

# Beyond the Divide

Women's Experiences in Rural Victorian  
Psychiatric Rehabilitation Services

by

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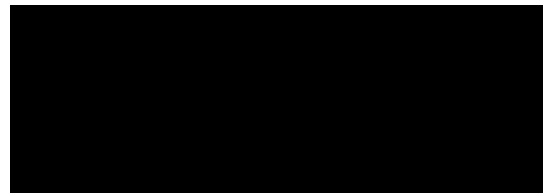
July 2003

We must learn to celebrate  
apparently minor and local  
victories in favour of those  
who are marginalised.

Healy (2000 p. 11)

**Declaration**

Except where otherwise indicated  
this thesis is my own work



Margaret Brooks  
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Beyond the divide : women's  
experiences in rural

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# Abstract

The objective of this study was to give voice to women experiencing psychiatric rehabilitation services in rural Victoria. A critical analysis of the literature revealed a landscape of marginalisation and alienation for women experiencing a mental illness in a rural area. This study used a phenomenological method to explore the meanings of women's experiences.

The understanding of meaning was developed through a dual perspective with women experiencing rural psychiatric rehabilitation and workers who delivered these services. The research centred on the voices of the women but encouraged a personal and collective reflective approach with workers.

As the researcher I also took a reflexive approach which highlighted the methodology as an evolving and ongoing process and demonstrated the integral nature of the researcher in the research process. A chapter on locating the researcher was included as part this reflective process.

The analysis of the collective stories produced a rich diversity of material that was drawn together thematically to include:

- Reflections of struggle;
- Long way from anywhere;
- The rural dimension;
- Construction of a caring relationship, and,
- Interlinking care.

Through this thesis I argue that women are marginalised and alienated by the social cultural conditions of their lives which impacts on their mental illness and rural experiences. However, women are not a homogenous group and a diversity of experiences exists which demonstrates women's active capacity to mediate their environment. As active participants in their psychiatric rehabilitation care the women were able to shift their identity from one of powerlessness and lack of control towards regaining control and managing their illness and environment. The thesis is a story of transformation as the women progressively moved forward in their journey.

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Firstly to the nine women who generously shared their experiences and allowed me to explore the landscape of their journey.

To the workers who participated and contributed their knowledge and practice wisdom.

My thanks to the Service Agencies who enabled me to conduct this research:

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Mallee Family Care

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To my family, friends and work colleagues for their patience, distraction, persistence and encouragement.

My sincere thanks to you all,

***Marg Brooks***

## Chapter 1: Introduction

The aim of this thesis is to explore the experiences of women using psychiatric disability rehabilitation and support services (PDRSS),<sup>1</sup> in particular the home based outreach programs, in the Loddon Mallee Region of Victoria.<sup>2</sup> In this process I wished to give voice to women using these services and to uncover the meanings they attach to their psychiatric rehabilitation experiences.

My interest in raising the voices of women using these services developed from my social work practice experiences within a rural welfare agency. In my practitioner role I witnessed the courage and strength of women with a mental illness as they moved towards recovery but observed that in general this was an area that was very little explored. The PDRSS services in Victoria are relatively new<sup>3</sup> and there is not yet a well established body of research to inform practice. It is therefore the intention of this research to add knowledge of women's experiences in rural psychiatric rehabilitation to the field. Therefore the research question guiding this research was:

*What are the experiences of women using psychiatric rehabilitation services in rural Victoria and what can we learn from this?*

This research focused in particular on women's experiences in home based outreach services which provide individually tailored rehabilitation for people living in their own homes, public housing, private rental accommodation, rooming houses or Supported Residential Services (VICSERV 1996). A focus on this service type was chosen because these are the largest in number and program type in the PDRSS sector (Mental Health Branch 2000).

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<sup>1</sup> The term Psychiatric Disability Rehabilitation and Support (PDRSS) is a newly adopted term for what were formerly known as Psychiatric Disability and Support Services (PDSS). Even though the revised title is still in the process of adoption by the Department of Human Services in Victoria for the purposes of this research 'psychiatric rehabilitation' will be used to distinguish the work of these services. Refer Appendix 1 for information on the service types available in PDRSS.

<sup>2</sup> Refer Appendix 2 for a description and map of the Loddon Mallee Region.

<sup>3</sup> These services have only been developed in the past 20 – 30 years in Victoria and they are not replicated in others states.

The rural context for this research is the Loddon Mallee Region of Victoria which comprises a large rural area in the north-west part of the state and covers more than one quarter of the area of Victoria (26%) (Loddon Mallee Regional Planning Branch 1999). The Loddon Mallee Region was chosen as the 'place' for the research as I am a service director in this rural region and have well established service contacts with other PDRSS providers.<sup>4</sup>

In this thesis the concept of 'rural' is broadly used to define smaller population areas distant from the major metropolitan centre of Melbourne. However, it is acknowledged that it is difficult to define 'rural' due to inconsistencies in the purpose of defining areas geographically and the inherently changing nature of rural communities (Welch 2000).<sup>5</sup> Rather than approaching rural as a purely geographical construct the concept of rural for this thesis has drawn upon the work of Judd, Murray, Fraser, Humphreys, Hodgins & Jackson (2002) which provides a broad conceptualisation of rural location as 'place' which shapes the social worlds that individuals experience. This model views social locations as complex and interdependent geographical, social, economic and cultural entities (Judd et al 2002:299).

To conduct this research and to inform my understanding I have drawn on a critical poststructural feminist perspective as an influence on the methodology and research design. A qualitative research design was chosen as I considered that the aim of giving voice to women was best achieved through listening to their subjective experiences. This is appropriate as '*subjective experiences are the ways in which people make sense of their lives*' (Egan 1994:1).

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<sup>4</sup> The author is Director of Community Services at St Luke's Anglicare which is the largest PDRSS provider in the Loddon Mallee Region of Victoria.

<sup>5</sup> Various definitions of rural and remote have been used and the main method used by the Australian Bureau of Statistics is by population size as an indicator (Cheers 1998). Another frequently used classification, Rural, Remote and Metropolitan Areas (RRMA), is based on population size and divides Australia into seven zones (Wilkinson 2000). However this has fallen into disfavour recently and the Accessibility/Remoteness Index of Australia (ARIA) is becoming more into usage. The ARIA is based on an assumption that remoteness can be interpreted as access to a range of services, some of which are available in smaller centres and others only available in larger centres; the remoteness of a location can thus be measured in terms of how far one has to travel to centres of various sizes (CDH&AC 1999). With this classification there are no remote areas in Victoria.

A phenomenological dual perspective research design was used in this research. This incorporated qualitative research methods for listening to the experiences of nine women using rural PDRSS combined with a reflective action research approach with fourteen workers to assist them in directly learning of women's experiences with the purpose of enhancing their understanding and raising awareness of women's experiences.

Through this thesis I argue that women are marginalised and alienated by the social cultural conditions of their lives which impacts on their mental illness and rural experiences. However, women are not a homogenous group and a diversity of experiences exists which demonstrates women's active capacity to mediate their environment.

This argument is developed through the four sections to this thesis:

- First a critical examination of the relevant literature
- Second a detailed account of the theoretical perspectives which informed the Methodology.
- A description of the methods I used to explore women's experiences
- The presentation of the results

In the first section I critically examine the literature to gain an understanding of the service context for mental health care, women's experiences in psychiatric rehabilitation, the mental illness experience, the rural context and the supports which are beneficial for women.

The second section examines the theoretical perspectives which informed the methodology. This is developed through a sequential discussion of the influences on the development of the research design.

The third section provides detailed information on the Methodology and examines the process and procedures used in the research. This is followed by a chapter on Locating

the Researcher which has been included as part of a reflective process on the research relationship.

The fourth section presents the analysis of the findings and these chapters are grouped around the themes that emerged from the data. These include:

- Reflections on struggle
- Long way from anywhere: the rural dimensions
- Construction of the caring relationship
- Interlinking system of care in rural areas

The next chapter provides a critical review of the literature.

## Chapter 2: On the margins: a review of the literature

This chapter critically examines the literature in relation to women's participation in mental health care with a focus on the rural context. This is explored with particular attention to an analysis of how processes of power intersect with care for women.

