Funding for budgeting and financial services was also available from the Ministry of Social Development (MSD). NGO providers in the mental health sector stressed the importance of linking with budgeting services. However, only one provider was found to offer the service independently.

The MSD provided a range of employment initiatives as well as funding employment services for people experiencing mental illness. This was external to the mental health funding streams but often in conjunction with mental health provider organisations. Those particular employment services were not considered in this project.

Range of Services

Access to a range of services in the Northern region was variable. Across the region more services were provided by one DHB and therefore accessed by people living within their DHB catchment. Many of these services were well established having been in existence since the deinstitutionalisation of mental health services. Service attendance was voluntary and consumers could self-refer or be referred from another source. People living in other districts were excluded from services not contracted by their DHB.

Since the research project done by Gifford (2004), there had been some small changes to service provision. A residential service had been closed and replaced with some day services in the same area. Furthermore, a number of NGO providers had flagged that they had undertaken their own internal reviews and major changes to current structure

and service delivery methods had taken place. Changes that they had made were also about creating more socially inclusive services.

Social inclusion criteria

Assessment of the levels of social inclusion within a service or the activities conducted can be made using social inclusion criteria of red, amber or green. According to the Social Inclusion model (Office of the Deputy Prime Minister, 2004), services in the 'red' are those services that are provided in a mental health facility and the people accessing the services have mental health problems. Traditional drop in centres were defined as red in this social inclusion model (Office of the Deputy Prime Minister, 2004) and some services within the region met this criteria. In other words, activities were held within the confines of the facility and interactions for people attending were limited to staff from the organisation and other people with mental health problems who may be attending the activities.

In some organisations, people accessing services were not confined entirely to the facility. For instance, in one a walking group ventured forth into the local community while in another, mini bus trips were arranged to visit the local shopping mall. Those exceptions were rated 'amber' as they facilitated an opportunity for the individual to participate in a mainstream or non-mental health specific environment. One provider encouraged programme participants to use public transport believing this to be an important aspect of promoting independence. Another organisation used the local community centre for their lunch group. Initially participants in the group would discuss a lunch menu and associated recipes. Next, a shopping list would be constructed, followed by an allocation of tasks and a trip to the local shops. On return to the community centre, there was an allocation of food preparation and cooking tasks followed by lunch served at the table. Every task had potential learning for individuals.

This organisation also facilitated visits to local markets, the supermarket, local beaches and held their own very popular and successful 'Bachelors and Bachelorettes' night. This night was the first of its kind to be held in the region and was a sell-out. There were many requests for a similar event to be held in the future. In addition, this organisation facilitated participation and leadership by consumers in local market stalls and community education classes. Another organisation converted its facility for use as a resource centre based in the community. The facility was used by people with and

without mental health problems. Other organisations had disinvested of facilities in order to provide community based services in non-mental health specific settings. Others used their facilities as more of a meet and greet setting before activities were commenced. Then in groups, consumers and staff left the facility to participate in the activity of interest in a mainstream setting.

Yet another organisation held community based weekends for consumers, families and whānau. This was an opportunity for family and whānau to embrace positive opportunities and to feel supported while working through challenges together. There were also supported employment activities in community settings and one provider even included a programme in the local prison. When this organisation realised that people within the service were seeking a place of belonging, innovative thinking led them to trial a base concept rather than a mobile model.

Services in the ‘green’ were those that were provided in ordinary community settings in an integrated way. This approach gathered people with similar interests’ together rather than grouping people by their illness. For example, one organisation provided integrated programmes for women from the community. Access to the service was not limited to those with mental health problems.

Peer support services facilitated participation by individuals into main stream settings. Mental health staff were in the community in a supporting and assisting role, which often meant visiting people in their homes or an environment of their choice. Individuals with mental health issues were encouraged to identify their goals and plan to achieve them. Peer support at a one-to-one level meant tackling the challenges of mainstream settings was more positive and successful.

Another way of considering the red, amber and green approach would be to consider some activities. A swimming activity undertaken in ‘red’ would involve a group of mental health consumers going swimming together at a swimming pool based in the grounds of a mental health facility. Under the ‘amber’ approach, that same group would go swimming together in the local community pool. For the activity to be in the ‘green’ and socially inclusive, individual consumers would be introduced to the local

community swimming pool and encouraged to join a mainstream swimming class. Following an introduction and orientation to the community pool, that may have been sufficient, for them to feel comfortable to access the pool independently.

Table one shows that the majority of provider organisations have programmes in the red or amber areas. Few had programmes in the green area. While the emphasis appears to be on the more socially inclusive services in the green, what is important is that mental health consumers are able to participate in activities that are in the red when they are unwell and as their health wellness improves, move to activities in the amber and green (Frado, 1993; Ministry of Health, 2005).

Community participation

In reflection, it would seem that strategies used to assist with the integration of programmes into mainstream settings and activities were far reaching and multifaceted. They involved service delivery approaches, staff recruitment, and active participation by the consumer. In a number of organisations, roles and responsibilities were delegated to consumers. In one programme for example, a consumer group leader was responsible for getting the key, opening up the allocated room, setting up for the programme and clearing up at the end of the session. In another, a consumer as treasurer of the group was responsible for managing the budget for the purchase of equipment and food for the planned activities. In yet another programme, all members were expected to sign up for a task or responsibility including kitchen duties, gardening, cleaning, and painting. The organisation had stated that it could not function, nor operate the programmes, without consumer participation.

The skills and competencies of staff supporting programmes that were more community based and socially inclusive were different to that required for facility based programmes. Some providers had recognised the difference and had processes in place to ensure people with the right skills were recruited. One staff member said that there were benefits in recruiting staff with a wide range of skills. Another said it was preferable that the worker did not have a background in clinical mental health services as it was believed to be limiting in a recovery setting (Sorensen, 2006).

An Education Assistant had been employed by one NGO provider to aid those attending the local university. This was consistent with some of the UK approaches to supported education in mainstream services. Some organisations sought joint ventures and partnerships with other providers to achieve greater integration. An example is a provider which has a joint venture arrangement with the local zoo producing garden fertiliser from animal excrement. All these contracted organisations were required to capture their activity as part of their contract requirements.

Table 1: Social Inclusion Criteria Mapping

Provider	Red	Amber	Green
1	Most	Some	None
2	n/a	n/a	n/a
3	Some	Some	Some
4	None	Most	One
5	None	None	Most
6	Most	None	None
7	None	Most	None
8	None	Most	one
9	None	Most	None
10	Some	Some	None
11	None	None	Most
12	Most	None	None
13	Most	None	None
14	Most	Some	None
15	None	Most	None
16	Most	None	None
17	Most	None	None
18	Most	None	None
19	None	Most	None

Code

Most	Most activities met this criteria
Some	Some activities met this criteria
One	One activity met this criteria
None	None of the activities held met this criteria
n/a	Information provided did not map to criteria

Further data

Quantitative reporting was a regular feature of these provider organisations but to date little data analysis had been done. All 24 provider organisations submitted quarterly reports as part of their contractual obligations and so to complete my reconnaissance, I wanted to compare the efficiencies of the provider organisations. This entailed looking at how they delivered their services, with what resources and with the understanding that a significant allocation of the contract funding went to the workforce.

Method

A statistical study of data submitted by these organisations as part of their routine DHB and Ministry of Health reporting requirements was prepared using the Data Envelopment Analysis (DEA) methodology. DEA has over the past two decades emerged as an important tool in the field of efficiency measurement. It is used to compare Decision Making Units (DMUs) such as individuals or groups using one or more inputs to secure one or more outputs. DMUs use the same inputs and secure the same outputs but generally at varying levels. The goal was to compare the money funded with the resources used to provide a service, while allowing for the workforce element. The aim was to compare the various organisations using inputs such as their funding allocation, how many staff they employ, and outputs such as the types and volumes of service provided.

Process

Each contracted provider submitted data quarterly to the Ministry of Health. This information was routinely recorded electronically and forwarded to the Mental Health Funding and Planning Portfolio Manager of the specific DHB. At my request all reports for the 12 month period of the financial year 2004/05 were forwarded on to me electronically and stored in an electronic file.

Findings

The data forwarded by Ministry of Health was incomplete, in as much as some months' data was missing from some providers. In addition, when I telephoned the providers to validate the data, only two providers were able to do that. The reasons for this were multifaceted. First, it would seem that there had been different reporting requirements

agreed to, by different funders, for a range of similar services. This had resulted in different information being collected and submitted by providers. Second, the reporting requirements were not defined in a consistent manner. This had led to individual personnel from the same organisation reporting differently. Some had differentiated between those attending for the first time and those attending as follow ups or members. Others did a head count at programmes or activities per session. One provider indicated that they did not know what had been reported in 04/05 as the person responsible for collecting the data had now left the organisation. Another organisation provided the information that they wanted to convey to the funder, for example, the numbers of interventions for the numbers of people in a service they were providing that was not funded by a DHB. The difficulties with the data and particularly the lack of validation made it unwise to proceed with further data analysis using DEA. This affected my plans in that the quantitative study was not completed.

Conclusion

In conclusion, reconnaissance had been undertaken to gather information about service provider organisations and their service delivery in order to better understand the contextual underpinnings of the research. A review of the raw data from the Gifford project (Gifford, 2003) as well as the data from the four questions I had addressed with the 24 provider organisations provided more information about the services. The failure of the DEA analysis confirmed the inadequacy of the reporting being collected by the Ministry of Health.

Overall, the information gave me a clear insight to set the context in terms of service (configuration) and intent. It also highlighted socially inclusive service delivery models and the potential service outcomes that could be achieved if life domains for consumers were addressed by the social, recreational and prevocational programmes. This information provided a foundation to inform the next phase of the action cycle, that of planning.

Chapter Six

Planning: Selecting the Questionnaire

This chapter will build on the actions undertaken in the reconnaissance or scene setting stage of the research process. The principles of stakeholder theory (Freeman, 1984), underpinned this next stage of the project which involved structured planning by stakeholders including consumers, as members of a reference group. Structured planning was required to determine how best to conduct the research in a meaningful way, particularly with regards to consumer participation.

Stakeholder theory

Stakeholder theory addresses the management of organisations in which the interests of various groups, the stakeholders, are heard and considered (Freeman, 1984). Stakeholders may be limited to those who are shareholders or employees of an organisation or extended to include other parties that influence the organisation in one way or another. This may include government, trade unions, communities and the public at large (Mitchell et al., 1997). Stakeholders are described by Grundy (1997) as people or groups of people who are influential and have the potential to impact decision making. This potential of stakeholders could affect the direction or success of any change an organisation may wish to make. For instance, stakeholders can support, hinder, or re-direct the change (Blair & Fottler, 1998; Freeman, 1984; Frooman, 1999). The way stakeholders influence an organisation is directly related to the relationships the stakeholders have with the organisation. Stakeholder theory focuses on the nature of those relationships, exploring and acknowledging the value of stakeholder relationships (Murdock, 2004). Stakeholder theory also proposes that no one group is more important than another. However, stakeholders may believe that their interests are more important than others and so issues of power may arise, leading to stakeholder conflict and tensions (Murdock, 2004).

Stakeholder analysis uses a range of tools to gather and define information about the stakeholders in a systematic way. The information is then used to better understand the stakeholders; it aids collaboration when planning activities that incorporate their

interests in the hope of achieving a more positive outcome (Shortell & Kaluzny, 1994). According to Turner and Muller (2003) projects may be viewed as an organisation with a fixed time span (therefore, stakeholder theory as applied to organisations can also be applied to projects). When undertaking such a project, the project manager must identify the project stakeholders and using stakeholder analysis, gather information that will inform the project planning as well as stakeholder relationship development and involvement (Pinto, 1998).

Analysis and review

The stakeholders for this research were categorised in a number of groups including: DHB funders and planners of services, DHB clinical services and the professional groups within those services, NGO service provider organisations, NGO network organisations, consumers and consumer networks, family, whānau, and carers and their networks, Māori and Pacific providers, Maori and Pacific consumers and union and professional association representatives. Stakeholder analysis is a key precursor to communication planning and underpins targeted project communication activity. There are various approaches to stakeholder analysis. I chose an approach from PRINCE 2 project management framework and tools (Office of Government Commerce, 2002), and modified it to suit the nature of the projects so that I could gather the information required in a systematic way. The approach considered the level and type of impact the project may have on the stakeholder groups as well as potential concerns. It also required the project manager to consider mitigating strategies for each impact.

Defining the stakeholder groups

The next step in the project analysis began by defining stakeholder groups and naming them. This was important, particularly for the mental health sector where the stakeholders' on-going commitment to the project was considered critical for a successful outcome (Mental Health Commission, 2004). The mental health consumer pathway was useful to determine the stakeholders by considering those contributors to the pathway such as consumers and their families and the providers of services. Having identified the specific stakeholder groups, I then assessed the likely impact of the particular project on each specific group. The levels of impact varied from low, medium to high. Based on my knowledge of the stakeholder groups, and further to their level of reaction to processes, I noted likely concerns with the project, or the potential changes,

that maybe brought about by the project. The potential risks to the DHB or Northern DHB Shared Agency caused by the stakeholder group were also documented along with proposed mitigating strategies. See appendix six. These risks included loss of service and/or changes in service, reduced service productivity, loss of workforce, and heightened anxiety in consumers, staff and family members. Table 2 outlines the stakeholder analysis process.

Table 2: Stakeholder Analysis

Stakeholder Group Name	Level of Impact High Med. Low	Impact on Stakeholder Group	Stakeholder Likely Concerns	Project Risks to DHB	Project Risks Mitigating Strategies
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(Table modified from Johnson & Scholes, 1993)

Another form of stakeholder mapping was adapted from Mendelow (1981). This model reinforced the increased level of project manager effort that needed to be directed at certain stakeholder groups with both high power and high interest (see Table 3 below). These groups had the potential to derail the project if their expectations were not managed.

Using the stakeholder analysis improved my understanding of the potential impacts the project may have on specific stakeholder groups. This allowed me to prepare strategies that included support, human resources/industrial advice, and career planning.

Table 3: Stakeholder Mapping: Power/Interest Matrix

		Level of Interest	
	Power	Low	High
Low		(A) Minimal Effort	(B) Keep informed
High		(C) Keep satisfied	(D) Key players

(Johnson & Scholes, 1993)

Effective communication is reported to be key to successful engagement with stakeholders therefore; communication and change management issues were taken into consideration when planning each step or phase of these projects (Office of Government Commerce, 2002).

Communication planning

The strategies which guided my communication planning included: ensuring the project stakeholders received consistent information about the direction and progress of the projects. In addition, existing communication channels were used as far as practicable, rather than creating new channels and possibly duplicating the efforts of others. Furthermore, communication was regular, concise and clear, compelling and convincing. In addition to goals and strategies, I had some clear objectives for communication. First, I wanted to target the right people, at the right time, at the right place and with the right message. Second, I wanted to raise awareness and interest in the project so that stakeholders were well informed and thus engaged. Third, I wanted to provide multiple accessible channels for feedback to reduce the risk of miscommunication.

With this early groundwork set in place, I was now ready to commence the next cycles of technical action research.

Cycles of Technical Action Research

This part of the project was of importance to the DHB mental health funding and planning managers and they had wanted this project undertaken for some time. During the reconnaissance stage it came to light that there had been issues about both capacity and capability when monitoring mental health services in the region. Some managers suggested that the problem was a lack of appropriate tools to assist with data capture and measurement. Other managers indicated that a consumer perspective was lacking from the current monitoring processes (Gifford, 2004). Meantime there had been little action in terms of increasing funding to current services, contracting for new services or improving current processes for managing social, recreational and prevocational services. It was a clear indication that action was required.

