

Services Under Challenge

Critical success factors in meeting high and complex needs of people in mental health care

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Commissioner's Foreword

The functions of the Mental Health Commission are listed in the Mental Health Commission Amendment Act 2007. One of the functions is to support providers of mental health and addiction services in developing integrated, effective and efficient methods of providing care that meets the need of their communities. Another of our functions is to act as an advocate for service users, and a third is to undertake research. By supporting the Mental Health Foundation, we have achieved all three functions in this research.

The focus of this report is predominantly on mental health services, although often people are identified as having high and complex needs because they experience both mental health and addiction disorders, and so we believe the research is relevant for those using or working in addiction services.

The people with high and complex needs are a small population. The definition of 'high and complex needs' is not clear and so the number of this small population is not known precisely. What this report seeks to do is to provide a perspective from that small group about the aspects that make services successful.

This research shows that addressing high and complex needs is not just the role of health services; stable housing and income are also determinants of wellness. The Commission believes strongly that intersectoral work is essential, and we seek more collaboration between organisations such as Housing New Zealand, Work and Income and the Ministry of Justice.

For some, this report will require a paradigm shift in their thinking and will be challenging. Out of the challenge, we hope that we can develop what one of the respondents refers to as a 'corporate attitude of hopefulness'. We believe that, if services provide hopefulness for service users and their families, this will go a long way to achieving the Mental Health Advisory Coalition's *Destination: Recovery* (2008).

The Commission hopes that you find this report useful, and we would welcome any feedback to info@mhc.govt.nz.

Ray Watson Acting Chair Commissioner

Contents

| Commissioner's Foreword | | ll ll |
|-------------------------|---|-----------------------------|
| Exec | re Summary oduction ckground ope of the project guage and concepts used in this report erature Review ople who have unmet needs: provider perspectives | |
| 1 | Introduction Background Scope of the project Language and concepts used in this report | 1 1 |
| 2 | Literature Review People who have unmet needs: provider perspectives People who have unmet needs: service user perspectives Service provision Conclusion | 3 |
| 3 | Study Method Data collection | 9 |
| 4 | Results Service characteristics Common problems What has made your care successful? | 10 10 11 12 |
| 5 | Key Findings Limitations of the research Success factors | 17 19 19 |
| Refe | rences | 21 |
| Appe | endix 1: Invitation to Participate | 24 |
| Appe | endix 2: Participant Information Sheets | 25 |
| Appe | endix 3: Interview Schedules | 27 |
| Table Table | of Tables e 1: Service characteristics e 2: Problems identified by 17 service user participants e 3: What has made your care successful? Service user responses | 10 11 13 |

Executive Summary

This report provides information about mental health services in New Zealand that have successfully adjusted service provision to meet 'high and complex needs' of some service users.

Some people with mental health and addiction problems appear unable to have their needs met through mental health and addiction services. They continue to cycle in and out of care, and for various reasons, they prove a challenge to services.

Rather than exploring the perceived failings of services, the Mental Health Advocacy Coalition (MHAC) wanted to discover what happened in services that stepped up to the challenge and changed what they did for the benefit of this group of service users. This project aimed to identify and analyse examples of such services.

The researchers conducted interviews with 16 service managers and key workers and 23 service users. Participating services included three District Health Board (DHB) providers and five non-governmental organisations (NGOs) across the middle and upper North Island.

In answer to the question: 'What has made your care successful?', the participants – whether managers, key workers or service users – universally identified 'relationships'. This answer applied to broad intrasectoral relationships between the mental health sector and social agencies such as Work and Income, Housing New Zealand and workplaces; intrasectoral relationships between specialist and community services, DHB provider arm services and NGOs; and DHB funders and planners and all contract holders. This answer also applied to the close, committed, 'give a damn' relationships between service users and their carers – regardless of the background and qualifications of the carer. These relationships formed the springboard for meeting needs such as having a settled and safe place to live, working, reconnecting with whānau and communities and making friends. Clinical expertise was not considered the foundation of these successful services; rather, it was the services' ability to negotiate the need for clinical care within those relationships and in support of meeting those human needs.

Key findings

Participating services indicated that they had set out deliberately to meet the needs of people whose needs had previously been unmet. They utilised change management processes, high-level support and adequate resources to meet needs.

Participating services prioritised interpersonal relationships and the management of the social determinants of distress. Indicators of success included the quality of the service user-carer relationship and progress towards the personal goals that were identified within that relationship. These indicators were supported by evidence of engagement with treatment and reduced reliance on inpatient or acute services. Clinical expertise was applied in support of meeting human needs for connection, housing and meaningful activity.

Participating services identified the differences between the needs associated with mental distress and the needs associated with loss of wellbeing and worked to provide a team of services and carers that could work effectively together. They gave priority to wellbeing, evidenced by the service user having their own safe place to live, meaningful activity, connection to friends and whānau, and someone who cared, to talk to about their mental distress.

Success factors for services identified in this study were:

- each person who comes into the service is viewed as having multiple needs in both wellbeing and distress that will require flexible intersectoral and intrasectoral responses
- successful services maintain a strong focus on stable housing, income and other basic human needs
- the priority is to work towards the connections and contributions people need in order to experience wellbeing; these are the services that take the lead role in co-ordinating care
- key workers whether peer, clinical or support workers are supported to develop sound, committed and loving relationships with the people they care for
- each service works from its own position of strength and does not attempt to be all things to all people
- all agencies and organisations that are involved in care meet regularly in person with the service user and support people
- expert clinicians act in support of the work towards wellbeing
- the sometimes tense relationship between clinical and peer or community support staff is brought to a point of mutual trust and esteem
- relationships between workers and management and among workers are viewed as important indicators of the organisation's potential for success or failure and are carefully fostered
- trusting relationships with funders and planners are prioritised
- funding decisions that relate to particular service users are made at the grassroots level, with the service user, their whanau and supporters, their key worker and the service manager
- when setting up or changing a service to reflect these changes, a change process is engaged with and change champions (people who will champion change) are employed.

The concept of the loving relationship that emerged from the study is similar to the notion of 'aroha', which breaks down to the practice of turning towards someone and sharing breath. This is also similar to the notion of 'presence'.