The argument is developed through a critique of the literature in relation to:

- mental illness and care,
- gender perspective on psychiatric rehabilitation,
- home based outreach support services,
- the experience of mental illness,
- the rural context
- beneficial supports and care for women with a mental illness.

### 2.1 Mental illness and care

The phenomena of mental illness / disorder<sup>1</sup> has become a major national and international health concern due to an increasing reported prevalence, associated distress and high social, human and economic costs (CDH&AC 1998).<sup>2</sup> In Australia, while men and women have similar overall prevalence rates of mental disorder there are gender differences by type of disorder (ABS 1999:2) and:

*Women were more likely than men to have experienced anxiety disorders (12% compared with 7%) and affective disorders (7.4% compared with*

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<sup>1</sup> The term 'illness' and 'disorder' are often interchanged in mental health literature. To simplify understanding the term 'illness' will be used in this thesis. The exception will be where the term 'disorder' has been specifically nominated/used by author/s who are discussed in this thesis.

<sup>2</sup> A definition of mental illness is problematic and the concept of mental distress framed as 'illness' is not universally accepted. Definitions and diagnoses of mental illness are not central to this thesis, however as entry to psychiatric rehabilitation services is guided by diagnoses it was thought useful to include medically accepted definitions as an appendix, thus leaving it for the reader to follow this through if desired - refer Appendix 3.

4.2%). *On the other hand, men were more than twice as likely as women to have substance use disorders (11% compared with 4.5%).*

ABS 1999 p. 2

In Victoria, publicly provided community mental health services provide a dual system of care through Area Mental Health Services (AMHS) (clinical treatment services) and psychiatric disability rehabilitation and support services (PDRSS). Care is complementary with both mandated to work with people with a serious mental illness<sup>3</sup> although PDRSS provide specialist rehabilitation and support for people with a psychiatric disability as a result of a serious mental illness (Mental Health Branch [MHB] 2002).

Although the treatment and rehabilitation sectors are distinct, Victorian policy imperatives direct high levels of collaboration and coordination of care across the services. Clinical staff including psychiatrists and case managers from AMHS, are expected to be leaders in this process (Health and Community Services 1994 a&b), although levels of collaboration across the services vary from area to area. The majority of referrals for people to participate in psychiatric rehabilitation services come from AMHS (DHS 2003), therefore it should be understood that although the work of each sector has a different focus, participants in PDRSS are often clients of both sectors or have been clients of clinical treatment services in their recent past.<sup>4</sup> By implication this also means that an understanding of the participation and experiences of people within PDRSS is contextualised by their broader mental health experiences.

Care across AMHS and PDRSS is complementary, however Spink (2000:11) draws attention to the difference:

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<sup>3</sup> Among the broad spectrum of mental illnesses there is categorisation into high prevalence and low prevalence conditions which are also termed 'serious mental illness'. Up to 3% of Australians experience a severe and enduring mental illness (Commonwealth of Australia 1995:3). Refer Appendix 3.

<sup>4</sup> This is further complicated as many of the AMHS also see themselves as providing psychiatric rehabilitation services but not with the psychosocial rehabilitation framework that characterises the PDRSS sector.

*The fundamental difference between psychiatric treatment and psychiatric rehabilitation is that psychiatric treatment relies on the medical model which focuses on symptoms or pathology while rehabilitation relies on a psychosocial model which emphasises the development of a person's strengths or assets.*

The medical model forms the basis of psychiatric treatment services as operated through AMHS's in Victoria. The medical model has been extensively critiqued by feminists who argue this is value laden with gendered constructions of the behaviour of women (Horsfall 1994, Astbury 1996). Orme (2001) asserts that the medical paradigm is overlayed with stereotyped notions of masculinity, femininity and gendered roles in society. Orme argues these processes are influenced by society's norms and institutionalised in education, training and so called common sense. Gender bias is therefore embedded in the system of care through medically dominated treatment services.

Although rehabilitation is fundamentally different to treatment on the basis of their focus and function it has been argued that the psychosocial rehabilitation principles<sup>5</sup> which guide practice in PDRSS are gender neutral in nature (Spink 2000). Reid (1995:46) asserts that principles guiding delivery should acknowledge gender inequalities of access and participation that are '*products of social relations characterised by an inequitable distribution of power between people on the basis of gender and social difference*'. As the Principles fail to acknowledge these inequities by implication they are discriminatory against women. This is supported by Spink (2000) who acknowledged the Principles failed to differentiate on the basis of gender, were developed on stereotypical assumptions about women and do not account for the whole lived experience of men and women with psychiatric disabilities. Therefore although as Spink (2000) argues, the treatment services operate differently than psychiatric rehabilitation services, the basis of care in each reflects inequities for women.

A further difference between treatment and rehabilitation services is the level of funding with rehabilitation services poorly resourced in comparison to treatment services. Within Victoria, PDRSS receive only 14% of the state's total mental health service funding with the majority of funds directed towards treatment services (Vicserv 2002:1). This significantly lower level of funding denies adequate resources to PDRSS to make them a genuine part of the mental health service landscape. The funding difference limits rehabilitation service provision, impacts on staffing levels within services and effects the availability and accessibility of services especially in rural areas where services are required to cover large geographic distances. The funding differential presents a structural inequity, marginalises the role of PDRSS's and reinforces the biomedical treatment model at the expense of rehabilitation (Gerrand 1993, Spink 2000).

Psychiatric rehabilitation has a beneficial effect on symptoms and quality of life (Anthony, Cohen & Farkas 1990, Hatfield & Lefley 1993), decreases the incidence and duration of hospitalisations (Anthony et al 1990) and offers economic advantage to the public mental health system (Ireland & Morgan 1996 cited in Morgan 1998:22). However it has been estimated that more than 75% of those who could benefit from rehabilitation are not receiving this (Morgan 1998:22). Lack of services, especially in rural areas, has been cited as a factor in the low level of take-up in rehabilitation, but the take-up level is still low in metropolitan Melbourne where services are more available. This indicates a gap in the numbers of people who could benefit from rehabilitation and those that actually attend.

In a study with a Victorian metropolitan AMHS, Morgan (1998) identified that the most common reason for individuals not participating in rehabilitation was a lack of awareness of the services in their area. Although others in the treatment services can refer clients, it was found that psychiatrists are significant in influencing client participation yet there was a substantial under-utilisation of rehabilitation programs or referrals by this group. Whilst a number of conclusions may be drawn from this, it does indicate that psychiatrists do not necessarily see rehabilitation as an integral component of psychiatric care. This lack of

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<sup>5</sup> Refer Appendix 4.

recognition of the value of rehabilitation may be an influence in the lower level of funding for the sector given the influence and authority of the medical establishment, or the result of the lower level of funding and service provision available. Whatever the reason it does demonstrate the continued dominance of treatment services in mental health care. Of those who do attend rehabilitation, women are in a minority in many program types.

## **2.2 Gender perspective on psychiatric rehabilitation**

Amongst registered clients of AMHS, women made up 48% of clients in 1999/2000 (DHS 2003:8), however the Victorian Burden of Disease Study (2000) found that women have a higher disability burden from mental illness than men although the reasons for this are unclear. Although almost equally represented in AMHS women are in a minority in participation in many psychiatric rehabilitation programs (Spink 2000, DHS 2003).

Statistical data for PDRSS indicates that in 2001 women used PDRSS equally to men, however this data is skewed by an over-representation of women using the mutual support and self-help programs and planned respite services (DHS 2003). Females are in a minority in participation in the Home Based Outreach, Day Programs and Residential Rehabilitation Services. A key theme among writers to explain these differences is the gendered nature of psychiatric rehabilitation (Gerrand 1993, Cox 1994, Reid 1995, HS 1997b, Spink 2000). Spink (2000:172) argues that:

*The area of psychiatric rehabilitation and in particular psychosocial rehabilitation day programs represent a microcosm of social relations in Australia, and is characterised by the unequal distribution of power with all its connotations.*

Gendered processes are evidenced through stereotypical assumptions about women (Gerrand 1993, Reid 1995, Spink 2000) and day program structures that are not always sensitive to the needs of women (Cox 1994, Reid 1995, Mowbray et al 1997, Spink 2000). It should be noted that psychiatric rehabilitation services are not homogeneous but are

complex and multifaceted both in culture and approach to delivery even within standardised program types such as day programs therefore there will be variations across services.