Consequently I met with the funding and planning managers to discuss my approach to this planning phase of the project and seek their advice on stakeholder engagement, particularly consumer engagement. I was keen to establish a Stakeholder reference group (SRG) to confirm the purpose of the services, explore outcome measurement and select a tool for testing as part of the planning phase of my research. The managers

nominated one of their colleagues to represent them on the SRG and made suggestions regarding the representation of other stakeholder groups as discussed in chapter 5. The groups to be represented included: DHB mental health funding and planning managers, DHB mental health service providers, NGO service providers, Māori and Pacific people mental health service providers, mental health consumers including Māori and Pacific people and family and whānau organisations.

Learning to initiate consumer involvement

Having reflected on the way forward, I asked the funding and planning managers about their preferred method of consumer engagement and participation. They advised that consumer participation in regional projects was managed via the regional consumer network and so I contacted the regional consumer network coordinator. After explaining the purpose of the project I asked for help recruiting a consumer representative. The coordinator felt that I would need more than one, probably four. The coordinator then asked about transport arrangements, refreshments, reimbursement for participants, and other meeting supports. I was unprepared for the questions she was asking me and in hindsight, realized that I had much to learn about consumer engagement and participation. At the time, I was unable to commit to any payment or to other requests and so I ended the conversation by saying that I would speak with the project sponsor and get back to her. I then contacted the project sponsor and reiterated the importance of consumer engagement and participation, before repeating my telephone conversation with the regional consumer network coordinator. The project sponsor advised me to look at other consumer participation approaches in the region including attendance payments and other support systems that were currently being provided.

Following this feedback I took some time to formulate a concise set of questions about these issues before contacting two DHBs to undertake a small benchmarking exercise. I also reviewed literature about consumer participation (Doughty & Tse, 2005) and, after further reflection on the information gained, I met with the project sponsor again. In discussion it was agreed that there would be four consumer representatives participating in the SRG and those currently not receiving a salary would receive a meeting attendance payment and a travel allowance. Moreover, all participants would receive refreshments during the course of the SRG meetings. The estimated costs of printing, stationary, documentation and other meeting resources were added to the project budget.

In reflection, I came to see that the actions I was taking to support consumer participation were mitigating perceived barriers to their participation in the SRG. Barriers such as: having transport to attend the meetings and not being reimbursed financially for time and knowledge. Other consumer related issues that were taken into consideration included the side effects of medication such as a dry mouth, which could cause discomfort during a lengthy meeting. By providing regular breaks in the meetings, ensuring refreshments were readily available and being an approachable facilitator, consumer participation was supported.

Accessing Māori participants

In seeking a Māori representative I approached Māori advisory groups within the DHBs. Following some debate regarding the most appropriate skill set required by the representative, the issue was resolved when a recognised Matua⁵ with experience in funding and planning, the NGO sector and lived experience of mental health agreed to take up this role. It was suggested that perhaps a Māori researcher should be involved as a co-researcher on the project however the project sponsor advised that there were insufficient resources to support an additional researcher.

Confirming nominations

Nominations were then discussed with the project sponsor before being confirmed with the specific individuals and their related organisations. Each member of the SRG had to agree to the documented terms of reference regarding the reference group structure, processes, meeting times and members obligations. The SRG consisted of 13 members. Figure 4, depicts the SRG membership.

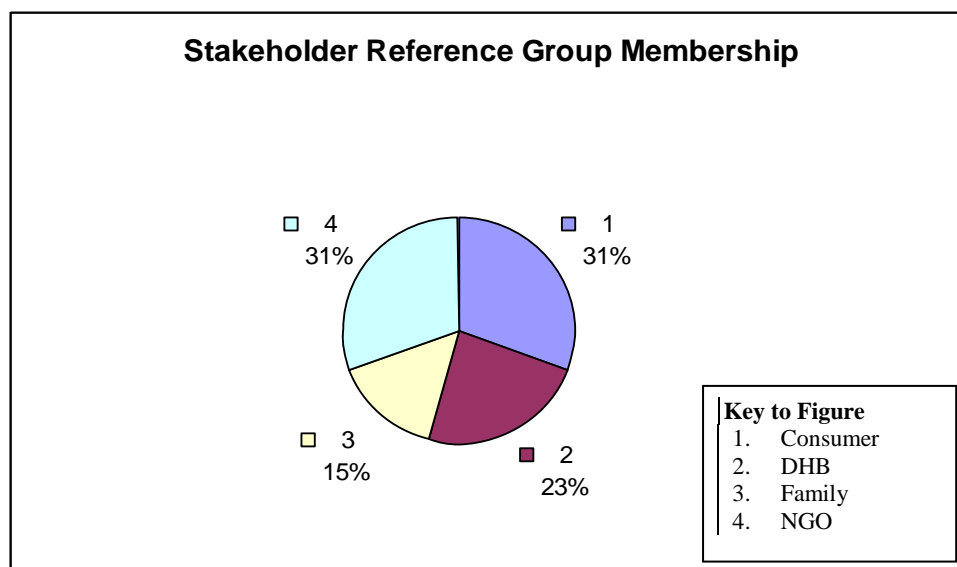
Demographics

Female members dominated the group and comprised 69% of the SRG. This is consistent with the health work force in New Zealand where generally more females than males are employed. The age of the members ranged from early 30s to late 40s. From an ethnic perspective the membership was made up of people who identified as Māori 38%, as European 38%, as Pacific people 15% and as Asian 8%. Of consumer representatives, 75% identified as Māori. Although Māori consumer representatives had

⁵ Matua is a word in Maori meaning seniority

not been specifically requested for the group, it was particularly useful to have their participation. Recent studies had shown that Māori people were over represented in the incidence and prevalence of mental illness in New Zealand; yet, Māori people do not access mental health services at similar rates as European people (Ministry of Health, 2008).

Figure 4: Stakeholder Reference Group Membership



Education varied in the group with some having achieved tertiary qualifications, including one DHB representative who was completing a Masters qualification. Others had secondary school attainment. Most group members were employed in fulltime work with the exception of some consumer and family representatives.

Setting the plan

Considerable time was spent reflecting on the tasks that the SRG would need to undertake. My particular focus was the planning phase and selecting a questionnaire for testing. I also had to keep in mind the deliverables that the mental health funding and planning managers expected. This included testing the questionnaire and making recommendations that would inform their planning and contracting processes for the next financial year. Due to time constraints, this meant the SRG had just four meetings to select a questionnaire.

Careful planning and preparation was required to bring all the participants to a point of shared understanding before commencing the group processes that needed to occur to select a questionnaire. Forward planning included: meeting preparation documentation such as agendas and pre-reading, specific tasks that needed to be undertaken at the meetings and key questions for reflection and follow up after the meetings. Each meeting of the SRG was intrinsic to the action cycle; and each cycle was connected and sat within a greater cycle. Each meeting and therefore each cycle had a specific theme and purpose, commencing with cycle one.

Cycle one: Reconnaissance and planning

Understanding the service intent

I reflected on what needed to be achieved in this first cycle which would set the context for the whole process. I knew group relationships such as people working together comfortably, gaining each other's trust, and feeling safe in order to participate in the discussion process were crucial. Stringer (2007) described the importance of the researcher being visible and open with the participants so before the first meeting I sent participants a pre-reading pack complete with an email of instructions and an agenda for the first meeting so that they would feel that they had a shared level of knowledge about the topic. I had previously spoken with the Regional Consumer Network Coordinator about the steps I intended to take and the Coordinator confirmed that the participants were all skilled in the mental health area and most had experience as mental health consumer auditors. I also mentioned that refreshments would be provided at the meeting and invited those with dietary requirements or preferences to contact me.

A key goal for the first meeting was to find out the stakeholders' perspectives of the social, recreational and prevocational services. Participants would need to be familiar with the 2001 service specification document describing the services and have the knowledge of other services that had been established for a similar group of people in New Zealand and internationally. With that knowledge base, and the SRG's personal experience from their different paradigms, I believed that they would be in a position to confirm future directions for social, recreational and prevocational services in this particular region.

Action

The meeting started without the nominated Māori advisor. He had been called away unexpectedly and sent his apologies. I invited one of our consumer participants, who identified as Māori, to formally open the meeting with a karakia⁶ and to bless the food prepared for a shared afternoon tea. In attempting to cater for a range of food preferences I was mindful of Healthy Eating Healthy Action (HEHA) which implies that as health workers we should be role modelling when catering for meetings (Ministry of Health, 2002). The food was an ice breaker, seemingly releasing tension in the room and creating some light conversation, mainly about food and eating.

We then progressed to introductions with a difference. Not only were participants asked to share some information about them but also why they wanted to participate in the group and what if any, expectations they had. Their stories revealed their ideas of the perceived benefits of participating in this SRG. One consumer representative talked about her recent experiences as a consumer auditor and her disappointment with the services that she had visited. She was of the opinion that there were few meaningful things for people to do at a particular service. The consumer hoped that by participating in this project she would be able to help improve similar services. Another participant, an NGO representative, spoke about the lack of funding and she had hoped that with this work there might be greater commitment by DHBs to invest in this area. Another participant spoke of the challenges of being a provider of services where the expectations of the funding manager were not clear. A participant with a family perspective spoke of the difficulties as a parent accessing services for a family member.

When providing an overview of the project to the group I was interrupted and told that some of the participants found my language offensive. This was a positive action step by the consumers- asserting their independence. It was a surprise to me and I found myself apologising and seeking advice regarding what was offensive and what language was preferred. It was agreed that the terms: '*their*' and '*our*' in reference to consumers would not be used in this project. Consumers did not believe that they belonged to anyone. It seemed to them that the language signalled that the consumer belonged to the service which was certainly not the case. The word consumer also raised some issues for them. In terms of the word *consumer* it was preferred that *people accessing services* be used. For me, this was useful learning. We agreed to use this phrase in the meetings

⁶ Karakia is a Māori prayer or incantation

however, I had concerns how *people accessing services* would be understood when documented in research reports and my thesis. I conveyed my concerns to the group.

We then discussed the service specifications. These were national documents describing the service to be delivered. Group participants who had previously been unfamiliar with the documents were surprised to know that they existed and were still being used in contract documents. The language was out of date and not consistent with the language currently being used in the mental health arena. The group alleged that the language needed to change. Group participants wanted the services to continue but in a different form. It was also suggested that staff employed to work as support people were usually poorly paid or contributed on a voluntary basis and as a result a lot of untrained and unqualified staff were employed. This made it challenging for service providers to offer consumers meaningful activities. A brain storming exercise resulted in the following comments: *“Bring people back into the community and provide them with a place where they are valued and feel that they belong”*.

Provide a service that:

- *“Allows recovery at your own pace and contributes to your recovery”*;
- *“Helps you support yourself and others around you”*;
- *“Helps develop healthy relationships”*;
- *“Allows you to do something meaningful; having intellectually challenging and interesting things to do”*;
- *“Allows you to live a life on your terms”*;
- *“Ensures people are part of the decision making process”*;
- *“Provides educational opportunities, real work, living skills, skill transference”*;
- *“Provides opportunities to take risks or to try to do things differently”*;
- *“Allows a person to express themselves as a person and recognise their talents; and able to go to council meetings and put their views across”*.

In reflection of the discussion the group summarised their thoughts. Together they agreed that people accessing the social, recreational and prevocational services should expect to:

- *“Feel welcome in a welcoming environment”*;

- *“Want to participate in the activities offered”;*
- *“Have a sense of belonging”;*
- *“Be able to join or attend on their own terms”;*
- *“Have conflicts with other participants resolved quickly”;*
- *“Be oriented to the service”;*
- *“Graduate from the service as part of a plan or goal setting but also be able to return”.*

They also considered the notion of recovery, how the service could contribute to a person’s recovery, and whether there would be a way of identifying that contribution using indicators of recovery. Expectations related to an individual’s recovery, were strongly supported by the consumer participants, and signalled a significant change from current practice would be needed for some services.

Observation and monitoring

In tracking developments, I observed the level of participation. In other words, I noted who was participating and what content was being put forward. Those who had recent experience with services were more vocal, particularly those who had been a service consumer, a family member of a consumer, or a provider of a service. The participant from funding and planning was familiar with services but only within her own locality. This encompassed about a quarter of the total number of services that were being reviewed. There were tensions within the different discourses, a funding discourse and a consumer discourse.

It was easy to get side tracked with some fascinating stories of personal experiences. One participant told of her experience visiting a Club House type service in Finland. The event had been significant for her and she had become quite animated as she described it to the others in the group. I invited her to bring some information on the Finland service to share with the group at the next meeting.

Reflection and revision

On reflection of this initial cycle, I realised I had become quite fixated with what I believed needed to be covered within the limited timeframe of the meeting and therefore I focused on moving conversations forward and avoiding or closing down distractions. In hindsight I felt I could have facilitated more free discussion about personal experiences. Those experiences may have seemed unrelated at the time but I came to realise that they assisted individuals to participate in the discussion and to feel part of the group. They also provided insight to the individual perspectives and the paradigm in which they were operating.

As a result, this outcome provided me with some ideas with which to improve learning at future meetings. I decided on another action, that I would let go a little of the control at future meetings otherwise I feared that innovation and creativity might be stifled due to my rigidity (Stringer & Genat, 2004).

Cycle two: Defining recovery

Reconnaissance and planning

In preparing for the next meeting, I considered the intent of the services and the strategic imperatives that were described in the *Blueprint* (1998). Recovery was a strong feature in the document yet when I spoke to people informally about recovery, there was seldom a consensus. Once again I reviewed the literature on recovery and considered what journal articles would be worth presenting to the group to stimulate a discussion on recovery. If these services were to be about recovery, an agreed definition or a shared understanding would be useful. Without this, future discussions on recovery indicators related to service outcomes would be difficult.

The literature described recovery as the attainment of a quality of life and a satisfaction with one's life, the ability of day to day functioning, achieving physical wellbeing, ability to have relationships with other people, related to the frequency and severity of illness symptoms, and illness management and management of illness relapses. Some authors suggested recovery was an ability to have hope, trusting an individual's own thoughts, enjoying being in the environment, feeling alive and alert, raised levels of self-esteem, believing in tomorrow, ability to work and relate to others, and an increased

spirituality (Mental Health Research Development Strategy, 2004; NIMHE, 2005; Rethink, 2003).

Another aspect I wanted to raise with the group, at this second meeting, was the notion of life domains which were being used in the UK. I had previously mapped services against those domains in part one of the project. Now I wanted participants to understand the relationship between a mental health consumer's recovery and their life domains. I circulated the information on both recovery and life domains to the group before the meeting in preparation for our discussion (NIMHE, 2003).

Action

The second meeting got underway with greater ease than the first. Participants appeared more comfortable with each other which were encouraging, and helpful to me as the facilitator. After a karakia from a Māori consumer participant, and brief introductions, we shared afternoon tea. A consumer participant who requested pineapple lumps at the first meeting was delighted to find a bowl of pineapple lumps on the table.

The timing of the meeting was raised for discussion. Apparently, following the first meeting, participants experienced rush hour traffic congestion on departure and so it was proposed, and agreed, that the meetings would commence 30 minutes earlier in future to avoid the congestion.