1 Introduction

Background

In recent years, there has been concern about accounts of mental health service users who feel that they do not receive care that is useful and that helps the person and their whānau to live satisfying and productive lives. At times, these service users seem to be perceived as 'being in the too hard basket' or 'to have fallen through the cracks'. They tend to be categorised as having 'high and complex needs' and provide a challenge to the 'business as usual' approach of many mental health services.

There is limited evidence, some of which is anecdotal, that a number of mental health services in New Zealand have enhanced or changed their 'usual care' in order to meet the needs of service users for whom the usual care is not effective (Mental Health Advocacy Coalition, 2008). However, there is little or no research into these services.

The present study aimed to identify and analyse examples of New Zealand mental health services that have successfully adjusted service provision to meet the 'high and complex needs' of particular service users. It has been possible to draw out from these examples common success factors that may have universal application for mental health service planning and delivery. This practical information will be of interest to clinical staff, managers, planners and funders, service users and their whānau.

The project aligns with Te Tāhuhu: The Second Mental Health and Addictions Strategy (Minister of Health, 2005) objectives to enable services to be more responsive, to build better services and to enhance strategic planning for this population of service users. Oversight of the project was by an advisory group from the MHAC, comprising service user, clinical, managerial, and Māori and Pacific perspectives from the mental health sector.

Scope of the project

The project required:

- identification of at least four examples of innovative practice and integrated service delivery involving primary, secondary and/or NGO services that have resulted in positive outcomes for people with high and complex needs in the mental health sector - these are outlined in Table 1
- identification and analysis of agreed critical success factors
- identification and assessment of at least 20 service users who have benefited as a result of four examples of innovative practice and integrated systems
- completion of this report.

The project focused on the common success factors for meeting high and complex needs. This encompassed the service user and their context, the service and its context and the ways in which the service user and the service connected.

Language and concepts used in this report

The language and concepts of this report are consistent with those used in the (2008) MHAC paper *Destination: Recovery: Future responses to mental distress and loss of wellbeing.* MHAC makes the distinction between mental distress and loss of wellbeing as separate but interconnected aspects of mental health. Mental distress encompasses problems of thought, perception and mood that are unpleasant and distressing to the person experiencing them. Loss of wellbeing is associated with poor self-worth, heightened vulnerability to stress, the inability to contribute to whānau and society, loss of cultural identity and lack of productivity.

2 Literature Review

International and national evidence suggests that there are times when mental health services, whether government or independent, do not meet the needs of particular service users (Meadows and Burgess, 2009; Oakley-Browne, Wells and Scott, 2006; WHO World Mental Health Survey Consortium, 2004). When described in the literature, such unmet needs tend to be presented in terms of the service user being 'different' and difficult to treat successfully. However, when a service is struggling to successfully meet the needs of a service user, this outcome is the result of an interaction; it may be that the approach the service is taking is not attuned or responsive to the service user's needs. In other words, the difficulty can be in the complexity of the service user's needs, the inability of the service to be responsive to their needs, or both.

Literature for this review was sourced from searches of medical, nursing and psychology databases for the term 'high and complex' associated with research. mental health and/or psychiatry. There was a paucity of quality research from the initial search, but isolating the term 'complex' yielded multiple international articles, most of which were associated with co-morbid mental and substance-use disorders, or mental and intellectual disorders. Risk and homelessness also featured commonly among these sources.

This literature review examines the notion of 'high and complex' associated with descriptions of a service user population with unmet needs and with evidence of services that aim to provide care for people whose needs are not being successfully met with usual approaches to delivery of mental health care.

People who have unmet needs: provider perspectives

There is no clear definition for the population of people who have 'high and complex needs' (Thomson Goodall Associates Ptv Ltd, 2002). Literature focusing on service provision for people with 'high and complex needs' tends to describe them in terms of people who 'fall through the cracks' (Hollingsworth, 1992) of mainstream systems of care, either by virtue of the severe nature of their mental illness or the complexity of the range of issues they encounter. They tend to be the people whose needs are not met by those systems designed for people with dual diagnosis, although dual diagnosis features prominently in the 'high and complex' literature. The system struggles with what appears to be the service user's 'rejection of services', 'noncompliance with treatment' and perceptions of 'aggressive and/or criminal behaviour'.

A draft report identified problems associated with this group as "psychological, mental health and other problems; learning and development difficulties and other problems; social problems, homelessness and other problems; crimes and other problems; drug and alcohol misuse and other problems ... all indicate the cooccurring nature of mental illness and other problems" (Mental Health Commission, 2009). Other New Zealand sources identify similar characteristics in this group. For example, the Northern District Support Agency suggests that the people whose needs remain unmet are likely to be:

Those persons with serious mental illness and problems of treatment responsiveness or engagement [including transience and homelessness] who have complicating factors of substance misuse or risk to others or criminality; or those persons with serious mental illness with at least one other complicating factor such as a major physical illness, pre-senile age related disability, acquired cognitive impairment, or intellectual disability that requires a complexity of funding and coordinated service response across agencies which is difficult to achieve (Northern District Support Agency, 2009, p.10).

In an earlier research project in the Midlands region, McGeorge adapted the Level of Community Support Scale (Kazarian, Joseph and McCabe, 1996) to aid in identifying those people most likely to have unmet need. His conclusions were:

The consumer does not take medication as prescribed, is unwilling to attend clinical appointments, has frequent and severe crises involving threats or violence (including physical and/or sexual events) to self and/or others requiring frequent hospitalisations, often uses alcohol and/or drugs in a hazardous manner, has been frequently asked to leave residences supplied by supported accommodation providers, needs help in most aspects of life, is unable to access community services on their own, and has needs that cannot be adequately met by a standard high level of community support (McGeorge, 2004).