The literature indicates that women are less often referred to PDRSS than men (Gerrand 1993, Reid 1995, DHS 2000a) and it has been argued that stereotypical assumptions about women disadvantage women's entry and participation in day programs (Gerrand 1993, Reid 1995, Spink 2000). Reid (1995) identified clinical sex role stereotyping of women as a key barrier to rehabilitation referrals for women. It was found that clinicians generally considered women were less likely to seek or need employment or vocational training therefore they were less likely to be referred and had limited access to rehabilitation. Women are stereotyped as more socially and economically dependent leading to lowered performance expectations on their participation in rehabilitation (Reid 1995).

However, a lower rate of referrals for women is not consistent across all areas or services. Spink (2000) in her study of women in metropolitan day programs in eastern Melbourne found that more women than men were referred. Although Spink's study focussed on a smaller number of services this difference demonstrates the complexity of patterns of use of services by women

A further dimension of structural inequalities that act as a barrier for women's participation is the way in which programs operate (Gerrand 1993, Reid 1995, Mowbray et al 1997, Spink 2000). Spink (2000) examined the structure of delivery in rehabilitation services and found that PDRSS's, day programs in particular, often privileged men and disempowered women. She argues that programs are characterised by gendered processes and structured around gendered assumptions and beliefs of the roles of women and disability. In general there was a limited understanding of gender disadvantage among service users or service providers.

It has been reported that safety issues, intimidation and threats of violence have been

identified as significant structural issues for women in their use of day programs. With the higher participation rates for men, women can feel alienated or threatened by predominantly male environments (Cox 1994, Reid 1995, HS 1997b). Often women feel intimidated by the behaviour of men in mixed day program sessions and this is exacerbated if women have past experiences of violence, sexual harassment and abuse (Graham 1994, Reid, 1995, Fraser et al 1998, Spink 2000). This negatively impacts on women's participation rates.

It should be noted that day programs are provided by a large number of PDRSS's and many of these have developed gender awareness and sensitivity in their delivery. Women only space and programs have been developed and implemented in a number of services and areas demonstrating attention to gender issues. Spink (2000) found this to be a useful strategy in terms of the number of women participating, although in some services it created tensions due to a perceived neglect of men's needs. This view was particularly represented from male participants. Some of the providers who were interviewed in Spink's study acknowledged the value of single sex groups but highlighted the need for more structural changes to address the needs of women.

Parenting and family responsibilities are significant for women as program delivery in PDRSS is not always sensitive to the needs of women as parents (Brooks 2002). Women need more flexible delivery, access to childcare and acknowledgement of the additional resources and supports required to assist and support them in their parenting role. There are few targeted programs available for women who are parents with a mental illness or the facilities to support their parenting role (Reid 1995, Spink 2000, Brooks 2002).

Both Reid (1995) and Spink (2000) found that the structure of day programs disadvantaged women with additional needs, for example women with marked psychiatric disabilities or particular emotional or education needs. They did not cater for younger women, women from indigenous or non-English speaking backgrounds or aging women (Reid 1995, Spink 2000). This indicates that there are large groups of women whose needs

are not being met in PDRSS.

Evidence suggests that women's participation rates in PDRSS has increased in recent years although there has not been a systematic analysis to understand the reasons for this increase. A 2003 data analysis report on PDRSS identified that in 1995/96 women made up 36% of the day program population and 40% of the home based outreach program compared to 1997 where women comprised 43% of both day program and home based outreach populations (DHS 2003:8). The data analysis report acknowledges that overall PDRSS *'are providing reasonable access to women, (but) it is necessary to look at ways to improve access in day, home based outreach support and residential rehabilitation programs'* (DHS 2003:8).

The emphasis in the data analysis report on services improving access for women builds on previous Victorian government reports that recognised the low level of participation of women in PDRSS and called for changes to improve access for women. *Tailoring Services to Meet the Needs of Women* (HS 1997b) identified priority areas for change across all mental health services with a key priority area of increasing the participation rates of women in PDRSS. However, the approach of focusing on services to improve access for women is only part of the issue. This approach identifies women as 'the problem' and fails to acknowledge the broader contextual issues such as the low number of people overall who are assessed as suitable for rehabilitation but are not referred (Morgan 1998) or the lower level of resourcing available to the rehabilitation sector (as discussed earlier).

The literature supports the view that multiple and complex social structural inequalities are relevant in an analysis of women's participation in psychiatric rehabilitation. Inequities are evidenced through referral processes, the operations and structures, particularly of day programs and the gendered nature of delivery. The diverse needs of women with a serious and enduring mental illness are not fully understood and multiple social and structural inequities intersect to marginalise and disadvantage these women.

Although PDRSS's provide a range of services,<sup>6</sup> research has predominantly focused on women's participation in day programs although home based outreach programs (HBO) are the most widespread service type (in delivery and funding) in Victoria (DHS 2003).

### **2.3 Home based outreach (HBO) support services**

Home based outreach programs are individually tailored programs designed to assist people with a psychiatric disability to attain housing stability, reduce their isolation, redevelop social skills, build their capacity to manage the multiple tasks of daily life and facilitate access to community services (DHS 2000a). HBO services include housing and support programs for people who are homeless, at risk of homelessness or those living in marginal housing.<sup>7</sup> A limited number of public housing units are available for long term tenure for participants in housing and support programs.

HBO programs are predominantly accessed by males (DHS 2003) and little is known about homelessness or housing issues for women with a mental illness. Although 75% of homeless persons are thought to have a mental illness the gender representation of people with combined homelessness and mental illness is not known (Hodder, Teeson & Burich 1998). However, it has been estimated that many women with a mental illness are continuing to live either with family and/or in unsatisfactory housing circumstances which masks the visibility of women in the homelessness population (Herman, McGorry, Bennett, van Riel & Singh 1989, Hodder et al 1998, Thomas & McCormack 1999). More knowledge is needed to understand the experiences of women and the barriers that impact on their access to housing services.

Robson (1995) found that women are more likely to try other options before approaching a housing service, they are less trusting that the housing provided through the agency will

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<sup>6</sup> Refer Appendix 1.

<sup>7</sup> The Supported Accommodation Assistance Act (Commonwealth 1994) has defined homelessness to include inadequate access to safe and secure housing that damages or is likely to damage a person's health,

be safe if they have had past experiences of violence and women generally consider themselves less entitled to housing. Casey (2002) takes a different view and argues that homeless women with a psychiatric disability are motivated to find permanent housing but they are typically unprepared for independent living due to the nature of their mental illness or psychiatric disability therefore they are less likely to approach a housing service.

However, home based outreach services offer a range of supports, other than housing, to enable people to live independently. These include counselling, social skill development, community access, activities, advocacy, financial management and general and specialist information sharing. Therefore issues such as homelessness rates for women may be only one part of the picture in explaining the minority participation of women in HBO programs. Complex social cultural conditions of women's lives such as women feeling less entitled to housing or safety issues related to past experiences of violence (Robson 1995) impact on women's capacity to seek housing support. This warrants further research to understand contextual issues and whether current service types are the most appropriate models for meeting the needs of women with mental illness. Much of this is unknown and a gender blind paradigm currently exists for the delivery of these services.

Relatively little is known about the everyday life experiences of women with a severe mental illness (Mowbray et al 1997, Spink 2000), although it is known that mental illness is a distressing and isolating experience.

## **2.4 The experience of mental illness**

The experience of severe mental illness is often devastating and disabling with the illness symptoms and experience making it difficult for people to care for themselves, work or stay socially active. Unlike other illnesses, the impact of mental illness is episodic in nature, can vary in severity over time and for many it may be characterised both by periods of relative wellness and acute distress requiring increased support or

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threatens the person's safety, marginalises or places the person in circumstances that adversely effects the adequacy, safety, security or affordability of housing.

hospitalisation. Whilst there is agreement on the distressing nature of mental illness there are differing views on whether gender is a useful point of analysis in exploring these experiences.