I had prepared the subject matter for this second meeting based on my literature review which focused on recovery indicators and life domains. I wanted to set a platform for the decision making that was to come in the fourth meeting. The questionnaire that this group would need to select needed to capture recovery indicators and life domains as service outcomes. I put the key points about recovery indicators, which were taken directly from a Health Research Council publication (MHRDS, 2004), on a set of power point presentation slides to guide the meeting and to help keep the discussions on track. While not dismissing the information that I had put forward, some group members felt that there was benefit in reviewing other work. They suggested that the topic needed more exploring. The term 'day to day functioning' that I mentioned as an indicator created some tension. This brought about debate as the consumer participants felt it was like an imposed institutional measure interpreted by a health professional. They

questioned what the individual's day to day functioning would be compared with, and by whose standard? A group member suggested that I follow up Patricia Deegan's (1997) work on recovery which I agreed to do.

I moved on to life domains consistent with the UK social inclusion literature. These domains were very similar to Maslow's hierarchy of needs (Maslow, 1954; NIMHE, 2003). Consumers suggested that essential needs such as food, warmth, and shelter must be met first. This was further reiterated in a literature review in which five specific domains were identified as critical to recovery (Onken et al., 2002). The group agreed that these five domains were critical to recovery and relevant to consumers. The five domains included:

- Resources/basic needs
- Choices/self determination
- Independence/sovereignty
- Interdependence/connectedness
- Hope

(Onken et al, 2002)

In general, participants believed that physical health was important but consumer participants stated that sometimes physical health was overlooked due to the mental health focus of health providers. Consumer participants acknowledged the need to be more aware of their own physical health, how to stay well and to recognise symptoms that may need attention. One consumer participant suggested that it would be helpful for mental health consumers if services could provide advice about going to the General Practitioner for physical health issues. This was confirmed by family and other consumer participants. The conversation progressed to aspects of self-management of health that were sometimes overlooked by health providers who assumed the knowledge was commonplace. The advice from consumers to service providers was that assumptions should not be made; rather they would welcome information about self-management of health issues. For example; healthy diets, weight management, and women's issues such as, menstruation and menopause.

Further discussion by the group involved the timing of service provision. It was suggested that services should be cognisant of the fact that mental health and its associated issues did not only occur between Monday to Friday and between the hours of 9am to 5pm. Mental health and wellbeing is contextual, it goes beyond the confines of the service. Illness symptoms are part of this context and only become an issue when they stop an individual doing the things that are important to them (Deegan, 1997). Consumer participants argued that illness symptoms should not be barriers to recovery. For some, it was important to learn to live with, and manage, their symptoms.

One participant suggested that understanding of whānau needed to be communicated in the services. In Māori communities, Māori specific domains are understood in the Māori model of wellbeing as: taha hinengaro, taha tinana, taha wairua, taha whānau⁷ (Durie, 2008; MHRDS, 2004). Whānau ora for Māori was raised by a member of the group. This regards whānau or family as not only people connected by blood lines but wider natural supports such as friends. This connection was considered very important for Māori. In Pacific communities, Pacific specific domains varied according to the sub culture. It was suggested by a Pacific participant that as with Māori, what was most critical for Pacific people in recovery was having the support of their family and their community (MHRDS, 2004). The Pacific representative said that Pacific family dynamics were different across the different Pacific cultures; however there were some common threads. They were mindful of the positive impacts of family and the importance of an individual being seen and treated in the context of the family rather than as an individual. The Lotofale Evaluation Measure (MHRDS, 2004; Nonu-Reid et al, 2000) was regarded as a useful approach for looking at outcomes for Pacific people.

In the UK literature (NIMHE, 2003) the question “*When did you last speak with your mother?*” was asked to determine connections with family as a recovery indicator. I asked the group whether this question was one that we should ask consumers here in New Zealand. This immediately caused some upset within the group. Several participants, mainly consumer and family participants, felt that this question in the New Zealand context was not helpful and would be more likely to cause distress to the individual consumer. The reasons for this were suggested as a possible history of family violence and abuse that impacted on the individual’s mental illness.

⁷ The domains include: taha hinengaro which is psychological and behavioural; taha tinana which is physical health; taha wairua which is spiritual and cultural; taha whānau which is social participation.

It was suggested by some participants that mothers, while not always the perpetrator of violence and abuse, may well have been aware that abuse was occurring and did not take action to prevent the abuse, and instead remained passive. Others suggested that mothers may have been the ones that had made the first connection with acute mental health services when the individual had become unwell. This first connection may not have been appreciated by the individual. Overall the group were in agreement that such a question should not be asked. However further discussion on mothers and families continued.

A family participant talked about the impact of mental illness on families. She spoke of family breakdowns that occurred due to the illness of a family member. Furthermore, she suggested that much work needed to be done with families in relation to forgiveness issues, promoting reconciliation and empowering families to be families. An example was provided by a participant who talked about a crisis episode whereby the police had to assist an unwell individual to calm down before escorting the individual to a mental health services inpatient unit. Everything occurred so fast, the family were in shock, traumatised yet unable to grieve at the time. Subsequently, they found it hard to re-build trust with the individual, fearing emotional hurt occurring again. The family representative said that facilitation meetings could be offered to families to promote healthy family relationships and support conflict resolution.

Raising the question about mothers and how it had made them feel as individuals a second time prompted a participant to ask about the potential risk of a consumer becoming upset with a possible question that was asked as part of a questionnaire. He wanted to know what could be done if this happened. The group thought that an independent counselling service should be offered as part of the process and that individuals who participated in the questionnaire should be able to have a support person or friend with them to minimise potential concerns.

One participant stated that in another pilot project, people often had their key worker present. For this project, involving the conducting of the consumer questionnaire, the information flyer explained that people may have a support person with them, they may stop answering the questions at any time, and they may withdraw from the project if

preferred. Consumers were advised that they could consult a friend, their support worker, or their key worker as required.

Observation and monitoring

During the course of these discussions I came to recognise that there would be some challenges in conducting the interview process and that the group participants had raised some valid concerns. Further to this, a group participant talked about a project that two NGOs were undertaking and which focused on consumers who were deaf. The participant wanted to know what supports could be offered to deaf consumers taking part in the interview process. It was also noted that interviewing Asian people would be challenging so interpreters may be needed for this. Language barriers to participation could be overcome by having interpreters available so these insights had the potential to become additional costs that I needed to consult the project sponsor about.

Reflection and revision

This second meeting in the action research cycle had raised lots of issues that had implications for the application of the questionnaire using an interview process. The questions needed to be answered for the consumers without causing offence, yet at the same time being specific, and measurable. The reaction about mothers in the New Zealand context had taken me by surprise and I needed to consider all the responses carefully, making no assumptions.

Engaging an independent counselling service to be available should a consumer become upset by a question was not feasible but I recognised the need to have strategies in place such as those suggested from other projects. For example, encouraging the consumer to bring a support person, giving the option to leave questions unanswered, and acknowledging the consumer's right to withdraw from the questionnaire process at any time.

Employing interpreter services to assist participation by consumers who did not speak English or who were deaf was reasonable and so I consulted the project sponsor as to the preferred process and provider for this. In addition, consumer participants were keen to test any questions before they were given to consumers in the services which meant I needed to consider how best to factor this in to my processes.

Overall I felt this second meeting had been productive with substantial input from all participants. Many issues had been raised such as the level of consumer participation I needed to address, and build into my processes for the application of the questionnaire. I also had questions to take to the project sponsor about possible additional resources to support the project.

Cycle three: Measurement tools

The aim of the third meeting, and therefore the third cycle, was to develop an overall understanding amongst group participants about outcome measurement tools and selection criteria. This understanding would be important as preparation to guide decision making in the selection of a consumer questionnaire at the fourth meeting and the fourth AR cycle.

Reconnaissance and planning

Planning for the third meeting initially began as part of planning the series of meetings. However it was only after reflecting on the group's progress, at the end of meeting two, that I thought seriously about what actions I needed to take in the third meeting. There were areas of specific knowledge that needed more clarity for some group participants and I perceived the overall level of understanding was weak in some areas. Too weak to support the decision making required in meeting four so I arranged the circulation of the following articles for pre- meeting reading:

- European Research Group on Health Outcomes (ERGO) *Choosing a Health Outcome Measurement Instrument* (Schug, 1996)
- Recovery, rehabilitation, reintegration: Words vs Meaning (Farkas & Harrison, 1984)
- Towards an outcome based mental health policy for New Zealand (Kreible, 2003).

I spent a lot of time thinking about how I would present the minutes of the previous meeting at the beginning of meeting three. I wanted to reflect my understanding of what the participants had expressed. I believed this was important to show them, that I had been listening and that I was keen to have their continued active participation.

Action

Our nominated Māori advisor, who had missed the first two meetings, was able to attend this meeting. He brought with him a certain māna⁸ and respect, which was apparent from the verbal and non-verbal actions of other participants in the room. I had known the Māori advisor as Mātua, the Māori word for father, suggesting seniority and status. Following my introduction of him to the group, he opened the meeting with a kārakia and more formally welcomed participants. He spoke of his own experience of mental health services and expressed an eagerness to participate in the group.

When reviewing the minutes of the last meeting with the group, I raised the unresolved issues. What support should and could be provided for the consumers answering the questionnaire? Should there be an independent counselling service offered? After some consideration, the group decided that this action would not be necessary. Consumers could be given the option of answering questions or not, and to have a support person, of their choice, accompany them as desired. Participants thought it would be helpful to capture the reason why consumers particularly chose not to answer a particular question. Therefore it was suggested that when a question was declined, where possible, the reason was recorded.

Participants also felt that asking questions or providing support for those answering questions was not straight forward and required skills and training. One consumer participant stated that there was a certain skill level in establishing a relationship, and building a rapport with the consumer in order to ask the questions. When advised that I had planned to conduct the interviews with the questionnaires myself, consumer participants were not so sure that I should be doing that. In discussion they pointed out that there were lots of aspects to do with asking questions that needed to be considered; such as the literacy level of the individual and the importance of creating a suitable environment for the questioning. Further to this, they suggested that a Consumer Surveyor, who was trained to provide appropriate support, would be more suitable to asking the questions. I thought about why I wanted to ask the questions from a researcher's perspective, and at the same time considered what they had said.

The next question I put to the group was whether they thought the same questionnaire could be given to all consumers regardless of the type of service being attended for

⁸ Māori word meaning to have authority

example a drop-in centre or an information advocacy service. After careful consideration it was agreed that if the questions were service specific, then different questionnaires would be needed. They also wanted to see the questions. Consumer participants suggested that keeping questions brief and realistic was important and some put their name forward to test the questionnaire to ensure that they themselves were comfortable with the process before it was put to other consumers.

One of the DHB participants presented an article called *Standardised Routine Outcome Measurement: Pot Holes in the Road to Recovery* (Lakeman, 2004). Published in Australia the article referred to measurement tools as being one method of capturing information but not the only way. Further to this, it recommended that critical reflection and debate should accompany measurement tools. It made us all think about the use of the questionnaire and that we should not rely on it solely to give all the information we required; rather it should be considered as part of a wider process.

I then asked the group whether they thought that because the social, recreational and prevocational services were voluntary, that we could assume that consumers wanted to attend. In response the participants decreed that individuals “*may not have enjoyed a high level of satisfaction from a service; however it might be the only one that they could access.*” In addition, it was stated that “*consumers may not be aware of any other services or may not have been given any other options.*” In reality, consumers may have been taken to the service by a key worker or family member, and their attendance was something that they had agreed to as part of their recovery plan, or simply to keep others happy. This caused me concern particularly since prior to this project it had been suggested that full attendance at a service implied satisfaction with the service.

The conversation progressed to the type of questions that ought to be included in a questionnaire. Participants strongly indicated that the questions had to be right and in language and context that fitted the New Zealand environment. For example, using simple commonly used language. No jargon and no acronyms. Questions implying a respondent had previous knowledge of services and service implications were considered unacceptable as consumers would need to have attended a service for a period of time to have the knowledge required to respond. In a discussion about rating scales consumer participants pointed out that these could be confusing. They referred to

people who were not keen to rate services too high or too low and instead ticked the middle columns just to be polite or because they did not want to be thought of as offensive.

I asked what should be prioritised in the services for individual consumers. Since many consumers were reliant on public transport, the location of services was crucial. Ideally a service within 5 kilometres of a consumer's home would be an asset. Participants also stressed that services needed to be flexible and reactive in order to better meet consumers' needs because: "*an individual's level of wellness varied from day to day*", and consumers would want to know that they were still welcome at the service even if they were having a bad day. Another participant talked about services needing to be "*culturally appropriate*" and that was not just from an ethnic perspective but in respect of "*an individual's religion or gender preference.*" Participants reiterated that services needed to be "*accessible and affordable*" and gave examples of services which charged consumers or where travel costs made it unaffordable.

In looking towards the next meeting, I advised participants that they would be selecting a questionnaire for application. Slaton and Westphal's (1999), article '*The Slaton-Westphal Functional Assessment Inventory for Adults with Psychiatric Disability: Development of an Instrument to Measure Functional Status*' provided a framework for reflection. Following discussion, during which I inquired how they would decide which questionnaire, would be best, the group agreed on the following criteria:

- Meaningful to the person experiencing mental illness
- Brief
- Relevant for further action
- Can be collated in a meaningful way
- Reliable as a research tool

Participants wanted consumer ownership of the tool and any comparative analysis and so I needed to consider whether that could be achieved. The MHRDS (2004) had short-listed six possible questionnaires for use following a recent review and so I explained that the role of this group would be to select one of those questionnaires based on our discussions to date and the agreed criteria. This would occur at our next meeting. Before the meeting closed I handed out copies of the six questionnaires (MHRDS, 2004):

- The Mental Health Inventory

- The Behaviour and Symptom Identification Scale - BASIS 32
- Assessment of Wellness Outcome Tool
- Crisis Hostel Healing Scale
- Lotofale development of the Fonofale model of health
- Hua Oranga

I then thanked the group for their participation, and assured them that I looked forward to meeting with them again. The Māori Advisor closed the meeting with a kārakia.

Observation and monitoring

It became obvious during this third meeting that participants had gained considerable knowledge from their participation in the first two meetings. The knowledge gaps that I had identified in meeting two appeared to have been diminished by the pre-reading and so I felt somewhat confident that this enhanced knowledge would assist them in selecting the appropriate questionnaire. Even those DHB and NGO participants who were more familiar with service perspectives seemed to have improved understanding of consumer and family perspectives.

Reflection and revision

By questioning processes that I thought were straight forward and not in need of debate, the group raised valid issues and so I had to demonstrate flexibility in my processes and to be prepared to make changes as warranted. I now questioned assumptions that I had made in the past, such as, whether a high service attendance indicated satisfied consumers. The consumer participants informed me that it did not.

Cycle four: Selecting a questionnaire

Reconnaissance and planning

Meeting four was to be the culmination of all the planning and preparation. This was the platform from which the learning of the previous meetings would be set in action. The group, now conversant with the intent of social, recreational and prevocational services, the philosophical underpinnings of recovery and consumer participation, would select a questionnaire for application. There had been a consensus of agreement in meeting three that a set of five items would be used to score the questionnaires. I planned to use these

five items in a score card to assist the decision making process and prepared them on an overhead transparency. Reflecting on the five items, I realised that in terms of importance to a consumer and/or to a service funder, they were not of equal value and so I prepared a weighting to introduce to the matrix. The weighting was presented to the group and with their approval I applied it to the process.