Criminal behaviour was commonly noted among the DHBs as contributing to the level of unmet need, as was poor physical health, trauma, eating disorders, borderline personality disorder and age-related need (Mental Health Commission, 2009). However, these types of problems are also a consequence of these complex unmet needs. Other consequences include safety and risk factors, accommodation issues (including transience and homelessness), poor response to treatment, difficulty engaging and difficult to engage with, issues with family/whānau and social isolation. These consequences are consistent with those reported by the Sainsbury Centre in the United Kingdom 12 years ago (Sainsbury Centre for Mental Health, 1998), although the centre adds racism, stigma and discrimination to the list of problems. These latter problems appear in New Zealand strategic and organisational documents (Mental Health Advocacy Coalition, 2008; Minister of Health, 2005; Ministry of Health, 2008; Peterson, Pere, Sheehan and Surgenor, 2004; Peterson, Barnes and Duncan, 2008) but tend to not appear in the academic professional literature.

Age-related need is particularly relevant for older adults in whom physical and mental co-morbidities, low income and social isolation create complex needs that, when unmet, exacerbate their other problems (Hahm, Speliotis and Bachman, 2008). Younger people in New Zealand in this group present "with a range of complex needs including substance use and mental health issues, criminality, family conflict and disengagement from school" (Schroder, Sellman, Frampton and Deering, 2008, p.963).

Dual diagnoses

Dual diagnosis issues are in many ways consistent with the problems experienced by service users with 'high and complex needs'. Needs for people with dual diagnoses are described by Edward and Munro (2009) as social, psychological and biological, relating to family and interpersonal relationships, isolation, social withdrawal and exclusion, financial problems, employment, education, high-risk behaviours, multiple admissions, increased accident and emergency presentations, increased need for

primary health care services, legal problems (possible incarceration) and homelessness.

The New Zealand Mental Health Survey (Oakley-Browne et al, 2006) found that people with more than one mental disorder (for example, anxiety and depression, or depression and eating disorder) tend to have more distressing experiences and more complex needs than those with one disorder. They found that the same increase in complexity occurs when people have co-existing mental and physical, intellectual and alcohol and other drug (AOD) disorders.

In a New Zealand study, it has been suggested that up to 90% of AOD patients in the larger DHBs may meet the criteria for a lifetime psychiatric diagnosis (Adamson, Todd, Sellman, Huriwai and Porter, 2006) and that the level of unmet need in this population is significant (Todd, Sellman and Robertson, 2002). The Australian Department of Health and Ageing suggested that the unmet need for treatment within this group is considerable "... the person ... is often left to fall in the gap between services" (cited in Edward and Munro, 2009, p.75).

Dual diagnoses incorporate more than mental illnesses and AOD problems. Intellectual disability and mental illness is considered to be the "other dual diagnosis" according to VanderSchie-Bezyak (2003), with psychiatric disorders being four to five times more common among individuals with an intellectual disability. Mohr, Curran, Coutts and Dennis (2002) reported that "service systems in health and community agencies are struggling to deliver mental health services to adults with an intellectual disability and many professionals feel ill equipped to assess and treat mental health disorders in this population" (p.171). Krahn, Hammond and Turner (2006) described a "cascade of disparities" that occur for people with intellectual disability and mental health problems. There is a measure of agreement in the literature, however, that significant advances have been made in addressing the problems of this client group.

Prevalence

It is a complex process to ascertain the numbers of people with complex unmet needs (Daly, 2009; Drake, Mueser, Brunette and McHugo, 2004). Bond et al (2005 cited in van Veldhuizen, 2007) estimated that this group constitutes 20% of long-term mentally ill persons or 0.1% of a population. Van Veldhuizen (2007) suggested that the 20% group of people whose needs are complex and largely unmet is not an absolute distinction but is fluid, as people's needs and problems change. The Sainsbury Centre in the United Kingdom estimates the group of people who have severe mental illness and are difficult to engage may vary from 14-200 per 100,000 (Sainsbury Centre for Mental Health, 1998).

The definition of 'high and complex needs' has not, as yet, been clarified in the New Zealand context (Mental Health Commission, 2009). This means that, although each region will estimate likely prevalence of this client group, the lack of a clear definition makes any discussion of prevalence problematic.

People who have unmet needs: service user perspectives

Literature that records service user positions and experiences of complex needs is available but difficult to find. Some of the first literature to record the service user voice is from the Mental Health Commission Recovery Series in which service users and their whānau/families were invited to tell their stories (Fenton and Te Koutua 2000; Malo, 2000; Mental Health Commission, 2000a, 2000b). These stories tell of the social, cultural, physical, emotional and mental experiences associated with mental distress and include many of the features discussed in the provider perspectives. The key difference is not in content but in the prioritisation of need. For example, the stories of forensic service users and of whānau identify problems such as mental disorder, AOD problems, social and cultural dislocation and psychiatric treatment, but prioritise whānau connection, cultural understanding and meaningful lives as the means of recovering.

Service provision

Without a clear understanding of why the needs of some service users remain unmet or the extent of their need, planning and providing effective services is challenging. The MHC report on high and complex needs found that New Zealand service responses are of two types:

- Targeted services including assertive case management as well as community and accommodation services (offering higher and more intensive levels of support and rehabilitation).
- Individualised packages of care that draw on a range of services supplemented with additional levels and types of support as required.

The first type aims to develop services to meet a wide range of needs, while the other develops flexible services and supports to meet individual needs. The report noted that most DHBs offer both types of services and concluded that neither approach appeared superior (Mental Health Commission, 2009).

The majority of the international literature that has examined service provision for people whose needs are not met by standard mental health services tended to characterise the service users as having dual diagnoses. In addition to the diagnoses, significant safety, trauma, family, social and/or financial problems are also identified. These problems, however, are given little attention in the discussion of service provision. Nevertheless, where dual diagnosis services are reported, there are usually profound difficulties in other areas of life, some of which are addressed within service provision and some of which are not attended to at all (Carney, 2006; Hahm et al, 2008). This is consistent with New Zealand literature, with Todd et al (2002) stating that systems issues were significant barriers to optimal care for New Zealanders with dual diagnoses.