In a study of women's participation in psychiatric rehabilitation Spink (2000) found that amongst participants in the program there were various views about gender differences in the experience of mental illness. Almost half of the group believed there was a gender difference whilst the remainder identified the uniqueness and diversity of individual experiences as more influential than gender. Amongst service providers there was a significantly different response as a majority of both males and females of this group believed there was a difference. Spink found that the providers' beliefs on difference were based on stereotyped assumptions about the differences between men and women. Key beliefs across both groups related to the vulnerability of women associated with experiences of violence and behavioural issues for men. However, within this analysis there were contradictions in beliefs about women's experiences among the providers such as women being more vulnerable but also more able to deal with difficult situations.

The experience of mental illness is complex and diverse but in the literature there are common themes presented which relate to gendered sources of stress such as bias exhibited through diagnoses and treatment, experiences of isolation, stigma and discrimination, violence and abuse along with family responsibilities for women. Gender is a valuable analytical perspective in exploring the coping and managing styles in dealing with a mental illness.

#### **2.4.1 Gender, psychiatric diagnosis and treatment**

When people enter the mental health system they are exposed to processes which focus on diagnoses, treatment and care with a predominance of considerations of individual pathology rather than contextual issues for women (Horsfall 1994, Russell 1995, Crowe 2000, Kohen 2000). Although PDRSS focus on rehabilitation many of the services require the participants to have a diagnosis of a severe mental illness for entry to the services

therefore the majority of rehabilitation participants have been clients in AMHS and exposed to diagnostic processes.

The gendered nature of diagnoses and treatment has been extensively critiqued by feminist writers. It has been argued that the Diagnostic and Statistical Manual of Mental Disorders (DSM) is based on stereotyped, value laden classifications which pathologise the behaviours of women and disadvantage those who don't conform to stereotyped roles of women (Gerrand 1993, Horsfall 1994, Mowbray et al 1997, Orme 2001). Research indicates that women are more frequently prescribed psychotropic medication and in greater quantities compared to men and are more likely to receive electro-convulsive therapy (Johnstone 1989, Gerrand 1993, Mowbray et al 1997). The literature consistently describes how these processes of psychiatric practice leave women feeling misunderstood and disempowered.

Receiving a psychiatric diagnosis is not a neutral event and research has indicated how the process of labeling people with a mental illness increases their vulnerability to discrimination and exposes them to negative community attitudes (Johnstone 1989, Brown 1996). Alternatively for some individuals, labeling and diagnoses can be a positive approach as it increases their access to resources such as pensions, benefits and services (Spink 2000). Paradoxes and contradictions such as this highlight the diversity of experiences and acknowledges that binary thinking is not always a useful framework for understanding.

Spink's (2000:129-132) study found there were gender differences in perceptions about the usefulness and use of diagnostic labels and the social impact of being diagnosed with a serious mental illness. Less females than males discussed being comfortable with using the language of diagnoses or labels and more female service users (53%) than male service users (23%) said they preferred not to use diagnoses or labels other than generic terms to describe their situation. It was also found that more female service users actively avoided public awareness than males which matched the finding that more females than

males discussed the negative social impact of a serious mental illness diagnosis. Given these findings it is probable that women are less likely to disclose or identify themselves as having a mental illness in the community. Women resisting this identification may isolate themselves.

#### **2.4.2 Isolation and relationship issues for women**

Mental illness often leads to a loss of interpersonal relationships, loneliness and social isolation (Davidson & Stanyer 1997). It can have multiple impacts such as family relationship breakdown and self-imposed isolation due to the distress of symptoms or fear of stigma. Whilst these experiences are not exclusive to women, women are more likely than men to isolate themselves from social interactions due to high levels of anxiety, feelings of incompetence and fear of stigma (Brown 1996). These are complex reactions to both the experience of mental illness and fear of negative responses by the community.

Paradoxically, while women are more likely to isolate themselves (Brown 1996), gender specific research on the significance of social connections demonstrates that women with a mental illness have a greater psychological need to feel integrated in their community and to become more involved in their environment (McLaren, Jude, Hopes & Sherritt 2001). Many writers argue the importance of gender relational issues as women are more in tune to a sense of connectedness with others and feel a sense of disconnection more acutely (Miller 1976, Gilligan 1982, Miller & Stiver 1993). Miller (1976:83) argues that women '*stay with, build on, and develop in a context of connections with others*'. The converse of this is that women's sense of self is dependant upon the maintenance of affiliations and relationships, and a disruption of connections may be seen as '*something closer to a total loss of self*' (Miller 1976:83).

The experience of isolation associated with a mental illness may be more profound for women as connection through relationship is a significant psychological factor in women's development and sense of wellbeing. Conversely a sense of disconnection, even if self-imposed, can lead to high levels of distress. Negative social attitudes can be a

determinant in women's isolation and disconnection.

### **2.4.3 Experience of stigma**

There is a good deal of agreement in the literature that many people with a mental illness experience negative community attitudes and stigma (ABS 1999, Jorm et al 2000). The experience of stigma can have a profound effect on people with a mental illness and the fear of being labeled and identified as 'other' with its implications of difference and inferiority is a negative force. Stigma is a powerful social sanction that disempowers individuals and groups who are seen as undesirable or destabilising of the community by dominant political and cultural groups within that community (Olsen 2002). Stigma and attitudes of non-acceptance negatively affect the shaping of individual identity or sense of self leading to feelings of powerlessness, shame, guilt and fear for those who experience a mental illness.

Some writers have argued a gender difference in the experience of stigma although there are differences in their understandings of this. Miller (1993) contends that stigma is experienced as a process of disconnection which is felt more intensely by women and at deeper levels than men. Brown (1996) views stigma as traumatising for women as it builds feelings of incompetence which negatively impacts on their daily lives and social activities. This view is supported by Spink (2000) who identified that women are more sensitive to stigmatising and alienating language than men, thus feeling a sense of separation and difference more acutely. The literature therefore indicates that gender is relevant in understanding the impact of stigma.

In the context of isolation and relationship issues for women (as discussed earlier in this chapter), the discrimination and marginalisation associated with the experience of stigma may be a significant contributor to women's distress. Experiences of violence and abuse are gender related sources of distress.

### **2.4.4 Violence and abuse of power**

There is an increasing community awareness of the significance of violence and abuse in

the lives of many women both as a precursor to the development of mental health problems and as an experience of women within the mental health system (Dennerstein et al 1991, Gerrand 1993, Graham 1994, Reid 1995, Mowbray et al 1997, Spink 2000, Stoppard 2000). Spink (2000) found that abuse and trauma can take many forms for both men and women diagnosed with a serious mental illness but women report significantly more sexual abuse than men. It has also been reported that many women experience physical or sexual assault or harassment in mental health care by other male patients (Graham 1994, Reid 1995, Spink 2000).

The impact of assault is traumatising and has broad impacts at different levels for women who have been subjected to this. Graham (1994) found that treatment services can add to the trauma for women if they inadequately respond to women's disclosures of abuse. Clearly gender is a significant concept in understanding the experience of violence in relation to women with a mental illness and their care.

The literature draws attention to experiences of trauma associated with the exercise of power within mental health systems. This includes the stigmatising consequences of psychiatric labeling (Reid 1995, Spink 2000), the dominating practices of mental health professionals and the statutory authority invested in this group (Gerrand 1993). Whilst acknowledging the significance and sometimes coercive nature of professional and statutory power, Healy (2000) argues that nominating the professional as a constant site of dominating power neglects the considerable differences in the kinds of power that emerge in human service practices. This approach negatively portrays people in a constant role as powerless clients. Considerations of the use and abuse of power and the impact of this for people who are clients in mental health systems requires further consideration.

Many women with a mental illness also have family and parenting responsibilities which warrant consideration in relation to mental illness.