The group participants had copies of the five questionnaires and would be considering them in preparation for the meeting. Considerable time was spent reading the five questionnaires and thinking about their potential application in preparation for the meeting. I wondered how I would feel asking the questions to a consumer. What sorts of feelings might the questions generate? I was mindful of the question about speaking with a mother and the consumers' reaction. Consequently, I looked for questions like that in the questionnaires and made my own notes.

This was the last meeting of the group and so I wanted to ensure that opportunities for further feedback from group members were maximised and that they left the meeting feeling valued, and that their contribution over the past weeks had been worthwhile. I rechecked my catering list and ordered the chocolate cake!

Action

Meeting four started with great enthusiasm. Everyone realised the importance of the meeting; that we were all there to achieve a certain goal. Following the welcome, I thanked the group for their diligence in preparing for the meeting and highlighted the processes that we would undertake. I went through the minutes of our last meeting, confirming the five criteria that we had agreed to use to assist the decision making process before reintroducing the questionnaires that we were going to select from. A consumer participant asked "*what will happen if we don't like any of them?*" I suggested that we go through the process and in doing that we would determine what was unacceptable and how we would manage that. I also advised that we still had to discuss exactly how we would go about recruiting the participants.

Recruiting the questionnaire participants

Questionnaire participants were those 50 service consumers who would complete the selected questionnaire. A draft flyer, which I had prepared, to advertise the opportunity

for participation had been circulated to SRG for feedback. One group member suggested that:

The flyer should be amended to explain the benefits of participation such as how the information collected and the process undertaken would be used to add value and benefit those people who were accessing the social, recreational and prevocational services

A consumer group participant said that “*all questionnaire participants should be acknowledged in the project report.*” This triggered discussion on informed consent and it was agreed that individual names would only be included with consent.

The consumer group participants identified the fact that when they first joined the services there were lots of things happening for them psychologically, filling in a questionnaire of this nature would not be helpful at such a time. Following that discussion it was agreed that only consumers who had been with a service for a minimum of six months would be interviewed with the questionnaire.

Another group member suggested that “*consumers might not be very keen to participate*”. A discussion followed on how best to acknowledge questionnaire participants. Financial reimbursement was suggested by one group participant. Another suggested petrol vouchers, while another mentioned a thank you card that reinforced the potential benefits of participation. My approach to the questionnaire participants was deemed important to engage them in the questionnaire process. It was agreed that there would be a specific process for Māori consumers led by the Māori advisor.

The process

I planned to meet with the consumer participants from this SRG, to consider and test the process however, it was school holiday time and so many had plans for the weeks ahead. The group participants advised me that to encourage participation, I needed to be able to offer something positive to participants. They were of the opinion that service consumers had been overly surveyed and that they seldom see the results of their efforts. It would seem that they wanted some ownership of the information that I collected. Most of all they needed to know that something useful was going to happen as a result. I was not in a position to make promises but assured the group that I would certainly endeavour to do the right thing.

With the scoring matrix prepared, I began discussions about each of the five questionnaires and encouraged group participants to consider the advantages and disadvantages of each. I also reminded them of the five criteria to assist decision making.

The questionnaires

The Crisis Hostel Scale (Dumonth, 1995, 1998). This was the first questionnaire to be discussed. It was not seen as consumer user friendly. The questions were deemed to be inappropriate for the service setting that we were focusing on. One of the questions implied that an individual had been the victim of physical abuse. This prompted questions from the group about *“the origin of the questionnaire and whether it had been used for a mental health service or other services such as a women’s refuge.”* Discussion highlighted the fact that some of the questions were totally inappropriate and asking them may generate issues for individual consumers. For instance, one question asked about having a healthy interest in sex. A group participant asked me: *“what is the right answer to that? What was expected?”* I did not have an answer rather I responded that this was why it was useful to have these discussions. Another participant wanted to know: *“how will we track trends in the answers and what will they mean?”* Questions such as this were difficult to answer and it raised the possibility of there being a list of correct answers or even an explanation sheet? I had not seen additional resources in the literature.

The group decided that this questionnaire was not brief enough and it would take a lot of time to fill in. Some parts were repetitive and this may annoy questionnaire participants. There seemed to be no themes within the questionnaire, making it difficult to graph or chart responses in a logical way. The linkage between individual consumer state or wellbeing and the impact of the service was not clear in the questionnaire. Overall the group were disappointed with the Crisis Hostel Scale; although one question was thought to be useful: *“I do not see myself as sick or allow others to see me as sick”* (Dumonth, 1998).

BASIS 32 (Andrews, Peters & Teeson, 1994; Bridgman, et al., 2000; Graham et al., 2001; Stedman, Yellowlees, Mellsop, Clarke & Drake, 1997).

This questionnaire was a challenge for the group as having spoken so much about recovery focused approaches and positiveness in previous meetings; the questions were negative and focused on difficulties leading to a sense of hopelessness. Group participants thought the language used was too academic, particularly if English was a second language, and that questions about symptoms suggested a medical model perspective. They wanted to know how responses to such questions would be actioned or followed up. From a researcher's perspective I thought working with this questionnaire would be challenging.

Some of the potential advantages of the questionnaire were the simple rating scale and the opportunity for direct learning and skills training presented where a question began with "*you have difficulty with....*" (MHRDS, 2004). However, overall the group did not favour this questionnaire.

Mental Health Inventory (Andrews et al., 1994; Stedman et al., 1997).

It was generally agreed that this questionnaire focused entirely on emotions and feelings and there was a patronising tone in the language used in the questions. The questionnaire could be used by an individual to track their own progress but again answers would vary from person to person. Overall, the group did not favour this questionnaire. Although the results could be graphed, its usefulness was queried.

Assessment of Wellness Outcome Tool (Bridgman et al., 1999).

Group participants were more positive about this questionnaire. They liked the fact that it started with a positive tone, had a New Zealand cultural flavour and a section where written comments could be added. They did not like the "*excessive*" number of questions, and suggested that some questions should be optional and/or on another page. They also thought the printed page looked crowded. One question, which was deemed "*inappropriate*" by the consumer participants, asked whether 'you felt more normal'. This gave rise to a group discussion about what was normal. Overall, with the exception of the one question, the group favoured this questionnaire.

Lotofale Evaluation Measure (Nonu-Reid, Lui, Erik, Puloto-Endemann, & Bridgman 2000).

This questionnaire originated from a local Auckland initiative and fortunately, a Pacific representative present was able to describe the formation of Lotofale. There were some useful questions, particularly from a family perspective. And while the group acknowledged the positive aspects of the questionnaire, particularly for Pacific people, it was thought that too much additional work would need to be done before it could be applied, and therefore it would not be suitable at this time.

Hua Oranga (Kingi & Durie 2000).

The group seemed particularly interested in the final questionnaire which had three aspects and each one captured the situation from the consumer from a different perspective: the service, the whānau and the key worker. In addition, the Asian representative thought the questionnaire, and its approach, would be applicable to a refugee community. However this was a questionnaire developed for Māori by Māori. The big question was, what barriers would there be to applying it to mainstream populations? A group participant informed us that the questionnaire was still being tested, and that the authors, Durie and Kingi (2000) were still discussing its potential use. Overall the group liked this questionnaire but recognised that availability needed to be confirmed.

Having discussed the questionnaires at length, I introduced the scoring process and the notion of applying a weighting. I reiterated that some selection criteria were more important to the task of assessing service outcomes, than others and hence the reason for a weighting. I had discussed this with the group several times and demonstrated the weighting on the white board, but there were still some group participants who struggled to understand it. I could sense uneasiness about this process and decided to abandon the weighting for the moment. Perhaps it would not make a lot of difference in the end. When suggesting that we would leave the weighting I felt sure there was a sigh of relief. I asked each group participant to consider a score between 1 and 10, from low to high for each questionnaire against each of the listed criteria. Scores were agreed as a group.

A summary of the scoring for each questionnaire is presented in Table 2. Two questionnaires scored higher than others: the Assessment of Wellness Outcome and Hua

Oranga. It was agreed that I, as the researcher, would contact the authors of the two short listed questionnaires with regards to the application and appropriateness of the questionnaires for this research project. Furthermore, the group participants decided that the questionnaires would have a pre-test prior to application in the services.

Before sharing refreshments, I thanked members for their involvement and explained that certificates of participation would be sent to all group participants to acknowledge their contribution. Information about project progress and findings would also be sent. For those who were to be financially reimbursed, I invited them to hand in claim forms for attendance at the meetings.

Observation and monitoring

By the end of this meeting, the group participants appeared to have more understanding of other perspectives and seemed to listen more intently to the different views. In considering the questionnaires from a consumer perspective, the participants raised valid points about how they would feel if they were asked some of the questions. They also pointed out possible reaction to questions like ‘*a healthy interest in sex*’ or ‘*feeling more normal*’. DHB and NGO participants wondered about the ways in which the questionnaire might help them to improve their management style. Would the results of the questionnaire tell them about service outcomes and how they could document changes in a graph or a chart? The different emphasis that each participant put forward reinforced the benefits of having a range of perspectives represented in the group.

Reflection and revision

I had felt anxious in the lead up to meeting four because in order for the next stage of the project to occur specific tasks needed to be achieved in a timely way. The concerns regarding the types of questions that could do more harm than good worried me. However, my anxiety was unfounded.

Overall, the series of stakeholder meetings had worked well and an outcome was achieved. Together the group had effectively planned how I would undertake the next step in the research process using one of the two questionnaires they had selected. The importance of consumer participation was discussed at length. The question of how best to create a safe and supportive environment, particularly when engaging with consumers

responding to a questionnaire was also debated. Preparations were almost complete, and I was now ready to move from planning onto the next stage of my research, the implementation, which is described in the following chapter.

Table 4: Scoring the questionnaires

The Criteria questionnaire was:	Crisis Hostel Healing Scale	BASIS 32	Mental Health Inventory	Assessment of Wellness Outcome	Lotofale	Hua Oranga
1. Meaningful to the person experiencing mental illness	1/10	1.5/10	1/10	8/10	3/10	9.5/10
2. Brief	2/10	3/10	2/10	4/10	1/10	9/10
3. Has relevance for further action	1/10	2/10	0	8/10	0	6/10
4. Can be charted or collated in a meaningful way- can be viewed	0	3.5/10	2/10	7/10	1/10	8/10
5. Is reliable as a research tool	0	2/10	0	7/10	2/10	8/10
Total out of 50	4/50	11.5/50	5/50	34/50	9/50	40.5/50

Chapter Seven

Implementation

The next step in the project required me to implement the two questionnaires that had been selected by the SRG using the list of instructions the participants had given me.

Preparation

My first task was to contact the authors of the questionnaires, introduce the project and describe the specific tasks undertaken by the SRG. I would then explain the questionnaire selection process and the proposed plan. Further to this, I would seek approval to use the questionnaires with a group of 50 consumers of social, recreational and prevocational services.

Contacting the authors

Upon making inquiries at the DHB I was told that the questionnaire called Hua Oranga (Kingi & Durie, 2000) would not be ready for use even with the authors' approval. Recent reports indicated there were some design issues that were currently being worked on and additionally, there were concerns about the questionnaire's use in mainstream settings, as it was designed specifically for use by Māori for Māori.

I then contacted Geoff Bridgman, author of the Assessment of Wellness Outcome Ttool (Bridgman, et al., 2000). Bridgman expressed interest in the project and approved the application of his Assessment of Wellness Outcome tool for use in the social, recreational and prevocational service context. During the discussion I explained that we planned to pre-test it for suitability. In response he advised that the questionnaire had been used, in a pilot project, by mental health consumers of an early psychosis service, and that he did not believe the questionnaire required a pre-test. When I asked about deleting the question "*I feel more normal than I used to*", he advised that his preference would be to leave the question, as this would affect the overall questionnaire. He suggested instead that consumers be given the option of choosing not to answer any of the questions in the questionnaire. He thought it would be interesting to find out which questions consumers most commonly chose not to answer. I thanked him for his

advice and indicated that I would share the results of the questionnaire with him on completion of the project.

Following this, I met with staff from the refugee service provider organisation, also regarded as part of the social, recreational and prevocational services group, to discuss the use of the questionnaires. After some debate, the group decided that neither of the two questionnaires would be useful or appropriate for refugee consumers. There were a number of factors, including cultural issues, influencing their decision therefore; I elected to exclude the refugee service provider from this part of the project. One particular DHB, and their local contracted providers, were also excluded as they had made a commitment to pilot several other questionnaires at that time. I did not want to overburden the providers or duplicate work that was already being undertaken.

When I reported my findings back to the project sponsor we agreed on the following actions:

- I would take the Assessment of Wellness Outcome Tool questionnaire to 50 consumers of social, recreational and prevocational services in the region with the exception of refugee services and one specific DHB area.
- I would support a pilot of Hua Oranga with a Kaupapa Māori Day programme, but not as part of this project or this report.
- I would conduct a focus group with the refugee service to consider the themes and questions to be included in a specific questionnaire that they would develop and use locally. This task would also be separate to this project and this report.

At the next meeting with DHB funding and planning managers, I gave a report on my actions to date and an update on future proposals. They reiterated the importance of the project and the need for clarity about what was being delivered by services to consumers. I then asked them to consider which 10 provider organisations should be selected to participate in the questionnaire process. They agreed on 10 provider organisations that would best reflect social, recreational and prevocational service delivery including a mix of large and small providers. This decision was in keeping with recommendations regarding sample size, 50 consumers would ensure the findings were credible (Waitemata DHB Knowledge Centre research statistician, personal communication, December 10, 2004).

Reconnaissance

Preparations began with designing and documenting the process for conducting the questionnaire before contacting each provider organisation to communicate and confirm the process and schedule the site visits. Once the questionnaire, information sheets, and consent forms were printed, I drew up a schedule, allocating two visits per organisation. The first visit would be to communicate with the organisation's personnel and consumers about the questionnaire and invite consumer participation. The second visit would be to conduct the interviews with the consumers using the questionnaire.

Both the process and associated documentation had been submitted as part of my application for ethical approval. An additional section was added to the consent form for participants who may want to request an interpreter. The key message in this section was in eight languages. The consent form had previously stated that the interview would be taped using an audio tape, however consumer members of the SRG did not want to be recorded. They believed that the audiotape would be "*intrusive and unnecessary*" given that the focus would be on the questionnaire responses.

Action

First site visits

I arranged wherever possible, to meet with groups of consumers in the service setting. A communication flyer was emailed to the organisations advertising my visit and its purpose. In most cases this flyer was displayed on the service's main notice board where it could be seen by all consumers of the service. The format of the first visit varied between organisations. In some, consumers gathered in a common room to hear about the questionnaire. In others, I introduced myself to consumers individually and told them about the questionnaire because staff thought it would be too disruptive to planned activities to call consumers together. In one organisation I discussed the project, and more specifically the questionnaire, over lunch with consumers. This visit was with a group called the 'Lunch Bunch' they functioned as a consumer support group, with some facilitation from a community support worker.

This group was previously mentioned in an earlier chapter whereby members shared the responsibility for food preparation before they all ate lunch together. Many of the

consumers in this group had limited skills in shopping or meal preparation due to their experiences in supported accommodation. However they all shared what little knowledge they had and with some direction, when required from the community support worker, they managed to create wholesome meals, learn life skills including socialising over a meal, and have fun doing it. I enjoyed the experience immensely and was amazed at the collaborative learning and sharing that continued over what seemed basic tasks. It was all done in a most respectful and empowering way.