Overwhelmingly, research on dual diagnosis has indicated that mental health and substance use disorders are best treated simultaneously (Drake et al, 2004). This accompanies a critique of traditional approaches of sequential or parallel treatment of the separate disorders. The research indicated that, ideally, treatment involves early detection, ongoing effective treatment, a long-term recovery approach, assertive outreach, as well as skill acquisition training to enable self-management of drug use

and symptoms (Edward and Munro, 2009). The majority of research on service models is from the United States, Canada and Australia where programmes have been in effect for a number of years. Johnson (1997) suggested that maintaining continuity of care by integrating treatment of severe mental illness and addictions is the central principle of innovative services in the United States. The United Kingdom dual diagnosis good practice guide (Department of Health, 2002) proposed a minimum standard of quality such as access to relevant services, especially in crisis situations, supportive housing and aftercare services such as therapeutic and legal services. However, Lowe and Abou-Saleh (2004) warned that the United Kingdom guide fails to address important issues related to social care and the interface between mainstream mental health services and addiction services.

The literature generally proposes that assertive outreach and continuity of care are preferred service models, although these alone may not be sufficient for this group of service users (Sainsbury Centre for Mental Health, 1998). Assertive community treatment (ACT) has been described by van Veldhuizen (2007) as a well defined service delivery model. Bond and Drake (2007) noted, however, that ACT has not been comparably effective outside the United States and called for a greater flexibility to recommended guidelines. In New Zealand, the addition of ACT teams has not been successful for many people whose complex needs were already unmet (McGeorge, 2004).

Alternatives to the ACT model include psychosocial treatments such as cognitive behavioural therapy, residential treatment and motivational interviewing (Cleary, Hunt, Matheson and Walter, 2008). Motivational interviewing was found to be the most cost-effective in the short term, with long-term residential treatment for addictions also being an effective intervention for mental illness and AOD dual diagnosis. The cost of providing a modified therapeutic community (modTC) treatment for complex unmet needs in the United States is explored by McGeary, French, Sacks, McKendrick and De Leon (2000). The study found that services for people who were homeless or itinerant, mentally ill and had AOD problems were more successful and cost-effective when all three issues were addressed. They concluded that treatments that do not address all three problems may be ineffective and expensive.

The literature has identified several service problems and issues that contribute to the level of unmet need. These include a lack of co-ordination and integration between mental health and other services. Heyman et al (cited in Krahn et al, 2006. p.78) suggested "the requirement to manage complex health needs with limited resources causes service providers to simplify, standardise and routinise care". Failure of mental health and social service organisations to take responsibility for those who are more difficult to engage has also been identified as a problem. Swedish researcher Per Lindqvist suggested (2007) that there is a service gap resulting in unmet needs for those who have the dual diagnosis of mental illness and substance abuse in addition to aggression and/or criminal behaviour. He identified this group of service users as "triply troubled", suggesting that their needs are unmet because they tend to reject services, frighten staff and very often leave treatment. There is a concomitant lack of formal and informal education and training among professionals for understanding the complex clinical and individual presentations and needs of dually diagnosed patients who are a challenge for services to engage with.

This is consistent with New Zealand research, which showed poor attitudes among clinicians and an unwillingness to recognise their own deficits in practice, with a "minority of clinicians [having] the range of clinical skills and the knowledge base needed to assess and plan effective interventions" for this group of service users (Todd et al, 2002, p.794).

This lack of education and training is somewhat explained by the notion that mental health and AOD clinicians tend to have different treatment philosophies as well as qualifications and expertise regarding assessment and treatment (Edward and Munro 2009). However, clinicians' attitudes toward clients have been identified internationally as a major systemic barrier to meeting service user needs, particularly where those needs are complex (Berry, Gerry, Hayward and Chandler, 2010; Newton-Howes, Weaver and Tyrer, 2008; van Veldhuizen, 2007). As noted above, New Zealand organisational literature has identified stigma and discrimination at the hands of service providers and the community in general as being significant barriers to engaging with and receiving successful mental health care (Lapsley, Nikora and Black, 2002; Peterson et al, 2008).

Conclusion

In this review, conclusions about the definition, prevalence and successful service delivery for people whose needs are unmet by mental health services have been difficult to reach because of the diversity of understandings and the lack of quality evidence. The literature generally proposes that unmet needs tend to be associated with more than one diagnosis and concomitant problems with housing, finances, relationships and sometimes with aggressive or criminal behaviour. There is no clarity about the extent to which the unmet needs contribute to the existence or exacerbation of the service users' problems.

It is suggested variously in the literature that the way services are organised and delivered tends to mean these people 'fall through the cracks' by virtue of complexity of need and that "the common way of (mis)managing people with mental disorder, substance misuse and violent behaviour has been exclusion by referral rejection" (Lindqvist, 2007, p.246).

There is no evidence suggesting that any particular treatment or intervention type is more successful than others, but the literature is consistent in calling for improved collaboration among the mental health sector, justice and social organisations at local and national levels. Government inquiries such as the Mason reports (1994, 1996) provide clear information about the consequences for people, families and communities where complex needs remain unmet. However, there is a need for data about services that successfully meet the challenge of those needs so service planning and delivery can be built on a foundation of evidence.

Study Method 3

Mental Health Commissioner Dr Peter McGeorge introduced the project to the national Mental Health Managers and Clinical Directors meeting in August 2009. Following this meeting, an invitation to participate, a participant information sheet and consent form were emailed to general managers and clinical directors of DHBs and larger NGO mental health providers. (A copy of the email is appended.) They were asked to forward the email to the relevant service manager if they identified their service as one meeting the needs of service users who challenged their usual process of service provision. There were four responses to this request, one of which was an NGO.

The term 'high and complex needs' was not defined in the information about the research, as this creates an additional data point given that each participating service made its own decision about whether they fitted the research criteria. This had the effect of broadening the inclusion criteria beyond diagnostic frameworks and allowed a comparison of participants' understanding with the accepted clinical understanding of 'high and complex'.

Data collection

The key criteria for services to be included in this study were that the service had a 'high and complex' focus and that service users agreed that their care had met/was meeting their needs and helped them to live a satisfying life.

Achieving an adequate sample for this project took considerably more time than was anticipated. Later informal contact with the recipients of the recruitment email suggested a general reluctance on the part of DHBs to identify themselves as achieving extraordinary results. A final sample of three DHB services and five NGOs were included. These services are all based in the North Island.