#### **2.4.5 Family responsibilities and parenting**

Significant for many women with a mental illness is the stress associated with family

responsibilities and parenting. This is a gender issue as women typically take on more of a role or responsibility for family care (Brown 1996). Many women with a mental illness fear losing custody of their child/ren especially if they become unwell and/or require hospitalisation (Mowbray et al 1997). The fear of losing custody of children is a powerful social control mechanism that reinforces the power of the medical establishment to control the lives of these women (Mullaly 2002).

Zemenchuk, Rogosch & Mowbray (1997) found that studies of mothers with a mental illness typically focused on the impact of the mother's illness on her children and evidence does indicate these children are at risk of psychological problems. While the importance of this need was acknowledged it was also found that parenting is difficult for mentally healthy women but may exacerbate the mental health status of those with a mental illness. Many of the women in these circumstances were limited in their social support networks, fearful of disclosure of their mental illness; needed assistance with parent related activities and often lacked suitable parental role models. These examples demonstrate the context of women's experiences with unsupportive social circumstances bringing additional stress for women.

The special needs of women with family responsibilities and parenting have not been recognised and few psychiatric rehabilitation services are available to specifically assist women with a mental illness in their parenting role (Spink 2000, Brooks 2002).

#### **2.4.6 Coping and managing**

Stoppard (2000) identified that in the literature on mental illness, women are often portrayed as adopting 'passive', 'problem avoidant' and 'emotion focused' coping strategies particularly in their experiences in dealing with depression. She discusses how several writers have explored gender related differences in coping, with women seen as more likely to adopt a passive, ruminating style in contrast to the more active coping responses of men. Stoppard challenges the label of 'passive' for women's coping style whilst also identifying that all women do not necessarily have more active alternatives

available to them especially if they have difficult life circumstances such as dealing with violence and abuse or struggling on a low income.

A dualistic approach of oppositions such as women's responses being defined as 'passive' whilst men's are labeled 'active' does not reflect the complex experiences and multiple capacities of both men and women (Healy 2000). It assumes the concept of 'woman' is a fixed category and denies the capacity of women to adopt a range of responses to the sociocultural conditions of their lives and their distress.

Stoppard (2000) argues that when research begins from a woman's standpoint a range of strategies to enable women to deal with their mental illness experiences and move towards recovery are revealed. These strategies demonstrate that women are active in developing coping styles that match their circumstances. This is consistent with Egan (1994) who found a range of recurring themes in the way women mediated their mental illness experiences and the difficulties in their lives. These included resistance to cultural stereotypes and prevailing social norms in connection to the medicalisation of their distress, the demonstration of self-agency by changing their difficult life circumstances and finding people to listen to them and validate their experiences.

Many first person accounts from women who have experienced mental illness recount the importance of the development of individual coping strategies to overcome the distress and disabling effects of their illness. Themes include acknowledging the importance of self-care, finding supportive people to talk to, establishing and working towards goals and developing successful coping strategies to deal with symptoms (Deegan 1988, 1993, Mowbray et al 1997, Stoppard 2000, Brooks 2002).

The literature has identified a number of key gender differences in the experiences of mental illness. The identities of women with a mental illness are shaped by the conditions of their lives such as isolation, experience of stigma, family responsibilities and parenting. These difficulties marginalise women and add layers of difficulties to their daily lives. The

literature suggests that despite their difficulty women resist a stereotypical passive paradigm and instead demonstrate their capacity to develop effective individual coping strategies.

A broad approach has been taken to develop a picture of women's experiences, however the experience of illness is diverse and uniquely individual therefore it is important not to universalise women's experiences (Egan 1994). It has been demonstrated that there are gender differences in the experience of mental illness but women are not homogenous and their needs and experiences differ and therefore should be responded to in gender sensitive ways. An added dimension to women's experiences is that of living in rural Australia.

## **2.5 The rural context**

Australia is one of the most urbanised populations in the world with the majority of Australians (70%) living in capital cities or major metropolitan areas (Vichealth 2002). Australian rural communities are diverse in size, demographic composition, economic and social infrastructure as well as the distance from the larger population centres.

Although it is generally accepted that rural Australians have a poorer health status in comparison to their urban counterparts,<sup>8</sup> there is less agreement about urban rural differences in mental health status (Phillips 1993, Cheers 1998, Cooney 1998, Strong et al 1998, Humphreys 1999, Dixon & Welch 2000, McLaren et al 2001). The *Australian National Survey of Mental Health and Wellbeing* (1997) indicated that there was no significant difference in the prevalence of mental illness between metropolitan and non-metropolitan areas. However, Judd and Humphreys (2001:255) argue that this finding must be treated with caution as the majority of subjects came from metropolitan areas and units of analysis as broad as 'metropolitan' and 'non-metropolitan' can average out important differences between communities. These communities may otherwise exhibit

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<sup>8</sup> This is in relation to premature mortality, morbidity rates and the higher number of rural suicides particularly for males living in rural areas (Phillips 1993, Cheers 1998, Cooney 1998, Strong et al 1998, Humphreys 1999, Dixon & Welch 2000, McLaren et al 2001).

considerable variation in factors such as poverty; deprivation and a number of other health damaging and health promoting behaviours that contribute to mental ill health.

Several issues related to rural life have been identified as creating disadvantage for people with a mental illness. These include access to transport, the conservative nature of rural communities in relation to perceptions and experiences of stigma, the accessibility of services and issues of declining population which negatively impacts on opportunities for social connectedness for rural members. Although much has been written about these topics there is little that directly addresses the gender implications of the rural experience.

### **2.5.1 Transport in rural areas**

In rural areas the structural disadvantage of limited public transport options means individuals are more dependent upon private transport. For those who don't drive or own a car, life can be very difficult as transport is a highly valued social and economic asset (Commonwealth of Australia 1999). In rural areas public transport options decrease the further the distance away from the major metropolitan centres (Cheers 1998). Outside of the regional centres there are few public transport options for residents, either within, or between communities.

People without access to adequate transport can be isolated from their social and support networks as transport dependence negatively impacts on the development and maintenance of supportive social relationships and builds a sense of social exclusion (Bostock 2001). This is relevant for people with a mental illness as supportive relationships are an important buffer, particularly for women, in the face of adversity (Brown & Harris 1978, NHMRC 1991, AIHW 1998).

In rural areas people are either dependant upon others for transport, the availability of public transport or they can only access services and activities within walking distance. In rural areas the long travelling distances between communities and lack of public transport can preclude people from actively participating in activities, the life of their community

or in services. Practitioners in rural areas are often relied upon for transport for clients to enable them to access services or activities and this places an extra burden on service resources and worker time. Access to transport is an important issue, particularly in rural areas and lack of access creates disadvantage.

### **2.5.2 The culture of rural communities**

There is considerable literature which portrays rural communities as more conservative, less informed and less open to enlightened attitudes than urban areas (Dixon et al 2000, Jorm et al 2000, Wainer & Chesters 2000). Rural conservatism reinforces stereotypical views which negatively impact on the role and status of women, devalue the female role and exclude women from full participation (Wainer & Chesters 2000, Stoppard 1997). Stereotyped views deflect attention away from difficulties in the conditions of women's lives whilst portraying women in the conventional modes of wife, mother and housewife (Stoppard 2000).

Among writers the rural community is variably described as less tolerant or open to diversity (Vichealth 2002), stigmatising of conditions such as mental illness (Fuller et al 2000), less accepting of behaviours and actions that are not seen as congruent with the community (Cheers 1998) and marginalising of those who are seen as 'different' from the norm (Wainer & et al 2000). A common reason put forward to explain the conservative nature of rural communities is linked to the geographic isolation and large travelling distances which bring less exposure to a range of attitudes and values (Dixon et al 2000).

The stigma associated with mental illness negatively impacts on help seeking in rural areas. Fuller, Edwards, Proctor & Moss (2000) in a study to understand the rural influences on people's identification, and response to, mental health problems found the stigmatised nature of mental health problems led to a reluctance for people to acknowledge difficulties or seek help. Participants in the research indicated that *'most people have stereotyped views related to people with a severe mental illness being equated with 'insanity', with conditions being 'incurable' and requiring 'detention'* (Fuller et al

2000:150).