By the time I had completed my first visits, I had generated significant interest amongst the provider organisations' staff and consumers. More than 50 consumers had indicated an interest in participating and so I left information sheets about the research process with them. I explained that I would bring afternoon tea with me on the second visit and asked about food preferences. Most consumers were keen for chocolate cake however, one group who were participating in a healthy eating and exercise programme asked for fruit juice and fresh fruit.

Conducting the questionnaires

Upon my return to conduct the questionnaires, I felt more comfortable knowing that consumers were interested in participating. However I kept thinking back to the words of the consumers on the SRG, who wanted to be sure that the consumers were not upset by the questions that I asked or the process. "*Do no harm*" they had said.

I sought out staff in charge at each provider organisation service setting to confirm which consumers would be participating. In most cases the consumers who had indicated an interest at my first visit, participated. There were some consumers who were unwell and had not attended the service on that particular day and so I arranged a further visit to accommodate those who wanted to participate.

Staff were helpful with the questionnaire process, often providing a quiet, pleasant room. Some staff offered to help in any way with the actual questionnaire but this was not an option as their presence may influence a consumer response. One provider

organisation had a consumer advisor who was available to attend as a support person if the individual consumer wished and several consumers accepted the offer. Another organisation had a consumer manager who was available to provide support.

The questionnaire process in each of the provider organisation service sites was completed with very few problems. I recorded the responses to each of the questionnaires manually, noted any additional comments, as well as my own observations. Following completion of the process, afternoon tea, was well received.

Observations and monitoring

I was keen to invite all consumers from a service to participate, however staff initially suggested who would or would not be suitable. Several consumers were deemed unsuitable by staff members because they had limited literacy skills. I found this challenging and so I explained that participation was still possible if I read out the questions on the questionnaire to consumers who wanted to participate. The consumers were keen and I warmly welcomed their participation.

For some of those who had limited literacy skills it would seem that some questions were not well understood, they needed greater explanation. Taking time to explain the questions helped me to identify which questions needed the explanation in advance. For some consumers the questionnaire was far too long. This became apparent with signs of restlessness and some requests of “*can I go now?*” before the questionnaire was completed.

The layout of the questionnaire was also confusing. It was divided into three sections. The first section was related to outcomes due to the service and the second section referred to outcomes due to other things. The final section was about levels of support required in the particular areas. The confusion appeared to contribute to lower completion rates for the second and third sections, and I believe this added to some individual’s restlessness.

Some of the questions were open to misinterpretation. For example, '*you are more content, calm or happy*'. This required one answer yet an individual consumer may well have had three different answers. Some questions were unpopular, particularly the question signalled by the consumers in the SRG about feeling normal.

Reflection and revision

Once I had completed the 50 questionnaires I reflected on the whole process. Each questionnaire had been a different experience for me, due to a range of factors. The questionnaires had been conducted in 10 different environments which varied from a minimum secure forensic mental health environment to a common room in a local community centre. The questionnaire was easier to apply in relaxed environments with a designated quiet area and minimal distractions.

Staff attitudes also affected the way the questionnaire process was received. Staff who were proud of their service and keen to promote it, were positive and encouraging of the process and of the consumers participating. Those positive attitudes appeared to relax the consumers and they seemed more comfortable while participating. Other staff did not seem so positive and may have misinterpreted the process by suggesting that only the very literate and well consumers should participate.

Questionnaire results

Consumers' responses about what had changed for them since attending the particular social, recreational or prevocational service were considered a service outcome. A summary of consumer responses is provided in Figure 5.

The services were expected to offer work opportunities, and/or enhance skills and experiences leading to meaningful activity, as defined in the contracted service specifications. Many consumers made positive responses about the services' capacity and capability to achieve this since they had been exposed to new opportunities and experiences which benefited them as individuals.

Figure 5: Consumer responses

To what extent has the involvement ofservice in your life mean you are having more fun:

- 92% were having better or much better fun
- 82% were more confident about future plans
- 80% had more control over choices in their lives
- 78% were more able to do the basic tasks of day to day living
- 70% had improvement in their relationships with friends, whānau and family
- 68% were better prepared or trained for work or better able to manage work.

Overall consumers expressed overwhelming support for the services which were putting fun and enjoyment into their lives. In particular, consumers indicated that services were helpful with the facilitation of new opportunities to participate in meaningful activities. The activities varied from walking groups, cooking classes and supermarket shopping, to participating in community life such as market days, festivals, and community meetings. The consumers responses to the questionnaire have been recorded in italics. Comments about the most helpful aspects of the services included:

Consumer A: *“Painting, drawing, billiards, it’s all good”*

Consumer B: *“I like the independence”*

Consumer C: *“Wonderful consumer resource”*

Consumer D: *“Various courses available”*

Consumer E: *“New art tutor starting”*

Consumer F: *“Gardening”*

Services

Services that provided a range of activities and were linked into community based services could offer more opportunities in a more holistic way. Providers did not necessarily provide all the services themselves rather they could almost seamlessly engage individuals in a range of activities and supports within the local community. This was particularly helpful for those with complex or multiple needs, for example, housing, community support, life skills, and employment. One consumer conveyed the benefits of accessing this particular service, by writing this response in the questionnaire: *“....has been a stepping stone for me. They believed in me when everyone*

else gave up. If it wasn't for their help, I would not be living in the community independently with my daughter."

Services which made specific efforts to address the social and physical needs of consumers by introducing information on body hygiene, oral care, physical wellbeing, such as medical checks, and personal clothing were seen as helpful by consumers. Other aspects of service provision that were regarded positively by consumers included a second hand clothing exchange where consumers could bring their washed unwanted clothing and exchange it with others. A second hand clothing cupboard that also included sundry household items such as cutlery, crockery and linen for those setting up a home also received positive feedback. Services that helped consumers to develop skills and the confidence to participate in normal daily activities were important to consumers. Of note, consumers mentioned things like shopping in local supermarkets, managing their own money, and preparing meals for themselves and others.

Social opportunities were also regarded positively. One consumer stated that the service was *"better than nothing"* and at least provided *"somewhere"* for him to go. However another said that his residential rehabilitation facility was so bad that he *"just had to get out"*, so he got a taxi twice a week to attend the drop in centre. His experience of the centre was positive. He stated that it *"allows me to spend time with nicer people who like me"*. In the main, consumers welcomed the friendships made and enjoyed the social activities whether it be trips to the beach, shopping mall, outdoor sports or the movies. Their comments about the positive aspects included:

Consumer C: *"Sense of belonging and stability"*.

Consumer E: *"I found it invaluable for information and meeting new people"*.

Consumer A: *"I feel my confidence has improved, trust and motivation as well"*.

Consumer D: *"Friends, able to talk to a friend"*.

Consumer B: *"Talking to ordinary people that aren't in the psychiatric system is helpful"*.

Consumer F: *"Being more active"*.

Consumer G: *"Contact with other people with the same problems"*.

Consumer H: *"Walking group"*.

Consumer J: *"Having a safe place to come to, be accepted, warmth, love, caring, fun"*.

Services which provided pathways to employment were seen as favourable as a real job was something to which most of those who were interviewed aspired. It was said that a real job brought in real money and that was helpful. One consumer felt that being part of a team in a working situation *“was the best”*. Others had been in and out of employment but they recognised the role that the service had provided in getting them ready for returning to work and finding the right job. *“My whole life has changed. I work here three days a week. I also do art, music group and attend the mens group. I have been so encouraged; Got a job, got job skills, involved in a team”*.

Staff

Consumers felt that staff attitudes toward them could be difficult to deal with. Comments related to this included: *“bossy, argumentative, limiting creates barriers, The Police, and patronising”*. Consumers also felt that negative staff attitudes needed to change. With reference to this they stated:

Consumer A: *“Better understanding”*.

Consumer C: *“Had a slight argument”*.

Consumer J: *“Need more empathy with clients”*.

Consumer A: *“Need greater ratio of staff to clients”*.

Staff skills were crucial to make a difference to the programmes particularly when specific skills or expertise was required to enhance the learning, for example, pottery, art, machinery, horticulture or computers. Consumers wanted staff with expertise in these areas to coach and mentor them.

Consumer compatability

Some consumers had issues with other consumers. One consumer expressed that she would not normally have mixed with people that attended the services. She felt that they had different backgrounds and perspectives on things that she did not necessarily share. Services that were not integrated into community or mainstream activities often resulted in an individual only mixing with mental health consumers or staff. This made social inclusion more challenging. This individual also had issues with the varying standards of hygiene of the programme participants:

Consumer AB: *“Other patients been sick”*.

Consumer AA: *“Some people smelling dirty and dressed dirty”*.

The environment

Consumers wanted improvements in facilities and equipment. Some facilities had become quite run down and there did not appear to be plans or funding for renovation. Changes in Smoke Free legislation had resulted in smokers being relegated to inadequate arrangements. Equipment was sometimes old and in need of repair and consumers had much to say about potential improvements:

Consumer A: *“Ask for better cooking utensils”*.

Consumer D: *“Flowers for the place”*.

Consumer M: *“More funding”*.

Consumer N: *“Van for outings and trips”*.

Consumer S: *“Social club”*.

Consumer W: *“More funding enabling more consistent and more generous recompense to participants being involved for expenses”*.

Consumer T: *“Better modern equipment ie computers”*.

Consumer C: *“Better food”*.

Consumer K: *“More rooms”*.

Consumers who had a strong desire for a place of belonging found drop in centres that were for mental health consumers only, helpful in that respect. However from another perspective an individual wanting to feel comfortable, accessing community facilities just like other people, staying at the drop in centre was not going to help that.

Assumptions are made when people turn up to a service voluntarily that they want to be there. Some explained that it was the easier option when a number of options are given by a key worker they wanted to stay on side with. Others stated that there were no other choices within their community.

Employment

Programme activities varied from service to service. Some respondents wanted access to more specialist employment help. One consumer who apparently asked staff about getting a job, was told that it was too early to think about a job, and that there was plenty of time for that. This was disappointing for the individual concerned and so the

consumer wanted: *“Help to go back to work and to go flatting”* as well as *“programmes, specifically for mothers and their children.”*

With regard to seeking employment and improvements consumers suggested:

Consumer W: *“Could invite an employment person to the centre”*.

Consumer S: *“Start an evening programme”*.

Consumer F: *“Room for improvement”*.

Consumer R: *“Not enough teaching in cooking and diet”*.

The payment aspects of work programmes or vocational programmes were a concern. While it was acknowledged that it may be therapeutic, the whole payment issue seemed fraught with dissatisfaction. One consumer said that getting three dollars per hour made him feel that he was only worth three dollars per hour. However the payment was not regarded as a salary by the organisation as such. Monetary allowances from organisational budgets were given to consumers who participated in work programmes as an incentive and in recognition of work done. The consumer perspective of this payment was obviously different and a hot topic of conversation with consumers from across services. Consumers who wanted the issue raised with management stated:

Consumer X: *“Support in self-employment”*.

Consumer Y: *“Normal hourly rate”*.

Consumer Z: *“More pay”*.

Consumer AA: *“Become more of a business and better pay when we can afford it”*.

Consumer AD: *“Higher wages”*.

Another consumer wanted to learn to cook but had yet to discuss this request with staff. Cooking classes could possibly be included in the programme. There was limited opportunity to get consumer input in a number of services. Not all services surveyed consumers consistently. Services did not always have suggestion boxes or other avenues for collecting people’s ideas about what they wanted to do. One service had a suggestion box but consumers indicated that they did not use it as they did not think things that they wanted would happen. They thought the suggestion box was a waste of time.

Summary

The consumer questionnaire Wellness Outcome Tool (Bridgman, et al., 2000), demonstrated an ability to measure the outcomes of social, recreational and prevocational services, from a consumer perspective. The information was relatively easy to collect and did not take up a lot of time. Service providers were able to observe the process, and consider how they would apply a similar process within their organisations, as part of their service quality system. Consumers demonstrated that by using the questionnaire they were able to provide a valuable perspective for planning, delivery, monitoring and evaluation of these services.

Overall, the findings showed that most consumers had a positive experience attending a social, recreational or prevocational service. They associated the services with improvements in their wellbeing and providing socially inclusive support toward their recovery. Many consumers found the questionnaire too long.

In this chapter I have described the implementation of a consumer questionnaire known as Assessment of Wellness Outcome Tool (Bridgman, et al., 2000). While this questionnaire had been used in the mental health sector before, it had not been used specifically for consumers of the social, recreational and prevocational services. Implementation of the questionnaire demonstrated that consumers were interested in participating, able to assist with the questionnaire process, and had much to offer, and in terms of the consumer perspective. These findings are discussed in chapter eight within the context of the mental health social, recreational and prevocational services.

Chapter Eight

Discussion

This research has focused on the mental health social, recreational and prevocational services delivered in the Northern region of New Zealand. As revealed in the previous chapters, the research was conducted in three stages, each stage a step in an overall project, and within each step, action cycles within cycles. Each stage was informed by Elliot's (1991) cyclic process of action, for example, reconnaissance, planning, implementation and evaluation.

Discussion of the findings

In the first stage, service providers and the services they were contracted to provide, were examined using a UK social inclusion model to map the services against recognised life domains. The services had originally been contractually established by funding and planning managers with the best intentions, based on assumptions of consumer need, and aligned to guidelines in the *Blueprint* (Mental Health Commission, 1998). However over time, some services had evolved to better meet consumer need, based on the beliefs of the service provider, and with some direction from their funding and planning manager. Other services had remained static in setting, philosophy and service delivery. This situation was not just a local issue but a national one and influenced at the upper levels of the Ministry of Health.

While mental health strategic documents had been updated and published, for example *Te Tahuhu* (Ministry of Health, 2005) and *Te Kokiri* (Ministry of Health, 2006), giving a description of the direction services should be taking, a critical component was missing. The service specifications that translated the strategies into operational service delivery were outdated; they had not been revised to reflect the recovery philosophy and the uniqueness of the lived consumer experience. Furthermore, the language used in the documents was inconsistent. This inconsistency in service contracts impacted dramatically on the way services were delivered.

Upon being seconded to the Ministry of Health, Mental Health Policy and Service Development Team, to lead a project to revise the mental health service specifications, I

applied new knowledge gained from the literature on consumer participation using a TAR methodology. In all, I was effectively putting new learning into action. I established a project structure where governance and operational structures were clear and documented in the terms of reference. I wanted to ensure that consumer participation was visible and consumer voices could be heard.

Armed with knowledge of stakeholder theory (Murdock, 2004) and Lewin's (1951) force field analysis I positioned the stakeholders strategically within the project structure. I had been informed that previous attempts to revise the service specifications had been abandoned mainly due to stakeholder engagement issues. Nonetheless, I was confident that stakeholder theory provided a strong framework to work from and I firmly believed that this review process could positively influence the way mental health services were delivered in the future.

Reflecting

An essential component of the first stage of the research project was to review documentation about provider organisational performance against service contracts and the service specifications and mapping using a UK model. At that time, I did not have any face to face communication with stakeholders. Consequently, the planning of the project required me to personally meet with the stakeholders who were described in the documentation, including the consumers of the social, recreational and prevocational services. As described in chapter six the consumer participants in the SRG were particularly outspoken and eager to give instructions.