Interviews took place with 16 staff members across the eight services. Of these, eight were in management roles and the remaining seven were in key worker/kaimahi roles. Of the key workers/kaimahi, four have formal health care qualifications at diploma level and beyond, and three have mental health certificates.

At least two service users from each service were interviewed. Each person was offered the opportunity to include whānau/support people in their interview. A total of 23 service users participated in the research. Only one whanau member opted to be interviewed. Of the 23 service user participants, there were 11 women and 12 men; 16 identified as European or Pākehā, three Māori and three Pacific. One person did not specify ethnicity. The ages of the service users ranged from 21 to 84 years, with the majority of participants being in the mid-20s to late 40s range.

Interviews took a semi-structured, open approach. Service user interviews focused on two questions: "Tell me about the care you are receiving" and "Why do you think your care has been a success?" Staff interviews included issues related to resourcing, philosophy of service, service parameters and staffing characteristics. Interview schedules are appended.

4 Results

Service characteristics

Data from Question 1 for both the service managers (SM) and service users (SU) are presented here to form an overview of the service characteristics. When data were compared, it emerged that the service users had discussed two additional outpatient services, but service staff hadn't. Because the service users identified the combination of the community-based and outpatient services as very successful from their perspectives, these services have been included.

Table 1: Service characteristics

| Location of service | Staffing | Number |
|--|---|---------------|
| Residential (service users live on site permanently or for a short period) | Peer support workers | 1 NGO |
| Outpatient (service users attend clinics and/or groups on an outpatient basis) | Clinicians | 2 DHBs |
| Community-based (staff travel to the service user) | Clinicians | 3 DHBs, 1 NGO |
| Community-based | Community support workers who are often also peer support workers | 3 NGOs |
| Total | | 10 |

Financial cost was identified as a descriptive feature of 'high and complex needs', that is, when people's ill health is perceived to be costing large amounts of health money but there are few visible benefits. Three of the services, two NGOs and one DHB, have access to flexi-funding, which enables the care team to apply funds to aspects of the service user's care that are outside the common clinical parameters of DHB funding. Most of the flexi-funding is spent to support recovery such as on the costs of setting up a home, for example, furnishings and bedding. However, it has also been applied to leisure activities such as guitar or art lessons, work assistance such as bus or train tickets or night classes, or physical improvement activities such as gym memberships or training shoes. Flexi-funding for these services is administered by the DHB and accountability is required in terms of staying within the allocated budget and maintaining accurate records, but spending decisions are made by the care team in partnership with the service user and their support people.

"The relationship with Funding and Planning is very strong. [We were told to] '... identify what the needs are then go find them, whatever that might be'." (SM2, NGO)

"The key to the success of [this programme] has been the flexi-fund." (SM1, NGO)

The application of the flexi-funding approach to care has resulted in significant overall savings.

"We have saved the DHB lots of money [in crisis admissions and length of stay]." (SM2, NGO)

"It costs \$600 per day in the [inpatient] unit and [the community support worker] rate is a fraction of that." (SU4)

"In the 12 months before [SU] was discharged, the two periods in the [inpatient] unit had a cost of \$93,012. [SU] started as a 15 hour-a-week cost, but is now 5 hours. His first 12 months was \$11,440. This year is looking more like \$4000." (SM5, DHB)

One service focuses on meaningful activities with a work focus so is able to generate income through external work contracts, thereby making it an economically sustainable programme. This income is used exclusively for the service users on the programme and can be spent on housing and furnishings, group or individual leisure activities or other items as decided by the group.

Common problems

Only two services had clearly defined inclusion criteria – one NGO: Axis 1 diagnosis (on the DSM classification system) and one DHB service: Axis 1 diagnosis with a comorbid AOD problem and high inpatient bed days. The other services defined need on an individual basis, incorporating such problems as social isolation, acute crisis, being 'stuck' and making little progress with the usual inpatient and community services. All the services identified high risk of harm to others or suicidal behaviour as exclusion criteria but did not have a universally applied method of evaluating risk. It is clear from the section below that there is flexibility in such assessments. Of note, one of the service managers explained that service users who are risk-assessed in the presence of a peer support worker tend to have lower levels of risk. She attributes this to the peer relationship and suggests that self-management is a clear expectation of such relationships. This is discussed further in the next section of the report.

At the beginning of each interview, the service user participants were invited to talk about the needs that brought them to the service featured in this research. Seventeen of the participants answered this question by listing diagnoses and other problems related to psychiatric symptomology. More than one problem was identified by 10 of the participants.

Table 2: Problems identified by 17 service user participants

| Problem | Identified by |
|--------------------------------------|---------------|
| Depression | 9 |
| Hearing voices/psychosis | 9 |
| Anxiety | 7 |
| Police/court referral or instruction | 5 |
| Alcohol and other drug use | 5 |
| Other abuse/trauma | 4 |
| Suicidal intent | 3 |
| Sexual abuse | 3 |
| Obsessive-compulsive disorder | 2 |

While the majority of the service user participants discussed their problems in terms of symptoms and diagnoses, six of the participants and the whānau member identified the need for social reconnection, someone to talk to and support for managing stress as their main reasons for engaging with these services.

What has made your care successful?

The second question asked of service user participants, service managers and key workers related to the factors that they believed made their care successful. Service managers and key workers identified relationships and the flexibility to adapt care to the individual as their key success factors. The relationships included focusing on the interprofessional, intra-agency connections as a means to ensure that their primary relationship with the service user and their whānau/family would be successful.

"We've worked very hard at these relationships, and now have a team that is known and trusted by clinical teams and the [DHB] funding arm." (SM2, NGO)

Only one NGO noted that boundaries imposed by contracts "impact on service users' rights to a seamless service" (SM7, NGO).

Of particular concern in services delivered by peer support workers was the relationship between the peer support worker and the staff of mental health services, who were usually both involved in the care of these service users.

"They needed to discuss how they could trust each other as experts in their jobs." (SM1, NGO)

The shift in status and responsibility for both groups required careful negotiations over time.

Multiple agencies are usually involved with the service users who have complex needs. Services identified as successful by respondents prioritise informal networking among agencies, as well as formal documentation and meetings to support particular people.