Depending on the size and relative isolation of the rural community, there is a higher visibility of individuals which makes it more difficult for people to hide their mental illness or any negative effects or behaviours in relation to their illness. A high visibility for individuals who may be regarded as not conforming to the norms of that community can lead to rejection or people perceiving themselves to be at threat of rejection by the community (Cheers 1998, Martinez-Brawley 2000).

A culture of conservatism and self-reliance in rural communities produces a mistrust of outsiders. This mistrust can be directed at those from 'the city' (metropolitan areas) as well as larger regional centres. This impacts on the acceptance of people who may have moved to the community or the acceptance of those providing services from other areas (Cheers 1998, Fuller et al 2000). People who are transient or relatively newly arrived in the rural community are more likely to be labelled negatively, marginalised and ostracised.

Other writers put forward the view that rural communities are not homogenous and whilst they acknowledge in general the conservative nature of rural communities it is argued there are significant differences both within and across communities (Cheers, 1998, Martinez-Brawley 2000). It is argued that the same condition of geographic isolation that creates conservatism also has positive effects. Some of these positive effects are the building of a sense of community cohesiveness among its members (Vichealth 2002), an enhanced capacity for social support and interaction for community members (Humphreys 1999) and tolerance of 'difference' among those who have been accepted as members within that community (Cheers, 1998, Martinez-Brawley 2000). However, as rural communities vary according to relative size, isolation and proximity of the community to larger centres it is expected that there is diversity and significant difference in these positive effects both within and across communities.

Women with a mental illness in rural areas have the double bind of stereotyped views of women's role and a devaluing due to negative community perceptions of those with a mental illness. The conservative nature of rural communities serves to exclude people with a mental illness by reinforcing stigma and negatively impacting on people's help seeking behaviour. Paradoxically rural communities can also be supportive, have high levels of social cohesion and be accepting of individuals in the community. Rural communities are heterogeneous and this leads to a diversity of understandings of the rural experiences.

### **2.5.3 Rural service access**

Economic changes, rural decline and a centralisation of services have led to many people leaving rural areas. This reduces local access and leads to significantly greater costs and additional time involved for rural people in accessing community services (Cheers 1998, McLaren, Jude, Hopes & Sherritt 2001). Services in rural areas are fewer, often have to cover large geographic areas and in smaller communities they may have less capacity for flexibility in their delivery due to limited resources (Cheers 1998, Brooks 2002).

People living in rural areas experience significant disadvantage with increasing distance from a major urban centre as there is less access to health care including General Practitioners (GP), pharmacists and medical specialists (Strong et al 1998). Rural Australia is less well supplied with GP's with only 20.2% of Victoria's GP's practicing outside the capital city (Wilkinson 2000). Of the female population of GP's, 83.6% of female GP's practice in Melbourne whilst only 16.4% practice in the rest of the state (Wilkinson (2000). The limited number and low ratio of female to male GP's in rural areas effects women's capacity for choice either between GP's or for a choice of gender of their GP.

In rural areas GP's take on a higher burden of psychological care in their practices than urban areas because they have less access to specialist services (Campbell, Walker & Howard 2001). However, psychological medications were more frequently prescribed in large rural areas than metropolitan areas but patients were more often referred to allied

health professionals in smaller rural areas (AusMed 2002).

Young, Dobson & Byles (2001) found that women living in rural areas are disadvantaged in access to a female GP, to after hours care and there is less availability to GP's due to the hours the GP's work with a long waiting period for an appointment. Young et al (2001) found there is a lower rate of bulk billing in rural areas and more than half the women in urban areas bore no cost for their GP visit compared to one quarter of women living in non-urban areas.

Difficulties in service access include participation in rural PDRSS. In the Loddon Mallee Region of Victoria there are a number of PDRSS providers although only a smaller number of these provide a broad range of programs.<sup>9</sup> The PDRSS service landscape in the Loddon Mallee Region is characterised by the location of services in the regional cities of Bendigo and Mildura and larger country towns of Swan Hill, Echuca, Castlemaine, Maryborough and Kyneton. In some areas of the Region there is only one provider which limits choices for individuals. Services outside of the regional centres of Bendigo, Mildura and Swan Hill are often small (with as few as two part time workers in some areas) and they are required to cover large geographic areas. Beyond the towns as mentioned, services are provided as visiting services in many smaller rural communities. This impedes access and availability of services for many people especially when individuals are reliant upon workers for transport as often people using these services don't have access to either a private vehicle or suitable public transport.

The literature describes a picture of multiple disadvantages experienced by women through a lack of choices between services which are often highly centralised, few in number and difficult to access. This occurs within a rural context of limited transport options, differing sizes of communities and distance between communities.

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<sup>9</sup> Those who provide multiple PDRSS programs include St Luke's Anglicare (in the Loddon Campaspe sub-region) and Mallee Family Care (in the Mallee, Southern Mallee sub-region).

#### **2.5.4 Social connectedness in rural communities**

Research emphasises the importance of a sense of belonging and the value of social connectedness to build resiliency as a protective factor in mental health. The social fabric of rural communities is often portrayed as promoting of social connectedness through their relatively smaller size, closer community ties and lower rates of residential mobility (Cheers 1998, Vichealth 2002). Baum (1999) found there was more local trust exhibited in rural communities because people were more likely to know everyone else, face to face contact was frequent and there was a relatively closed and smaller number of people with few strangers in these communities. This evidence suggests that the capacity for social connectedness is linked to the nature of rural life and the benefits of living in less populous areas. The capacity to be known and accepted is a positive factor in rural communities enabling supports from the community, reduces isolation and strengthens people to deal with adverse life circumstances.

Baum (1999) also found that for those born and bred in the country the connectedness of social life was an important aspect of rural living. However people's experiences were diverse and in the research there was an acknowledgment that whilst the social life in rural communities is beneficial for some, it may also be experienced as exclusionary for others. This exclusion was played out as a distrust of strangers or those seen as 'different'. Acceptance or inclusion in rural areas is linked to time and historical connections in the community, however it may be different for those who don't have long established connections.

Rural communities are diverse in size, infrastructure and distance from metropolitan and regional centres. The economic and population decline in rural communities reduces the community's capacity to support strong social connectedness among its members (Vichealth 2002). Decline also leads to a loss of services and social structures e.g. sporting clubs which contributed to a supportive environment. Lack of employment, education and services leads people to access these resources elsewhere. These combined factors

undermine a sense of belonging and limit people's opportunities to participate in their community thus heightening a sense of isolation.

Rural communities are not homogenous and the experiences and opportunities for social connections within communities vary. A sense of belonging builds resiliency but if there are few opportunities for this a sense of alienation can develop (Vichealth 2002). The literature describes how rural communities can provide a sense of belonging and acceptance for members but conversely this is dependent upon historical links in the community. Changing economic circumstances have reduced the rural infrastructure leading to fewer opportunities for connection. There are levels of diversity and difference within the rural context. Paradoxically whilst the environment can serve to strengthen resiliency and social connectedness there are many elements that make life difficult for rural residents.

An exploration of the rural context presents a complex, multilayered picture of diversity where individuals are socially, culturally and structurally disadvantaged but paradoxically the rural environment can serve to strengthen resiliency and social connectedness. This supports the concept put forward by Judd et al (2002:299) who argue that 'rural' is best seen as a conceptualisation of 'place' rather than a geographical construct. It is argued that to understand rural Australians and mental health an appreciation of the environmental context which encompasses location in a broad sense is crucial. The concept of location covers aspects such as geography, patterns of social connections that link both individuals and individuals to community as well as the socioeconomic and cultural constraints and opportunities that influence rural life. This is relevant to understanding the experiences of women in rural areas.

Whilst an understanding of the issues for rural women are important so too is the value of understanding the supports and care that assist women to move beyond their difficulties towards recovery.

## **2.6 Beneficial supports and care for women with a mental illness**

A number of studies have explored helpful elements of care and support for people with a mental illness. In the literature significance is given to the caring relationship with the nature of the care relationship being important. There are gender differences in access to support although there is often the experience of stigma in non-mental health services. The notion of collaborative care across services is relevant along with support from friends and community members.