The TAR methodology was instrumental in engaging SRG, including consumers, and facilitating focus groups in a relaxed and fluid way. Initially it was an exhausting experience which involved watching, waiting, and listening for cues as to when I should intervene without impacting the flow of conversation. Maintaining equilibrium in the group was essential so that all the stakeholders voiced their opinion. Most stakeholder groups had only one representative however, four consumer representatives were necessary to meet the requirements of the Consumer Network; consequently, at some meetings there was more discussion by the consumer participants than others. This was challenging because although I was eager to hear what they had to say; the potential changes as a result of this work, would impact all stakeholders so it was important to make sure no one 'voice' dominated the conversations. Dick (1996) suggested that AR

is useful to prepare and engage participants in change. This was endorsed when one of the consumer participants, moved to a new role with a DHB after this project. His/her job was to lead a team of consumers conducting consumer evaluations of the different mental health services within the DHB (Te Pou, 2008).

Summary of the findings

This research project has clearly shown that the consumer and his or her recovery process needs to be at the centre of the recovery system. Recovery is paramount (Antcliff, 2003), therefore the role of mental health services, including social, recreational and prevocational services, is to support the individual in his or her recovery journey. Recognising this shift from a medical paradigm to a recovery paradigm (Cowan, 2008), with consumers and their needs at the centre of the system of care, will ensure that care services are in the interests of the consumer. This stance is endorsed by the Ministry of Health's plan *Te Tahuhu improving mental health 2005-2015* (Ministry of Health, 2005).

The social, recreational, and prevocational services examined in this research, varied in terms of their implementation of a recovery approach. To build on the strengths of the individual with an emphasis on hope and self-determination recovery is defined as:

The process by which a person with mental illness makes sense of their experiences and learns how to make their life work for them, using tools available in society including the mental health services, which need to be based on a model of recovery (Cowan, 1998, p. 38).

Although it was commonly reported that the service was recovery focused, the standards varied significantly between service providers. Comments in the consumers' response to the questionnaire indicated that the programmes delivered by service providers did not take individual consumer's strengths, interests, and goals into consideration. Some services delivered standard programmes based on assumptions about what consumers wanted to do.

A comparison between the Lunch Bunch and a programme run in a community centre is a prime example. A consumer, who actively participated in the Lunch Bunch including finely slicing a tomato for a salad, sat in a corner at the community centre staring at the wall. When I approached and spoke with him at the community centre, he smiled but

said nothing. Out of concern, I asked staff at the community centre what he would be doing that afternoon. They replied that he just likes to sit, he was quite happy. At the community centre I saw little emotion in this individual, yet when participating in the Lunch Bunch activities he was smiling and keen to be engaged. This consumer's participation was clearly grounded in having active engagement in his own recovery. The Lunch Bunch programme built on individual strengths by engaging them in processes, including peer support, to achieve individual and group outcomes. Experiencing progression in personal recovery enables an individual to participate at other levels of care including planning, funding, and evaluation and monitoring (NIMHE, 2005a).

The consumer role in planning and funding

Drawing on the unique mental health lived experience is a valuable asset for both consumers and the services (Mental Health Commission, 2002). The resulting information can contribute positively to the funding and development of services that better meet consumers' needs. Consumer participants in this research conveyed useful ideas about what should be provided in terms of services and programmes to enhance their recovery.

This research has shown providers the benefits of mental health social, recreational and prevocational services from a consumer perspective. It also told them what consumers thought worked well and where there was room for improvement. The interview process, coupled with the questionnaire, demonstrated how easy it was to gain a consumer perspective to inform planning and funding. The application of the questionnaire showed funding and planning managers how simply and effectively consumers could be utilised to monitor services.

DHBs are required to monitor the provision of contracted mental health services (Ministry of Health, 2001b). Traditionally, this is done with regular audits undertaken by an audit agency. Consumers could readily inform that monitoring process with a questionnaire specifically designed to capture the opinion of consumers of social, recreational and prevocational mental health services. Thus, consumers could contribute to monitoring services in spite of the barriers to consumers participating in this way.

Key outcomes

Ultimately, the outcomes of this research raised awareness of the impact of inadequate service specifications at a national level. The evidence has been influential in bringing about major changes in practice at national, regional and local levels. The key result of this research project was to have the service specifications pertaining to the social, recreational and prevocational services revised, officially signed off and implemented at a local service level. Prior to this, some smaller DHBs had already undertaken a change process, consistent with *Te Tahuhu* (Ministry of Health, 2005). Their venture resulted in the closure of drop-in centres and the redirection of funding to more socially inclusive and purposeful activities. These DHBs were vindicated when the revised service specifications endorsed their direction. Other DHBs are now making the changes to ensure that all outdated service specifications are revised by 2012, and services are reconfigured, or the funding redirected. With services currently being reconfigured to meet the requirements of the nationwide services framework for mental health and addiction, this is an ideal opportunity for services to engage consumer participation in new ways of working.

To reinforce the new direction for social, recreational and prevocational services, I undertook a further step in the action by presenting the findings to providers nationally. Following this, one service provider decided to exit their service contract, in recognition of the fact that their service was not delivering to the required standard. It would seem current service provision in this instance was perceived to be unhelpful to consumers and so the mental health funding was reinvested in a more contemporary service within the sector.

Comparing the findings to other literature

In the course of this research I wanted to be inclusive and to create an environment in which participant consumers felt respected as equal peers. In order to do that I needed to understand the issues consumers have to cope with in their way of life.

Social inclusion

With regard to social inclusion, this research clearly showed the importance of ensuring that mental health providers do not practice in isolation as consumers cannot make progress in their recovery journey or readily get the support they need should they have a relapse, when there is no room for movement. These findings are consistent with

research done by Sutton (2008) which described recovery as the lived experience of personal growth and search for meaning after the onset of mental illness. Providers who focus on just one particular aspect of the social inclusion model as described by NIMHE (2003) need to construct smooth pathways to other providers, to ensure the consumer's needs are met at whichever point they may be in their recovery. Research confirms that social inclusion is supported through participation and furthermore, engaging in activities is an important medium for change as well as a recovery outcome in itself (Sutton, 2008).

In light of this improved knowledge I changed my style of managing meetings in an action step that caused me to move away from the rigid timetable in the documented agenda to become a responsive and flexible facilitator. This step which was intended to be more inclusive, added depth to the data. Reason and Bradbury (2006) suggested that AR is about the growth of individuals. Within the course of the meetings, that growth was evident both for me and the participants inasmuch as we gained new knowledge and shared understandings.

Valuing social inclusion, and addressing potential barriers to participation, helped me to understand that changing attitudes and approaches to consumer engagement would increase consumer confidence thus leading to improved benefits for consumers. Efforts to establish mental health facilities in neighbourhoods amidst discriminatory attitudes were described by Cowan (2003). However as the findings reveal with knowledge and understanding about mental health, attitudes can change.

Gaining insight into the reality of consumer interactions with the mental health care system, seeing first hand, the significant impact staff behaviour and attitudes had on the consumer's level of participation and engagement was revealing. When determining which consumers would participate in the questionnaire, some staff made discriminating and biased comments about certain consumers, which I found offensive. Opinionated comments were not restricted to staff, consumers' described staff as: "*Being bossy*" and "*need more empathy.*"

Good days and bad days were described as being dependent on the staff who were working at the time. It would seem that staff attitudes affected the tone of the day and staff who were keen, motivated and inspiring, enabled consumers to feel more

encouraged to participate. Thus staff and consumer relationship affected participation and ultimately, service outcomes.

Power dynamics and power imbalances

The literature described power imbalances between the consumer and the provider of a service, and the resultant effects on working relationships (Chinn, 2004; Sang, 2004). Good communication forms the basis of any relationship and sometimes poor communication, be it verbal or body language, reinforces a power imbalance (Habermas, 1984). This stance is endorsed by Kidd et al. (2007) whose study on consumer participation found that the attitudes and behaviours of clinicians towards consumers could be problematic, in as much as clinicians limited the scope of consumer participation.

Bourdieu (1984) developed four key concepts to help make sense of the power dynamics and relationships that occur in the social world. These concepts: species of capital, field, habitus, and symbolic violence provide a useful framework to examine the power dynamics and imbalance identified in my research project.

Bourdieu (1984) described species of capital under four types. Economic capital such as cash and assets; cultural capital developed through knowledge, experiences and reconnections; social capital from relationships and networks; and symbolic capital based on status or honour. A mental health consumer's journey may well mean that their economic capital is poor from periods of unemployment and low income. Their cultural and social capital may also be under-developed due to social isolation and reduced access to educational opportunities (NIMHE, 2005). The symbolic capital, should it exist, does not necessarily benefit a mental health consumer in the same way it would an individual without a mental illness. When an individual of status or honour has a mental illness, it is often hidden due to the stigma and discrimination that a mental illness brings. Subsequently the total capital for a mental health consumer is usually markedly less than a non-mental health consumer and even more so if the consumer is from another marginalised group, for example a Maori or Pacific ethnic group.

Bourdieu (1984) described 'field' as a centre or agency, and those who have a stake in the field are known as agents. In the mental health field stakeholders are primarily engaged in services as providers or consumers. Roles and responsibilities are allocated to agents according to Bourdieu based on their capital and in this in turn brings with it power. The mental health consumer does not have a sufficient level of capital to compete with other agents (service providers) and as a result falls into place at the lower end of the power hierarchy.

Habitus shapes the 'field' through internalisation of external structures. In this regard, Bourdieu (1984) suggested habitus constrains the field by shaping it in a sensible and practical way. When agents within the field are on an equal footing there is cohesion. When there is a mismatch between the agents some will feel disadvantaged, and they will not fit in. Symbolic violence is more likely when agents feel marginalised, or a poor fit in the field. This leads to domination by the more confident agents and submission by the marginalised agents.

In some instances, it would seem that the mental health consumers participating in this research had in many ways, accepted 'their lot'. They had doubts that their participation in service revision and the research per se would be recognised as having value. TAR processes demonstrated that their participation was crucial, alongside others, to challenge power dynamics in a useful and meaningful way. The findings confirm and complement a number of studies undertaken by researchers who make a similar claim (Chinn, 2004; Kidd, et al., 2007; Sang, 2004; Sutton, 2008).

Developing the capital described by Bourdieu (1984) was possible for consumers with programmes that were offered by some of the mental health social, recreational and prevocational services as described in earlier chapters. Acquisition of new knowledge and skills leading to further education and/or employment was a service outcome, developing consumers' economic capital. Additionally, some services were able to coach consumers in social etiquette and provide environments that built and fostered social relationships thereby developing an individual's social capital. An increase in capital according to Bourdieu (1984) meant an increase in power.

Environmental considerations

The environment was also shown to contribute to power structures (Sang, 2004). This finding concurs with theory and evidence which indicates that the environment influences actions (Habermas, 1989; Sang, 2004). Here I will use a sporting analogy to explicate my meaning. Often it is perceived that a home team has an advantage because they are playing on their own sports ground. This notion is reinforced by reports of success being experienced by teams when they play in front of their home crowd, at their home ground. So it is for the health professional or service provider and the consumer. An environment in which the consumer is comfortable and receiving the right support is conducive to achieving a balance of power and reducing tensions in order for the consumer to feel confident about participating. On occasion, during the research process, I was aware of power imbalances and consequently had to try and establish a relaxed rapport with the consumer participant. Knowing tension would negatively affect my questionnaire results I felt it important to meet consumers on their terms and to establish a platform from which to build positive relationships. In my observations, provider settings with an apparent power imbalance negatively affected the tone and culture of the service.

The lived consumer experience

The value of embracing the unique 'lived' consumer experience was evident throughout this project and gave me a revealing insight to their world. Their eagerness to make choices and to determine their way of life was instructive. The saying, 'nothing about me without me' is grounded in this sentiment.

Interestingly, a study which explored clinicians' perceptions of consumer roles in rural mental health services found that some mental health professionals supported consumer participation but only in certain situations (Kidd et al. 2007). Similarly, this research found that support for the uniqueness of the lived experience varied amongst settings, service providers and individuals. Some clinical staff reported that they did not feel comfortable telling their colleagues they had lived consumer experience fearing it would affect their employment and as a result they would experience discrimination and stigma. Equally, some staff in specific consumer roles indicated that although mental illness was in their job title, they believed they were excluded from certain aspects of service decision making.

Alternatively, one service provider reported that staff, who did not have a health background, looked to consumers to support each other using their own lived experience. Consumers endorsed this approach and regarded it as beneficial to their recovery.

Implications for mental health service delivery

This research has demonstrated four important messages for planning and funding divisions. First, planning and funding managers need to engage with, and listen to, consumers. They are a valuable yet under-utilised resource. Second, health professional and lay staff require training and education to fully grasp the benefits of supporting consumer participation in service review or questionnaire process. This is key to facilitate change in attitudes. Third, when engaging consumers in a review or questionnaire process, they need time and resources to conduct pre-requisite training to ensure they are well prepared and confident to undertake the task. Fourth, when providing information to participants, the purpose and perspective presented in the information must be considered as there is the potential for bias in the choice of information presented.

Limitations of the project

The project was limited in terms of its stakeholder requirements. The DHBs wanted the project undertaken within a tight timeframe to inform their contracting processes. This created pressure in terms of scheduling meetings and consumer interviews in a short space of time. In excess of 50 consumer participants may well have been recruited to engage in the process if more time had been allowed.

The failure of the quantitative data collection due to the Ministry of Health reporting systems and inconsistent definitions was limiting. With the new national service specifications and purchase unit codes, more reliable data would now be available if this project was repeated.

Further research

This project, with its focus on consumer participation, identified a number of areas that would benefit from further research. Evidence of consumers being involved in service planning, assessment and in some cases service evaluation was found however, there

was little evidence of their effectiveness in these roles. Evaluation of the effectiveness of consumer participation would be useful for future reference.

Research in Australia (Happell, Pinikahana, & Roper, 2002) showed that the attitudes of stakeholder groups were barriers to consumer participation in services. Once that was confirmed, services sought to address those attitudes and to increase the quality and quantity of consumer participation in services. In New Zealand, there is anecdotal evidence that similar attitudes prevail here but, without research confirming this state of affairs, it is challenging to implement programmes designed to tackle discriminatory stakeholder attitudes. Therefore a study exploring stakeholder attitudes in New Zealand would be informative.

DHBs indicate they have been engaging consumers in participatory activities for some time. Alternatively, discussions with consumers reveal that engagement varies nationwide. Research evaluating the levels of engagement would also inform future developments in consumer participation.

Members of a national New Zealand mental health network for consumers have been in discussions with DHBs recently to consider how to shape on-going service monitoring and auditing. Research designed to assist them to determine an effective approach using a tailored questionnaire and focus groups would be worthwhile, as the findings of such a study would usefully inform practice.

Conclusion

The question being explored in this research asked: How can consumer participation contribute to the monitoring of mental health service performance? Consumer participation has been shown to offer a unique and valuable contribution to the system of care in New Zealand's mental health service delivery by anchoring service provision in the needs of individuals who use the service.

By sharing their unique perspective, consumers in this research project showed that in addition to aiding recovery, inclusion was timely and cost effective. Moreover, the participants demonstrated a willingness to undertake roles and a range of tasks that

would significantly increase and enhance the monitoring of the effectiveness of service provision.

This research clearly shows that consumers have a vital role to play in helping to shape the future of mental health service provision to ensure that the services effectively meet individual needs. To exclude their voice would be to miss the most important message of all.

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Appendices

Appendix A

8 August 2005

Ms Rozlyn Sorensen
54 Black Teal Close
Unsworth Heights
Albany
Auckland.