"WINZ have dedicated staff members who understand [mental health] issues and are available to work with." (SM1, NGO)

"It's important to maintain ongoing networks with the community as a whole." (SM7, NGO)

"We need to be more integrated. The community needs to be aware of what is happening within and around it." (SM3, NGO)

Flexibility in care is perceived as very important, as these services identify that service users' needs and capacity for engagement with their carers and communities will change over time.

"The service changes and moves with him." (KW1)

"The service has been able to respond to my differing needs as time goes by." (SU11)

Flexibility was also demonstrated with team members being willing to step outside usual professional practice:

"They gave me ... home visits including visits from a psychiatrist ... the psychiatrists saw the real me." (SU12)

"To my surprise they [key worker and psychiatrist] came to my house." (SU10)

The commitment to stay with the service user even when they appeared to have made significant improvements is viewed as important by key workers and service users. Leaving them at this point could be experienced as desertion.

"I would get overwhelmed by the pain ... I wanted a long-term commitment and [KW] offered that." (SU7)

A further commitment the services identified was the facilitation of ongoing involvement with the families, whether or not the family was a part of the day-to-day care.

"They involved my family in things as well so my family felt supported and I didn't feel like such a burden on them." (SU15)

Key workers identified the organisational culture as an important supporting feature of their care. They included ongoing training opportunities, quality recruitment processes, respect from their employers and colleagues, being accepted as individuals and "a corporate attitude of hopefulness" (KW7, NGO). Clinical/professional supervision was also noted by several key workers and service managers as supporting the carers' ability to deliver and maintain successful care.

The service users' answers to this question were also unanimously associated with relationships, social connection and purposeful activity.

Table 3: What has made your care successful? Service user responses

| Successful care | Identified by | |
|--|---------------|--|
| Someone listens to me | 18 | |
| Freedom to do my own thing and be in control | 11 | |
| No pressure | 8 | |
| Peer support | 8 | |
| A reason to get up in the morning – job, purposeful activity | 8 | |
| Helped me get a house | 7 | |
| Family included in care | 7 | |
| Feel safe | 5 | |
| Part of the community | 5 | |
| Lots of information and support to make good decisions | 5 | |
| Prepared to work with other services for my benefit | 3 | |

These 11 groups of answers were combined to form five themes, which are discussed further below.

Someone listens to me

Table 3 shows that the most frequently identified success factor in care was 'being listened to'. This factor was more complex than simply listening, however, as it included the opportunity to talk as often and as long as was desired, with the knowledge that one was understood and taken seriously.

"She [key worker] just let me talk and talk and talk." (SU3)

"It was great to talk to [the community support worker] about the real issues for me." (SU6)

"Just to be able to talk to someone makes the world of difference." (SU10)

"I needed to just talk and get things in perspective." (SU13)

Being liked was an important aspect of being listened to and was described in a variety of ways:

"Having clinicians who really like me ... has been very, very important." (SU16)

"They cared about me." (SU17)

"[I have a] real love for people." (KW6, NGO)

"What made a difference ... [was] someone walking beside them and literally 'giving a damn'." (SM5, DHB)

Being understood was demonstrated most clearly when the carer/listener did not 'over-react' to what was being said by suggesting or enforcing admission to hospital or medication.

"I'm not locked up like in the hospital and I'm not pumped full of drugs either. So I can think and I get to talk to people when I want to." (SU2)

"I didn't have to pretend everything was all right." (SU13)

The service users did not differentiate between the contact being made by them or by the carer, as long as there was no pressure brought to bear.

"They phoned me every day and I could text them any time." (SU12)

"They made themselves very accessible ... knowing I could phone and have a chat was very helpful." (SU9)

The freedom to do my own thing and be in control

The freedom to 'do my own thing' and 'be in control' was closely linked to being understood and the absence of pressure. For example, being able to define and pursue one's own needs was an extension of being understood as an individual.

"I needed to feel in control, not treated as if I had come in for a car service." (SU7)

"They let me play around with my medication ... I would like to be medication free. [My key worker and doctor] are helping me with that and I'm doing really well." (SU3)

It was also associated with the opportunity to act independently and take responsibility for one's own health.

"I needed to get off my bum and do something for myself." (SU6)

"I felt that I was an equal." (SU18)

"I am the key player in the team." (SU20)

"I didn't need anyone to 'fix' me – I'm not broken!" (SU7)

No pressure

The absence of pressure to respond to the carer or to comply with their expectations was highly valued and included a focus on what can be achieved and is desired

rather than what was unable to be achieved at that point.

"I was allowed to be what I was." (SU17)

"I'm just not a social person ... no pressure is put on me." (SU10)

"Our approach was about doing it at my pace." (SU7)

Several of the participants discussed those times when being in control and making decisions was not possible to achieve. At those times, services were valued for their ability to be directive and supportive for a short period of time.

"Both [key workers] have been able to make decisions for me when I haven't been able to." (SU16)

"They didn't let me sit around feeling sorry for myself." (SU15)

"We hold the hope until someone is able to do this for themselves." (SM4. NGO)

"One day they took me out of hospital and put me in support accommodation." That was a real breakthrough ... I am now on my own in a flat." (SU20)

Peer support

Eight of the participants identified peer support workers as key to their successful care, noting the relief of talking and working with someone who has gone through similar distress and come out the other side.

"It makes a big difference having people who have been through the same sort of thing as you have ... When you talk to them [peer support workers] it's more real, not like talking to a psychologist who does it all from a textbook." (SU2)

"You don't feel so alone in your distress." (SU14)

"As peer, the support workers were able to maintain expectations re behaving 'like everyone else'." (SM5, DHB)

"My perception is that the peers see more distress – the service users don't have to hide it from them out of fear, you know? On the other hand, it's not okay to 'act out' when the peers are there, so although they see more distress, they see less of the bad behaviour." (SM3, NGO)

Peer support included, for the Māori participants, that their primary carer was Māori. One service manager considered that the dual identification of peer by experience as well as peer by culture was also vital to their successful service.