A limited number of studies have taken a gendered perspective on supports and care but the majority of studies exploring helpful aspects are gender neutral as few effectiveness studies state gender composition of the sample and often there is a predominance of male participants (Mowbray et al 1997). The male perspective has been taken as the norm and women's experiences and understandings have been marginalised and little understood.

### **2.6.1 Significance of the caring relationship**

A number of studies involving consumer perspectives have explored the helpfulness of mental health services in general and these have consistently found the helping relationship to be critical (Sullivan 1994, McGrew et al 1996). Valuable elements of the relationship included caring, welcoming and accepting (Sullivan 1994), attributes of therapist, availability of staff, non-specific assistance, someone to talk to/listen and problem solving support (McGrew et al 1996). Relationship building is regarded as central to assisting the person to move through their difficulties. However, Anthony et al (1990) focus more on the importance of workers' assisting people in the re-development of skills as being the most helpful aspect.

Other studies demonstrate the importance of a therapeutic relationship development for women in particular (Miller 1993, Reid 1995, Cagne 1996, Watkins 1996, Cogan 1998). Several writers have identified human companionship and relationship building as healing factors in assisting women to recover a sense of self worth and positive self-image (Herman 1992, Cagne 1996, Watkins 1996). This connection with others allows women to

feel valued and affirmed and leads to '*increased mutuality and empowerment*' (Miller 1993:430). The factors that assist with this are caring, compassion, empathy, kindness, being there, being real, listening and empathy (McLellan 1995, Watkins 1996). These helping aspects assist women to overcome their social dislocation and marginalisation.

The caring relationship is cited as important for both men and women however the literature indicates relevant gender issues with women developing and moving towards recovery through participation in a positive relationship. This is particularly relevant given the marginalising nature of living with a mental illness in rural areas as discussed earlier in this chapter. However, the nature of the relationship with an emphasis on the equalising of power has also been shown to be significant.

### **2.6.2 The nature of the helping relationship**

Onken, Dumont, Ridgway, Dornan & Ralph (2002) found that while helping relationships were positive, equal collaborative partnerships promoted recovery. This supports earlier work by McGrew et al (1996) who found the professional was most helpful by joining with the consumer and engaging and working in a partnership based approach. Mosher and Burti (1992:15) discuss the partnership orientation as not necessarily meaning equality or complete reciprocity of relationship but one that moves in the direction of '*more or less reciprocal (friend-like) ones over time*'.

For many consumers in mental health services the helping relationship is not always positive. This has variously been described in many consumer stories as oppressive, hurtful, abusive, dehumanising and disempowering (Deegan 1989, Leete 1997, Deegan 1997). These stories describe negative experiences where individuals have been subjected to the statutory power of professionals in mental health care.

Several writers explore a relational approach as important to women in the context of care. (Jordan, Kaplan, Miller, Stiver & Surrey 1991, Miller & Stiver 1993, Jordon 1997). The interplay of power as hierarchical and 'power over' i.e. directing and controlling others, is

disempowering of women and inhibits women's development and growth. Women develop through growth and connection in relationships when there is a mutuality, where power means '*having power with*' (Miller et al 1993). This is growth enhancing and women can exert power through the process of fostering growth in others.

This is an alternative way of exploring the caring relationship that has synergy with earlier discussions in this chapter where it was explored how experiences of isolation led to a sense of disconnection for women as women develop in the context of connections with others (Miller 1976).

Gender distinctions are also relevant in help seeking behaviour.

### **2.6.3 Accessing support**

There are identified gender differences in service access and women are more likely to access a range of mental health services and supports than men (Dennerstein et al 1991, Gerrand 1993, Astbury 1996, ABS 1999, Kohen 2000, Spink 2000). This includes care from general practitioners, private psychiatrists and generalist health and welfare support services. According to Kohen (2000) issues such as perceptions of women having a greater willingness to admit to psychological distress and seek treatment and differences in the way men and women react to psychological distress are relevant for understanding the gender differences in help seeking. This is contested by Zimmermann-Tansella et al (1991, cited in Spink 2000:68) who argues that it is the identification of a problem that is different between men and women. Once men identified a problem they are equally likely to obtain help.

Spink (2000) found that in addition to using more services, women use a range of services and networks differently to men. Women relied on other services to meet their needs and supports for social activity. Spink argued that overall women seemed more skilled than men in finding appropriate services for themselves.

People with a mental illness can be deterred from seeking help from services because of

the negative stereotyping and risk of stigma from those services. Spink (2000) in her study found evidence in the literature that stigma and discrimination against people with a mental illness presents difficulties for people in accessing a range of general community services. Spink (2000:123) argued that service users with a mental illness are discriminated against if they use community services but alternatively their choices are restricted if they only use specialist mental health services. The potential for discrimination presents women with a dilemma if they wish to access other services and supports. The rural context with limited availability of services and choices further disadvantages women in these circumstances.

#### **2.6.4 Collaborative care**

Several writers argue that the development of effective linkages and coordination between mental health services and other community services and supports enhances the value of the service system to clients (Reynolds, Inglis & O'Brien 2002, Martin 2003). The Second National Mental Health Plan (1998) seeks to implement an integrated flexible service framework with collaboration and coordination across services to improve the outcomes for people.

Holmwood, Groom, Nicholson (2001) argue that the development of linkages between GP's and mental health services has the potential to significantly improve outcomes for the majority of mental health consumers but found that the relationship between these groups is relatively underdeveloped. In the literature the focus of collaboration is between GP's and clinical treatment services whilst the role of PDRS Services and the importance of linkages with GP's for clients of these services is not acknowledged. The focus of discussions related to 'mental health services' are taken to mean clinical treatment services and the role of PDRSS is not recognised in these discussions. This reinforces the marginalisation of PDRSS in the mental health service area.

Although many writers acknowledge the importance of coordinated care, Holmwood et al (2001) found there was little evidence in the Australian context that care planning

improves consumer outcomes. They concluded that while the concept may represent an intuitively better way to provide care, improved outcomes are yet to be demonstrated. Reynolds et al (2002) acknowledge the lack of evidence, but argue that linkages are a responsibility across the service system as people with a mental illness are found amongst the client group of many services. This is supported by Fleming (2001) who argues that rural practice works best when there is wide collaboration and integration between services.

There are constraints and challenges to providing effective linkages across services with differences in the orientation of sectors. The rural context with limited services and availability issues limits the capacity for collaboration. However La Nauze & Weeks (1999) found a high level of connection and networking in community work in rural areas. Whilst this study explored the benefits and practice of feminist community work and the value of networking, it is unclear whether this provides a direct benefit to consumers. In my own experiences of rural practice the networking does appear to strengthen awareness and consciousness of providers of mental health difficulties, facilitate access for people with a mental illness to other services and promotes collaboration and integration between services. However given the geographical and resource constraints it requires effort and goodwill on the part of practitioners to achieve levels of integrated care. In my experience this is more easily enabled in smaller communities where practitioners across services are more readily known. It would be useful to explore this further through research.

In the context of the distressing experiences supportive friends and community have also been considered beneficial for women with a mental illness.

#### **2.6.5 Supportive friends, family and community**

Welch (2000) found that in rural areas social support is a key determinant of mental health status. It was found that social support can come from a variety of sources, including family, friends, work colleagues, the family doctor or community organisations. Social support was found to provide a range of benefits such as emotional support, esteem

support, tangible assistance, information and network support. Although this research was conducted in a rural area it is unclear whether these findings are distinctive to social support in rural areas.

Positive social supports can modify the effects of ill health. This benefit is supported by Onken et al (2002) who found that the process and supports for people with a mental illness extend beyond the mental health system and there was value in connecting with others including family and community members.

In relation to social support, research suggests that women receive more social support from their friends than men do (Welch 2000). Spink (2000) also found women more readily accessed other services and individuals for social supports and activities. Miller et al (1993) argues that as relationships are a central organising feature in women's development, women are more often searching to participate in interaction with others and receive greater benefit and social support from connection with others.