Dear Roz,

**NTX/05/06/050 Implementing the blueprint in the New Zealand mental health sector
measuring the performance and outcome of social, recreational and
prevocational mental health services: PIS/Cons V# 3, 16/07/05.**

Thank you for your resubmitted application, received 18 July 2005 and for again attending the meeting on Wednesday 3 August.

The above study has now been given ethical approval by Northern X Ethics Committee for the Northern Region.

It is understood that although the research is to be conducted out of the Waitemata DHB, a letter has gone to the Auckland, Northland and Counties-Manukau DHBs for the study to be conducted there as well.

Approval is subject to final Waitemata DHB Maori Research Review Committee approval (interim is received).

It should be noted that Ethics Committee approval does not imply any resource commitment or administrative facilitation by any healthcare provider, within whose facility the research is to be carried out. Where applicable, authority for this must be obtained separately from the appropriate manager within the organisation.

Certification

It is certified as not being conducted principally for the benefit of the manufacturer or distributor and may be considered for coverage under ACC.

Accreditation

This Committee is accredited by the Health Research Council and is constituted and operates in accordance with the Operational Standard for Ethics Committees, March 2002.

Documents Approved:

- Information Sheet/Consent Form: Group One: Provider Organisation, V#3, 16/07/05.
- Information Sheet/Consent Form: Group Two: Stakeholder Reference Group, V#3, 16/07/05
- Information Sheet/Consent Form: Group Three: Consumer Group, V#3, 16/07/05.
- Provider Questionnaire.

Progress Reports

The study is approved until 8 August 2006 (to cover writing up and reporting). A progress report is required for this study by that date

A form should come off our database requesting this information two months prior to the review date but if a form is not received, it is still your responsibility to provide a progress report and this may be obtained from the website below. Please note that failure to complete and return this form may result in the withdrawal of ethical approval.

Please advise the Committee when the study is completed and under the ethical approval process, final report is also required at the conclusion of the study.

Requirements for SAE Reporting

Please advise the Committee as soon as possible if there are any serious adverse events that may relate to this study.

General:

All amendments to the study must be advised to the Committee prior to their implementation, except in the case where immediate implementation is required for reasons of safety. In such cases the Committee must be notified as soon as possible of the change.

Yours sincerely,



Pat Chainey
Administrator, Northern X Committee

Cc: Waitemata DHB
Auckland DHB Research Office
C-M DHB Research Office.

NORTHERN X ETHICS COMMITTEE

DATE OF MEETING

1 June 2005

Tim Dare, PhD	<i>Lect.Ethics PHD Ethicist, LLB UoA, Scl of Philosophy, :BA(Hons)</i>	Ethicist, Chairperson	Present
Adina Halpern, Solicitor,	<i>LLB, BA Law (Hons), (Consultant)</i>	Lawyer	Present
John France, <i>Reproductive Scientist, PhD (Dr of Philosophy) DSc FAACB, Univ. of Auckland (Retired). PhD(Philosophy), DSc, FAACB</i>		Researcher	Present
Patricia Hanlen	<i>Mstr. Social Work</i>	Community Representative	Present
Jeffrey Harrison	<i>PhD. DipClinPharm</i>	Pharmacologis/Pharmacistt	Present
Scott Macfarlane	<i>MBchB.FRACP, BSc</i>	Health Practitioner	Present
Emma Ngawhare	<i>NZDipBusStudies</i>	Consumer Representative Maori	Present
Robyn Northey	<i>MA(Hons) Social Welfare & Dev.</i>	Consumer Representative	Present
Stephanie Palmer	<i>PhD</i>	Researcher, Maori	Present
Louisa Wall	<i>Mphil(Social Policy)</i>	Community Representative	Present

The total Ethics Committee is responsible for the decisions taken.

Committee members, who may have a conflict of interest in any of the proposals being considered by the committee, must declare that interest and excuse themselves from any part of the discussion relating to that proposal.

Appendix B



8th March 2012

Roz Sorensen
National Health Board
Ministry of Health
Email: Roz_Sorensen@moh.govt.nz

Bupa Care Services Ltd
Level 5, Bupa House
5-7 Kingdon Street, Newmarket
PO Box 113-054
Auckland 1149

Tel 64 9 985 9700
Fax 64 9 985 5578
www.bupa.co.nz

Dear Roz

I wish to confirm that as CEO of the Waitemata District Health Board, I granted approval for the study to occur as part of your doctoral research, and subject to final approval by the Northern Region Ethics Committee.

I was satisfied that the processes you adopted would suitably safeguard the interests of any participants in the research.

This note confirms the original approval that I gave you in writing at the time.

Yours Sincerely

Dwayne Crombie
Managing Director

Appendix C

26 July 2005

Dr Cheryl Waters
KG05.04.97
Faculty of Nursing, Midwifery and Health
UNIVERSITY OF TECHNOLOGY, SYDNEY

Dear Cheryl,

UTS HREC REF NO 2005-0043 – WATERS, Dr Cheryl, WHITE, Professor Edward, (for SORENSEN, Ms Rozlyn, Doctor of Nursing student) - “Implementing the Blueprint in the New Zealand Mental Health Sector Measuring the performance of Social, Recreational and Prevocational Mental Health Services”

Thank you for your response to my email dated 20 May 2005. Your response satisfactorily addresses the concerns and questions raised by the Committee, and I am pleased to inform you that ethics clearance is now granted.

Your clearance number is UTS HREC REF NO. 2005-043A

Please note that the ethical conduct of research is an on-going process. The *National Statement on Ethical Conduct in Research Involving Humans* requires us to obtain a report about the progress of the research, and in particular about any changes to the research which may have ethical implications. This report form must be completed at least annually, and at the end of the project (if it takes more than a year). The Ethics Secretariat will contact you when it is time to complete your first report.

I also refer you to the AVCC guidelines relating to the storage of data, which require that data be kept for a minimum of 5 years after publication of research. However, in NSW, longer retention requirements are required for research on human subjects with potential long-term effects, research with long-term environmental effects, or research considered of national or international significance, importance, or controversy. If the data from this research project falls into one of these categories, contact University Records for advice on long-term retention.

If you have any queries about your ethics clearance, or require any amendments to your research in the future, please do not hesitate to contact the Ethics Secretariat at the Research and Commercialisation Office, on 02 9514 9615.

Yours sincerely,

Professor Jane Stein-Parbury
Chairperson

Appendix D



Te Poari Tautoko I Nga Rohe Ki Te Raki

Northern DHB Support Agency Ltd

Working with District Health Boards towards excellence in

Health and Disability services

To :	Funding and Planning Managers, Mental Health Divisions ADHB, WDHB, CMDHB, NDHB
Cc:	GM Funding, DHB Research Centres
From :	Roz Sorensen, Project Manager/ Researcher
Date :	16 July 2005.
Re:	Social, Recreational and Prevocational Services Project Phase Two

I met with you and provided a presentation to you about this proposed project at a Regional Mental Health Funding Team meeting in December of last year. The project is currently progressing ethics approval processes.

This project, as you are aware is part of a programme of service improvement in the Northern region (Metro Auckland and Northland), by the Northern DHB Support Agency (NDSA) on behalf of the four District Health Boards.

The Social Recreational and Prevocational services as you know, are provided under contract to District Health Boards by Non Government organisations (NGOs) and form part of the continuum of mental health services provided by District Health Boards to their populations. The cost of these service contracts is approximately \$5.1m per annum. The volume of service contracted for is variable within individual District Health Boards throughout the Northern Region.

Preparations for Phase two of the project began in November of last year and the project itself is due for completion by November 2005. This work will also be part of my Doctor of Nursing programme that I am undertaking at University of Technology Sydney (UTS).

The key objectives of this phase of the project will be to:

- *increase the capacity of DHB mental health funders and planners to monitor service performance*
- *provide direction to mental health funders and planners in future funding and configuration of these services.*

The project is in three parts.

Part One: Provider Organisations- Quantitative and Qualitative Data Analysis

The first part focuses on the 32 provider organisations. Data about the providers and the services they deliver (collected in phase one of the project conducted by the NDSA) will be analysed. A statistical study would also be conducted on data submitted by these organisations as part of their routine Ministry of Health reporting requirements, using Data Envelopment Analysis (DEA) methodology. DEA has over the past two decades emerged as an important tool in the field of efficiency measurement. DEA is used to compare Decision Making Units (DMUs) such as individuals or groups of individuals which use one or more inputs to secure one or more outputs. The DMUs use the same inputs and secure the same outputs but generally at varying levels. There is widespread acceptance of DEA as a management tool. The revenue funded will be compared with application of resources to provide a service, with attention to workforce.

Part Two: Stakeholder Reference Group- Technical Action Research

The second part focuses on the stakeholder reference group and cycles of technical action research. The researcher would lead the group in a review of standardised consumer self assessed measurement tools. The Health Research Council has published a number of documents aligned with The Mental Health Research and Development Strategy that will be used. (The tools will be considered and a specific tool selected for application using the stakeholder reference group and technical action research action cycles. Technical Action Research methodology will bring together the perspectives of the different stakeholders and enlarge the stock of knowledge. With that knowledge the group will collaboratively problem solve. Thus achieving a tool to test, that is considered to best reflect the requirements of the group of services. It is likely that specific tools will be sought for Kaupapa Maori and Pacific programmes in addition to a tool for mainstream services. This would be decided by the stakeholder reference group. (HRC research suggests cultural specific approaches are more useful)

Part Three: Consumer Group- Qualitative approach

The third part focuses on testing the standardised consumer self assessed measurement tool with a group of consumers. The consumers will be currently users of the contracted social, recreational and prevocational services. They will be invited to participate and assess the outcomes of the service that they access.

The expected timeframe for the delivery of this project is:

Quantitative data analysis on previously submitted data (using DEA) and qualitative data from phase one analysis (August)

Stakeholder reference group meetings (August- September)

Consumer Qualitative Outcomes Study (October)

Collate results, produce report, presentations (November)

If you have any concerns about this project please contact me on ph 09 486 8920 ext 3746 or mobile 021 346 943 or email roz.sorensen2@waitemataDHB.govt.nz.

You may also contact my academic supervisor Dr Cheryl Waters, University of Technology Sydney, Sydney ph 0061 2 951457 41 or email Cheryl.Waters@uts.edu.au.

You may also contact Derek Wright, Regional Director of Mental Health and Addictions on ph 09 580 9000 or email: derek.wright@ndsa.co.nz

You may also contact Gary Brown, Tihi ora, MaPo on ph 09 3661993 or email garyb@tihiora.co.nz

You may also contact
Health and Disability Commissioner:
Ph/TTY: 0800 11 22 33

Website: www.hdc.org.nz

To contact an advocate call the service in your area.

Upper North Island
0800 555 050

I will be seeking a mandated representative from the Regional Mental Health Funding Team to participate in the stakeholder reference group.

Looking forward to meeting with you again to discuss the project further.

Yours sincerely

Roz Sorensen

Appendix E

Project Brief

Title	Social, Recreational and Prevocational Services
Prepared by	Roz Sorensen
Project Sponsor	Frank Tracey
Project Manager	Roz Sorensen
Date	13 October 2004

Recommendations	That this project brief be accepted
Project Objectives	<p>To increase the capacity of the Funder to monitor services performance in meeting the needs of service users, by the application of DEA methodology and analysis.</p> <p>To support a mental health outcomes focused approach that is consistent with the Blueprint.eg Quality of Life Skills Profile.</p> <p>To enhance better outcomes for mental health consumers through provision of an accessible service that sits within the continuum of care.</p>
Background	<p>A review of these services was conducted on behalf of the Northern region DHBs.</p> <p>The review was to determine the mode and effectiveness of the services and to establish whether they were incorporated into the continuum of care. It was also to look at opportunities to maximise the outcomes for the money spent by both health and other agencies.</p> <p>The review found that a total of \$5.1 million was spent on 32 contracted Social and Recreational and Prevocational mental health services.</p> <p>Other findings can be grouped:</p> <p>Service Delivery- reliant on specialist tutors funded by one off grants and volunteers, qualifications vary, avoid waiting lists</p> <p>Access Management- referral processes vary, main entry criterion is 18-65 years with a mental illness.</p> <p>Legislative and Contractual- overall services recognised the standards, some working towards accreditation, complied with safety regulations.</p> <p>Enhancing Outcomes- main reasons for exiting were positive however varied methods for measuring quality outcomes</p> <p>Reporting- current reporting methods don't reflect service performance.</p>
Accountability	WDHB Funding and Planning

	Regional Sponsor, NDSA - Frank Tracey Technical Support from the Auckland Regional Benchmarking Group.
Assumptions	Services will continue to be delivered as per current contracts
Key Milestones and time line	<p>October – Nov 2004. Preparation</p> <p>Document information about the 32 providers of Social, Recreational and Prevocational Services in the Auckland region. Prepare ethics proposal for University of Technology, Sydney. Link with Regional Benchmarking Group and Technical Advisors Meet with Auckland University advisor to Regional Benchmarking Group. Get Project Sign off at Line Management and Regional level. Confirm local ethics requirements Communicate project intentions to key stakeholders.</p> <p>Nov-January 2005 Literature Review</p> <p>Survey the literature locally, nationally and internationally and relevant documentation and correspondence. Prepare findings grouped in key themes. Provide presentations to key stakeholder groups regarding project</p> <p>Jan- Feb 2005 Explore DEA Measurement/ Performance Methodology.</p> <p>Consider the methodology as used in the Health sector. Consider previous specific Health focused projects Identify the key inputs and desired outputs that would best reflect the Social, Recreational and Prevocational Services. Confirm with Technical Advisors and Sponsor Set up data requirements.</p> <p>March- July 2005 Analysis based on DEA</p> <p>Collect data Analyse data Prepare findings Validate with Technical Advisors Validate with Provider Management Workshop- do providers find this useful, agree with results, how would they intend to use it.</p> <p>July- August 2005 Qualitative Study to validate DEA findings</p> <p>Identify key informants for semi structured interviews Prepare interview questions Conduct interviews Analyse information</p> <p>September- October 2005 Collate Results</p> <p>Write up findings, conclusions and recommendations. Communicate first draft to sponsors and technical advisors. Amend where necessary. Final draft.</p>

Appendix F



Northern DHB Support Agency Ltd

Working with District Health Boards towards excellence in

health and disability support services

Consent Form

Group One: Provider Organisations

REQUEST FOR INTERPRETER

English	I wish to have an interpreter.	Yes	No
Maori	E hiahia ana ahau ki tetahi kaiwhakamaori/kaiwhaka pakeha korero.	Ae	Kao
Cook Island	Ka inangaro au i tetai tangata uri reo.	Ae	Kare
Fijian	Au gadreva me dua e vakadewa vosa vei au	Io	Sega
Niuean	Fia manako au ke fakaaoga e taha tagata fakahokohoko kupu.	E	Naka i
Samoan	Ou te mana'o ia i ai se fa'amatala upu.	Ioe	Leai
Tokelau n	Ko au e fofou ki he tino ke fakaliliu te gagana Peletania ki na gagana o na motu o te Pahefika	Ioe	Leai
Tongan	Oku ou fiema'u ha fakatonulea.	Io	Ikai

I (participant's name)
of (name of organisation)
agree to participate in the research project *Measuring the performance and outcomes of mental health social, recreational and prevocational services*, otherwise known as *Social, Recreational and Prevocational Services Project, Phase two*, being conducted by Rozlyn (Roz) Sorensen, ph. 09 4868920. Funding for this research has been provided by Northern DHB Support Agency (NDSA).