"The key thing was that they were able to build a relationship with the consumer as a starting point for trying to see the world through their eyes." (SM5, DHB)

A reason to get up in the morning - job, purposeful activity

Practical engagement with the community was often achieved in the first instance by getting out of hospital and into co-operative or independent housing and by having meaningful activity such as work or chores. This was described eloquently by SU20 earlier, when he noted that moving to supported accommodation was the 'breakthrough' for him to want to engage with his future. Being a part of a community is a basic human need.

"I need to work because it gives me back my self-respect." (SU2)

- "I had chores like cooking and cleaning. It made me feel more worthwhile, like I wasn't completely useless." (SU15)
- "I now feel part of the community." (SU5)
- "I am now flatting ... I pay rent and help with the bills. I see no reason why I will not recover." (SU19)
- "[In supported accommodation] I had a base and was able to rebuild myself." (SU20)
- "I have something to get out of bed for." (SU22)
- "... a reason to start to develop hopes, dreams and goals for the future. From this foundation, progress was able to occur." (SM5, DHB)

This concludes the overall results from the 39 interviews. The focus of these successful services on relationships, social reconnection and someone to talk to is discussed more fully in the next section of the report.

Key Findings 5

The first key finding was that the services that participated in the study reflected a range of services that may or may not have been established with a complex need response in mind. Participating services indicated that their approach was to successfully meet the needs of people whose needs had previously been unmet. They had deliberately set out to achieve this, regardless of the origins of their service. Indicators of success included the quality of the service user-carer relationship and progress towards the personal goals that were identified within that relationship. These indicators were supported by evidence of engagement with treatment and reduced reliance on inpatient or acute services, rather than led by them. In deciding to meet 'complex' needs, the services utilised change management processes, high-level support for their new processes and adequate resourcing.

The second key finding was in the prioritisation of interpersonal relationships and the management of the social determinants of distress. This finding was highlighted further by the absence of data that discussed clinical expertise as a success factor. Clinical services such as medication, psychiatric consultations and talking therapies were included in the data, but they were not prioritised. Service users invariably discussed their key worker/community support worker/peer support worker, rather than the service as a whole or any particular approach, when identifying why their care had worked for them.

Successful service provision in this study has taken the personal relationship between the carer – whether professional, community or peer – and elevated it to the central position of the whole service. Budgetary decisions, the pace of treatments and interventions, decisions about which goals to work towards and who to connect with were all taken on the basis of a sound, committed and loving² relationship between the service user and the carer.

The social determinants of distress that were addressed by these services included homelessness or transience and a lack of meaningful activity. Service users in this research reported that 'breakthrough' moments in their recovery occurred when they had the freedom and safety of their own place to live and when they began to undertake meaningful activity on a regular basis. These two achievements were reported to be the foundation of people's willingness and ability to engage with their carers and their communities on a more equal footing than ever before.

These two key findings together move the discourse about 'high and complex needs' away from the list of service user problems found in the literature and into the ways in which services include or exclude particular service user needs. The results from this study suggest that the perceived complexity of need arises more from the singular approach of services than the people to whom it is applied. In fact, in successful services, the involvement of multiple approaches to meet multiple needs is viewed as an advantage, and processes are put in place to ensure that respectful connections are made and sustained. The need for multiple approaches is an indicator of why

The concept of the loving relationship that emerged from the study is similar to the notion of 'aroha', which breaks down to the practice of turning toward someone and sharing breath. This is also similar to the notion of 'presence'.

needs are viewed as complex and how they can be successfully met.

The third key finding was that viewing the list of problems for this service user group from a clinical perspective may have the effect of making the problems complex. Abraham Maslow famously commented: "If the only tool you have is a hammer, you are likely to perceive every problem as a nail." The natural extension of this concept is that if you have a really expert hammer and the nail won't respond, then the nail is a 'complex' problem. The solution to this complex problem is to find out exactly what the problem is and then expand the toolkit to match it.

Examining the problem of complex unmet needs through the literature has had the effect of expanding the list of service user problems, and doing so through this research has likewise created expansion. However, there is evidence that what is clinically perceived as a complex conglomerate of problems has been the combination of two quite different concepts – mental distress and loss of wellbeing. The Mental Health Advocacy Coalition (2008), when envisioning future responses to mental distress and loss of wellbeing, made a clear distinction between the two concepts. Mental distress, encompassing problems of thought, perception and mood that are unpleasant and distressing to the person experiencing them, is related to but separate from loss of wellbeing. Loss of wellbeing is associated with poor self-worth, heightened vulnerability to stress, the inability to contribute to whanau and society, loss of cultural identity and lack of productivity. While these two aspects of mental and emotional health clearly interconnect, it seems unreasonable that, when a person is at their most vulnerable in both areas, only one kind of service should be tasked with helping them. It is clear from the literature that, when either of these needs is unmet, the whole of the picture for that person becomes more distressing, more intense and more complex. As previously noted, heightened complexity is likely to result in services and the workers within them refusing, withdrawing or poorly performing care.

The successful services in this research have identified the differences between the needs associated with mental distress and the needs associated with loss of wellbeing and have worked to provide a team of services and carers that can work effectively together. These successful services have given priority to wellbeing, evidenced by the service user having their own safe place to live, meaningful activity, connection to friends and whānau, and someone who cares to talk to about their mental distress.

The location of clinical expertise in this study has been to support and promote wellbeing first, often through supporting the key relationship with community support worker or peer support worker. When people developed a sense of wellbeing, they were more likely to connect with clinical service providers and actively engage in their care from a position of strength. This model is consistent with the New Zealand primary mental health care direction (Ministry of Health, 2009), which focuses on whānau ora and locating health supports in the community, and has also been discussed by the Mental Health Commission in its vision of how future mental health services might look (2004, 2007), as did the Mental Health Advocacy Coalition (2008).

Limitations of the research

The overall size of the sample is sufficient for qualitative research; however, different results may have been obtained had there been a wider geographical and philosophical spread of successful services.

Conducting 'snapshot' research (O'Hagan, not dated) does not fully present the realities of those people who participated. Understanding this research should include recognition of the dynamic nature of such information.