I have read and understand the information sheet dated 16 July 2005.
I also understand that the purpose of this project is to select and test tools that measure the performance and outcome of social, recreational and prevocational services.
The findings will assist Mental Health Funders and Planners make informed funding decisions about this group of services.

I understand that my participation in this project, will involve my consent for the data that was collected from my organisation during an interview which involved the completion of a questionnaire in phase one of the Social, Recreational and Prevocational Review conducted by the NDSA to be used for qualitative analysis. In addition the data submitted by my organisation to the Ministry of Health as part of regular quarterly reporting of output data pertaining to social, recreational and prevocational services, during a twelve month period, will be used for quantitative analysis with my consent.

I am aware that I can contact Rozlyn (Roz) Sorensen if I have any concerns about the project. I also understand that I am free to withdraw my participation from this project at any time I wish, without consequences, and without giving a reason.

I agree that Rozlyn (Roz) Sorensen has answered all my questions fully and clearly.

I agree that the research data gathered from this project may be published in a form that does not identify me in any way.

Further to this, I am able to contact the following if I have any questions:

Academic supervisor
Cheryl Waters
University of Technology Sydney
Sydney
Ph. 0061 2 9514 57 41
Cheryl.Waters@uts.edu.au

Field Supervisor
Derek Wright
Regional Director
Mental Health and Addictions
Northern District Health Board Support Agency
Auckland
Ph. 09 5809000
derek.wright@ndsa.co.nz

Cultural Supervisor
Gary Brown
Tihi ora MaPo
Ph. 09 366 1993
garyb@tihiora.co.nz

Version No. 3
Consent Form
Group One
16 July 2005.

2

Appendix G



Northern DHB Support Agency Ltd

Working with District Health Boards towards excellence in
health and disability support services

Consent Form

Group Two: Stakeholder Reference Group

REQUEST FOR INTERPRETER

English	I wish to have an interpreter.	Yes	No
Maori	E hiahia ana ahau ki tetahi kaiwhakamaori/kaiwhaka pakeha korero.	Ae	Kao
Cook Island	Ka inangaro au i tetai tangata uri reo.	Ae	Kare
Fijian	Au gadreva me dua e vakadewa vosa vei au	Io	Sega
Niuean	Fia manako au ke fakaaoga e taha tagata fakahokohoko kupu.	E	Naka i
Samoan	Ou te mana'o ia i ai se fa'amatala upu.	Ioe	Leai
Tokelau n	Ko au e fofou ki he tino ke fakaliliu te gagana Peletania ki na gagana o na motu o te Pahefika	Ioe	Leai
Tongan	Oku ou fiema'u ha fakatonulea.	Io	Ikai

I.....(participant's name)
Representing.....(stakeholder group)
agree to participate in the research project *Measuring the performance and outcomes of mental health social, recreational and prevocational services*, otherwise known as *Social, Recreational and Prevocational Services Project, Phase Two*, being conducted by Rozlyn (Roz) Sorensen, ph. 09 4868920. Funding for this research has been provided by Northern DHB Support Agency (NDSA).

Version No. 3
Consent Form
Group Two
16 July 2005.

1

I have read and understand the information sheet dated 16 July 2005.

I also understand that the purpose of this project is to determine and test tools that measure the performance and outcome of social, recreational and prevocational services. The findings will assist Mental Health Funders and Planners make informed funding decisions about this group of services.

I understand that my participation in this research is part two of a three part project. It will involve my attendance at a series of stakeholder reference group meetings, lasting 90 minutes over two months. This means a total of 4 meetings.

The purpose of these meetings is to select a standardised consumer self assessed outcome measurement tool to be tested by consumers of Social, Recreational and Prevocational services in the Northern region. Technical action research methodology will be used to capture the activities and interactions to select the tool. The resources produced by the Health Research Council will provide a menu of tools to choose from.

I am aware that I can contact Rozlyn (Roz) Sorensen if I have any concerns about the project. I also understand that I am free to withdraw my participation from this research project at any time I wish, without consequences, and without giving a reason.

I agree that Rozlyn (Roz) Sorensen has answered all my questions fully and clearly

I agree that the research data gathered from this project may be published in a form that does not identify me in any way.

If I have further questions I may also contact:

Academic Supervisor
Cheryl Waters
University of Technology Sydney
Sydney
Ph. 0061 2 9514 57 41
Cheryl.Waters@uts.edu.au

Field Supervisor
Derek Wright
Regional Director
Mental Health and Addictions
Northern District Health Board Support Agency
Auckland
Ph. 09 5809000
Derek.wright@ndsa.co.nz

Version No. 3
Consent Form
Group Two
16 July 2005.

2

Appendix H



Northern DHB Support Agency Ltd

Working with District Health Boards towards excellence in

health and disability support services

Consent Form

Group Three: Consumer Group

REQUEST FOR INTERPRETER

English	I wish to have an interpreter.	Yes	No
Maori	E hiahia ana ahau ki tetahi kaiwhakamaori/kaiwhaka pakeha korero.	Ae	Kao
Cook Island	Ka inangaro au i tetahi tangata uri reo.	Ae	Kare
Fijian	Au gadreva me dua e vakadewa vosa vei au	Io	Sega
Niuean	Fia manako au ke fakaaoga e taha tagata fakahokohoko kupu.	E	Naka i
Samoan	Ou te mana'o ia i ai se fa'amatala upu.	Ioe	Leai
Tokelau n	Ko au e fofou ki he tino ke fakaliliu te gagana Peletania ki na gagana o na motu o te Pahefika	Ioe	Leai
Tongan	Oku ou fiema'u ha fakatonulea.	Io	Ikai

I (participant's name)
agree to participate in the research project *Measuring the performance and outcomes of social, recreational and prevocational mental health services*, otherwise known as *Social, Recreational and Prevocational Services Project, Phase Two*, being conducted by Rozlyn (Roz) Sorensen, ph. 09 4868920.

Funding for this research project has been provided by Northern DHB Support Agency (NDSA).

I have read and understand the information sheet dated July 2005, for volunteers to participate in this research project. I understand that the design of the research project is to determine and test ways of measuring the usefulness of social, recreational and prevocational services. These are the services that are provided for people that experience mental health issues. They include day programmes, support groups, networking groups, sports and cultural activities, educational opportunities and job training and preparation. The findings of this project are expected to assist Mental Health Funders and Planners to make decisions about providing services like this in the future.

I have had the opportunity to ask questions about this research project and am happy with the answers that I have received. In addition I have been able to bring a family/whanau member or a friend to help me with the questions and to understand the research project.

My participation in this research will involve me completing a questionnaire about the social, recreational or prevocational services that I am receiving. It is likely to take me thirty minutes to complete this questionnaire.

I am aware that I can contact Rozlyn (Roz) Sorensen if I have any concerns about this research project. I also understand that I am free to withdraw my participation from this research project at any time I wish, without consequences, and without giving a reason. I understand that I can stop completing the questionnaire if the questions make me feel uncomfortable. Such action will in no way affect me continuing to receive the current service.

I have had time to consider whether to take part

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

I agree that Rozlyn (Roz) Sorensen has answered all my questions fully and clearly.

If I have further questions I may also contact:

Academic Supervisor
Cheryl Waters
University of Technology Sydney
Sydney
Ph. 0061 2 9514 57 41
Cheryl.Waters@uts.edu.au

Appendix I



Northern DHB Support Agency Ltd

Working with District Health Boards towards excellence in health and disability support services

7 April 2005.

To whom it may concern

Re: Mental Health Social, Recreational and Prevocational Services Project

As part of a programme of service improvement in the Northern region of New Zealand (Auckland City and Northland), the Northern DHB Support Agency (NDSA) on behalf of the four District Health Boards in the region commissioned a review of the Social Recreational and Prevocational Service sector (SRPS). Phase one, of this two phase process, began in November 2003 and concluded in September 2005.

The SRPS services are provided under contract to District Health Boards by Non Government organisations (NGOs) and form part of the continuum of mental health services provided by District Health Boards to their populations. The cost of these service contracts is approximately \$5.1m per annum. The volume of service contracted for is variable within individual District Health Boards throughout the Northern Region.

The overall aim of phase one of the project was to determine the scope, mode and effectiveness of current service delivery. The data derived from this piece of work was used to assist DHBs in their planning to enhance and develop the continuum of care and better integrate existing Mental Health Services with other government funded health, social and recreational services in the region.

Preparations for Phase two of the project began in November of last year and the project itself is due for completion by the end of September 2005.

The work will be undertaken on behalf of District Health Boards/NDSA by Roz Sorensen. This work will also be part of Doctor of Nursing programme that Roz is undertaking at University of Technology Sydney (UTS). Her Supervisor is Cheryl Waters at UTS, ph. 9514 57 41 or email Cheryl.Waters@uts.edu.au

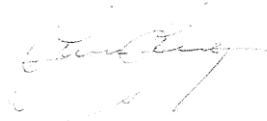
The key objectives of this phase of the project will be to;

- increase the capacity of DHB mental health funders and planners to monitor service performance
- provide direction to mental health funders and planners in future funding and configuration of these services.

The project deliverables for phase two will help ensure that DHBs in the northern region are purchasing a type of service that appropriately targets the mental health population and promotes better outcomes for mental health consumers by supporting recovery and subsequently enriching the lives of those involved.

Further detail regarding the project scope and deliverables are provided in the appendix to this document.

Yours sincerely

A handwritten signature in dark ink, appearing to read 'Frank Tracey', with a stylized flourish at the end.

Frank Tracey
Manager Mental Health
Northern District Health Board Support Agency (NDSA)

Cc Roz Sorensen (Project manager)

Appendix J



Northern DHB Support Agency Ltd

Working with District Health Boards towards excellence in health and disability support services

3 October 2005.

People Accessing Services

You are invited to participate in a project that involves answering a list of questions. The questions are about you and your experiences in relation to accessing social, recreational and prevocational services.

The list of questions will take about 30 minutes for you to answer and you are welcome to bring a support person with you.

The questions would be answered here at the place where you currently receive a service.

Your views are important to us and this process will demonstrate the benefits of your participation.

For more information about this contact your service administrator or Roz Sorensen, Project Manager on ph 09 486 8920 ext 3746.

Appendix K

Appendix B: Selected Organisations

Where Consumer Self Assessed Measurement Tool was used.

Test tool	Name of Organisation	PU code	No. clients To test	DHB
Wellness Outcome	Te Ata	MHCS21.1	5	WDHB
Wellness Outcome	Consumer Network	MHCS21.1	5	ADHB
Wellness Outcome	Arahura Charitable Trust	MHCS21.1	5	ADHB
Wellness Outcome	Challenge Trust	MHCS21.1	5	CMDHB
Wellness Outcome	Regional Work Rehab	MHCS14 MHCS14C	5	WDHB
Wellness Outcome	Richmond Fellowship	MHCS14C	5	ADHB
Wellness Outcome	Day Springs Trust	MHCS 16C	5	WDHB
Wellness Outcome	Mt Albert Community Centre	MHCS 16C	5	ADHB
Wellness Outcome	Te Korowai Aroha	MHCS 16C	5	CMDHB
Wellness Outcome	Maranga House	MHCS 16C	5	ADHB

List of 24 Providers that participated in First Stage of the Research Project

Arahura Charitable Trust
Auckland Refugees as Survivors Charitable Trust
Baptist Action (Te Korowai Arohoa)
Challenge Trust
Council for Mental Well-Being Trust (Consumer Network)
Dayspring Trust
Eating Disorders Association (NZ) inc.
Framework Trust
GROW New Zealand inc.
Maranga House Trust
Mind and Body Consultants
Nga Morehu Whaiora
Northland Mental Health Trust
Pacificare Trust
Postnatal Psychosis Charitable Trust
Richmond Fellowship New Zealand inc.
The Cottage Farm Trust
The Mt Albert Community Club inc.
The Phobic Trust of New Zealand inc.
Toi Ora Live Art Trust
West Auckland Living Skills Homes Trust
West Auckland Mental Health Support Trust (Te Ata)
Whau Valley Whaiora Support Trust
Work Enterprises (Regional Work Rehab)

Appendix L

(Developed by G.D. Bridgman, re-formatted for use by Regional Mental Health Team, October 2005)

For each question tick one box in the first group. If you tick no change check whether there has been change for other reasons (second group). In the third group tick one box to show the amount of support you need in this area.

To what extent has the involvement of service in your life means you are:

	(in this area due to service)				(due to other things)			(to what extent do you need support)			
	Much better	better	No change	worse	Much worse	better	worse	No support needed	Small support	Regular consistent support	Long term support
1. You are having more fun											
2. You are more confident about future plans											
3. You have more control over the choices in your life											
4. You are more normal or like you used to be before you became unwell											
5. You are more content, calm or happy											
6. You are less anxious or stressed											
7. You have more spiritual strength or wairua											
8. You have more awhi or trust in people											
9. You feel more aroha or love from others											
10. You have a stronger connection with your culture, whakapapa or ancestral background ie Maori, New Zealand, Samoan, Hindu, Jewish											
11. You are able to behave in a more socially acceptable and responsible way											
12. You are better treated & more accepted by the community in which you live											

	Much better	better	No change	worse	Much worse		better	worse		No support needed	Small support	Regular consistent support	Long term support
13. You are more clear and consistent in your thinking													
14. You are more able to live more independently													
15. You are more able to do the basic tasks of day to day living (eg getting up, feeding yourself, keeping tidy)													
16. You are more able to live without abusing drugs or alcohol													
17. You have less unpleasant side effects from the use of medication													
18. You have less psychotic symptoms (hearing voices, seeing visions, bizarre or grandiose thoughts)													
19. You are better prepared or trained for work, or better able to manage work													
20. Your personal safety at home or in the community has improved													
21. Your relationship with friends, whanau and family has improved													
22. You are able to live with less involvement from mental health services													
23. All aspects of your life are more in balance or harmony													

24. What have been the least helpful aspects of your contact with the service?	
25. What have been the most helpful aspects of your contact with the service?	
26. Where things have changed without the service's involvement can you tell us why?	
27. How do you think the service offered could be improved?	

Page 12 of 12
 Page 12 of 12
 Page 12 of 12

Appendix M



This is to certify that

Roz Sorensen

has completed

Social Inclusion-Focus on Education

by Blueprint Centre for Learning

Date: 11th October 2005

Signed

A handwritten signature in black ink, which appears to be "D. Morris", is written over a horizontal line. Below the line, the name "David Morris" is printed in a standard font.

Dedicated to training in mental health

Appendix N

Australian Technology Network

*Curtin University of Technology
Queensland University of Technology
Royal Melbourne Institute of Technology
University of South Australia
University of Technology, Sydney*

Learning Employment Aptitude Program (ATN LEAP)
for ATN Postgraduate Research Students

Rozlyn Sorensen

has participated in the ATN LEAP module on PUBLIC POLICY.
The aim of this module is to:

- Understand public policy debates in Australia, the dynamics and politics of the policy making processes and the extent to which research influences that process
- Develop and enhance skills in putting together research proposals and in carrying out research projects
- Develop employability and career development skills and knowledge



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"Public Policy" was developed and coordinated by RMIT
as its contribution to the ATN LEAP program.
Postgraduate Research Students from the ATN universities participated in this module.

This 10 week online module addresses:
The public policy environment in Australia; the public policy process through a case study of water; how to formulate a research grant application for project funding; the relationship between research and public policy.