Further research is needed to understand the full potential of the peer support workforce. A literature review examining the effectiveness of services run or led by service users concluded that there are mixed results for such services, and that there is a need for more information (Doughty and Tse, 2005). It is indicated in this research that peer support workers have great value in all areas of mental health service provision, including those with perceived high risk; however, more targeted research is indicated.

A further need for research is in the interface between this potentially unengaged group of service users and the primary care sector. Given the direction of primary health care in New Zealand, such a project would provide valuable information for planning the support of people with complex needs from the community.

Success factors

The success factors identified for the services in this study were as follows:

- Each person who comes into the service is viewed as having multiple needs in both wellbeing and distress that will require flexible intersectoral and intrasectoral responses.
- Successful services maintain a strong focus on stable housing, income and other basic human needs.
- The priority is to work towards the connections and contributions people need in order to experience wellbeing; these are the services that take the lead role in co-ordinating care.
- Key workers whether peer, clinical or support workers are supported to develop sound, committed and loving relationships with the people they care for.
- Each service works from its own position of strength and does not attempt to be all things to all people.
- All agencies and organisations that are involved in care meet regularly in person with the service user and support people.
- Expert clinicians act in support of the work towards wellbeing.
- The sometimes tense relationship between clinical and peer or community support staff is brought to a point of mutual trust and esteem.
- Relationships between workers and management and among workers are viewed as important indicators of the organisation's potential for success or failure and are carefully fostered.

- Trusting relationships with funders and planners are prioritised.
- Funding decisions that relate to particular service users are made at the grassroots level, with the service user, their whānau and supporters, their key worker and the service manager.
- When setting up or changing a service to reflect these changes, a change process is engaged with and change champions (people who will champion change) are employed.

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Appendix 1: Invitation to Participate

Memo to General Managers and Clinical Directors, Mental Health Services

Your service is invited to participate in a study to explore successful service provision to a person or people whose needs have been challenging to meet via usual service delivery approaches. These service users may be known a people with 'high and complex needs', although this is not a universal term and may not describe the service you are providing.

About the study

This research project will focus on the critical success factors in delivering mental health services and support to people who challenge 'business as usual' service provision.

We propose to seek up to 15 examples of such care. This project will take a 360 degree view, encompassing an interview with the service user and whānau (if consent is given), service manager most closely connected to the service, and the clinical key worker (approximately four interviews for each example).

Service user involvement is critical and their consent will be sought for each phase of the research.

If your service provides successful care to a person or people who challenge 'business as usual', and you would like to participate, please forward the attached Participant Information Sheet and Consent Form to the service manager who is most closely involved, and the key worker(s).

This study has received ethical approval from the Multi-region Ethics Committee, which reviews national multi regional studies; ethics reference number MEC/09/11/121.

If you would like more information, please email or call me on the numbers below.

Kind regards

Jacquie Kidd Principal Investigator

Appendix 2: Participant Information Sheets







Faculty of Medical and Health Sciences School of Nursing The University of Auckland Private Bag 92019 Auckland, New Zealand

Services under challenge: critical success factors in meeting service user needs

Participant information sheet (service user)

You are invited to participate in a study about successful mental health care for people who need mental health services to provide different kinds of care. You have been identified by your key worker as someone who has received care for your particular needs that has worked well and assisted you in living a positive life.

Your participation is entirely voluntary (your choice). You do not have to take part in this study, and if you choose not to take part this will not affect any future care or treatment.

If you agree to participate, we will arrange to interview you (by yourself or with a person of your choice), and your family/whānau or supporter, the service manager and your key worker. The interview will be with a researcher who is also a service user, and will take about an hour. The interview will take place at a place that suits you. Although you may agree to take part in the study, you are free to withdraw at any stage of the research until one week after your interview is completed.

Our questions will be focused on the care you receive: what it is, what is different about it, and why it is working successfully. We will also ask questions about how long you have been involved with mental health services, your diagnosis and treatment plan, risk assessment, medications, and the other people involved in your care plan. We will not have access to your clinical files.

Notes will be taken throughout the interview and if you agree, the session will be recorded on audiotape to provide back-up for analysis of the notes. The audiotape can be switched off at any time if requested. The notes and audiotapes of the discussion will be kept in a locked location at the University of Auckland and destroyed 10 years after completion of the study. Data will be stored on password protected computer files and kept on the University of Auckland server.

Information will be included in workshops, research articles that will be published in peer reviewed journals, and in a report and database that will appear on the Mental Health Commission website.

No material that could personally identify you will be used in any reports on this study.

If you have any queries regarding this study please do not hesitate to contact me on (07) 839 8750, or 0800 61 62 63, <u>j.kidd@auckland.ac.nz</u>. Alternatively contact Associate Professor Judy Kilpatrick, (09) 373 7599 extn 82897 or 0800 616 263 <u>j.kilpatrick@auckland.ac.nz</u>.

If you have any queries or concerns regarding your rights as a participant in this study, you may wish to contact an independent health and disability advocate:

Freephone: 0800 555 050

Free fax: 0800 2 SUPPORT (8088 278 77678)

Email: advocacy@hdc.org.nz

This study has received ethical approval from the Multi-region Ethics Committee, which reviews national and multi regional studies, ethics reference number MEC/09/11/121.

Please feel free to contact the researcher on 07 839 8750 if you have any questions about this study.

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Appendix 3: Interview Schedules

Service user

Firstly, can you talk to the person about what kind of problems they bring to services - mental illness, forensic history, AOD issues - use your own language, but collect information about their needs.

Also, their age, gender and ethnicity.

Interviews with service users and whānau will take an informal, open approach with two key questions:

- "Tell me about the care you are receiving."
- "Why do you think your care has been a success?"

Service manager

- What is the service you are providing? 1.
 - What staffing is used?
 - What additional resourcing is needed? b
 - What relationships are necessary (eg, whānau, NGO, WINZ, etc) to make it successful?
- 2. The service user: what kind of problems do the service users bring to your service?
- How would you describe your philosophy of care? 3.
- 4. What had to happen in your organisation to enable this service to be provided?

Key worker

- 1. What are your qualifications?
 - Have you had additional training?
- Your service is doing something special here. What do you think has made it 2. possible to provide this service?