Whilst supportive friends and community have been identified as important for women with a mental illness it is unclear whether these supports are readily available for women in rural areas. Earlier in this chapter it was found that rural communities are conservative and potentially stigmatising of women with a mental illness although other factors that intersect to mediate the negative landscape such as connection and history with the community were identified. Opportunities for social connectedness in rural communities are varied and a declining rural infrastructure limits opportunities for social connection and the development of a supportive friendship or community network for women. It would be relevant to explore this further.

## **2.7 Conclusion**

The key themes from the literature present a complex and multidimensional picture of marginalisation and disadvantage for women living with a mental illness in rural areas.

These experiences are embedded in the broader social cultural context and the discussion demonstrated the significance of gender as a key definer of women's experiences.

The concepts of marginalisation and disadvantage were explored from a number of perspectives: the dominance of medical treatment services, the marginalisation of psychiatric rehabilitation services and the constraints on women's participation in these services, the gendered nature of the mental illness experience and the rural context. The discussion of beneficial supports and care for women with a mental illness provided many clues to ways to support women experiencing a mental illness.

However a diversity of experiences and understandings exist alongside a variety of paradoxes. This combination acknowledges the heterogeneous nature of women's experiences and of life in rural areas.

The next chapter will discuss the theoretical perspectives which influenced the research design and method as a way of understanding the experiences of the women who took part in this study.

## Chapter 3: Multiplicities of understanding: theoretical perspectives

This chapter discusses the development of the conceptual understanding which informs the methodology. This conceptualisation builds on the literature in the previous chapter which demonstrated the nature and structure of marginalisation and inequalities for women whilst also showing heterogeneity of experiences and interests.

The conceptual understanding is presented through a discussion of:

- The research question
- Shaping the theoretical perspective
- Uncovering multiple oppression
- Towards the methodology
- Refining the method

### 3.1 The research question

The research question guiding this thesis seeks an understanding of the meaning and structure of women's participation in rural psychiatric rehabilitation through an exploration of experience. The research question thus developed was:

*What are the experiences of women using psychiatric rehabilitation services in rural Victoria and what can we learn from this?*

My interest in exploring this subject developed both from my practice experience and from knowledge that this was an area that was very little explored. The psychiatric rehabilitation services provided by PDRSS in Victoria are relatively recently developed and only minimal research has been conducted to date to underpin the work of the sector.

As a practitioner working with many rural women with a mental illness I witnessed both their distress and courage as they went about their daily lives. My assumption in working with these women and in understanding their distress was the significance of gender oppression and the social constructions of women's mental health experiences

through a dominant medical paradigm.

My objective in this research therefore was to acknowledge the inequities of power and to centre women's experiences by 'giving voice' to women participating in rural psychiatric rehabilitation, in particular the home based outreach services. The research question was purposively broad to enable women's stories of the meanings of their experiences to emerge. It is not enough to just understand experiences as the focus of critical social work practice is always on change. Hence the second part of the research question was to enable a focus on learning of opportunities for change and how services and practitioners could benefit from the shared knowledge.

In developing this research I acknowledge that there is not a fixed category of 'woman'. Within the notion of 'woman' there are a multitude of diversities and heterogeneity of experiences although there is some degree of consistency in the political environment which constitutes the social cultural conditions of women's lives.

Whilst arguing for methods which reflect difference, Oakley (1998) raises questions about the use of woman-only samples as they allude to authentically female ways of knowing. Oakley argues that this ignores the tendency for sex differences to disappear when direct comparisons are made between samples of men and women.

In response to this, I draw attention back to the literature in the previous chapter where it was shown that the concept of gender is a significant definer of power relations in the context of mental health care. Whilst recognising the complexities of the theoretical concept of gender I am conscious of the paucity of literature on psychiatric rehabilitation alongside the vastness of mental health literature that deals with clients of mental health services as a homogenous group without a recognition of gender distinctions and differences in experiences. In this context I argue the importance of adding to the body of knowledge by centering women's experiences and bringing them in from the margins whilst challenging essentialist assumptions about women's nature.

Reinharz (1992:191) explains why it is important to gain knowledge in areas where

there is a paucity of knowledge and research:

*'Because the needs and opinions of these groups are not known, their views have less influence on the conditions under which they live. Thus the study of certain groups is political because it demystifies. In the demystification framework, researchers believe that the very act of obtaining knowledge creates the potential for change because of the paucity of research about certain groups accentuates and perpetuates their powerlessness.'*

The development and shaping of my thinking in relation to the theoretical perspective which influenced the research design was an reflective process that was both inductive and deductive at various stages where I drew upon both my practice experiences and the literature to inform my thinking. To reflect this process this chapter is presented as a series of sequential stages that led to the development of the methodology and research design.

### **3.2 Shaping the theoretical perspective**

The research question emerged from practice and my theoretical assumptions on the inequalities for women in mental health care. However, I wished to gain a broader understanding both as a way of testing my assumptions but equally as a way of developing a more in-depth understanding of women's experiences in psychiatric rehabilitation. As the research commenced and my examination of the literature proceeded my thinking began to develop around the notion of difference between individual women's experiences and how these were explained. I proceeded to explore this further through both the literature and reflections on my practice experiences.<sup>1</sup>

Through this reflective process my theoretical perspective developed towards critical theory influenced by poststructural feminism. A commonality of these perspectives is the attention drawn to power relations although there are differences in the understandings of how power operates.

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<sup>1</sup> This was not a linear process but one that developed over a lengthy period and involved a repetitive cycle of visiting the literature, reflection and revisiting the literature etc. Through the ongoing process of the research my understanding of the analysis has continued to proceed in this cyclical manner.

Traditional critical theory draws attention to oppositions such as powerful and powerless and the coerciveness of power. This perspective locates sources of domination and social problems in broader social, cultural and structural processes and practices and understands differential experiences as framed by dominant ideologies which privilege one group over another. Examples are males over females, the privileged over the poor, urban over rural, able persons over persons with disabilities, worker over client and so on (Mullaly 2002).

Whilst traditional critical theory matched my earlier assumptions I found that poststructural feminism informs this position by recognising gender oppression whilst moving away from dualities such as powerful and powerlessness, toward a recognition of diversity and difference in the processes of power (Healy 2000, Mullaly 2002). A poststructural perspective asserts that power and oppression are not single unifying concepts as the experiences of individuals are characterised by heterogeneity both within and across groups.

Poststructural feminism refuses fixed social identities such as 'women' but acknowledges this as a political identity for the purposes of struggle against oppression (Healy 2000). Thus it informs this research by allowing contextualised understandings of the marginalised position of 'women' within mental health care whilst being less ~~prescriptive~~ prescriptive of how power relations take shape. Poststructuralism acknowledges that the concept of power is multiple, diverse and creates meaning through identity formation.

In relation to the research question therefore, poststructural feminism informs this by enabling a contextual understanding whilst searching for diversity both within the identity construction of individual women in psychiatric rehabilitation and across the number of women who participate. This will allow for diversity and contradiction in experiences in relation to power to emerge.

The notion of identity is a key concept in understanding the processes of power and there are commonalities in understanding of this concept across critical theorists and

poststructuralists. Consistent with this theoretical perspective Mullaly (2002:57) describes identity as the '*conditions or distinguishing features that mark or characterise or identify an individual*'.

From a psychological standpoint such as Erikson (1968 cited in Bird & Drewery 2000) identity is based on experiences which are influential in the identity formation period during the path to adult development. This definition describes identity primarily as an internal phenomenon which becomes a fixed formation in adulthood. This refers to the notion of identity as a fixed and stable essence for individuals whose form and impact on a person's life operates regardless of the surrounding environment.

In contrast critical psychological and sociological perspectives distinguish identity as an ongoing construct of contextualised internal and external phenomena (Bird & Drewery 2000, Jackson & Stewart 2000). Identity is conceived as a process of self-definition where the way we define ourselves internally is influenced by the external environment linked to a sense of how one is valued by others. Identity construction is therefore a complex set of interweaving factors where the external environment influences the self-concept, the individual's general capacity to function and how one relates to the world (Jackson & Stewart 2000).

The construct of identity is a product and conduit of power which is not only mitigated by contextual social cultural conditions such as social status, gender, race, class, urban, ability, education, employment etc., but also by the value accorded to one's social identity by more dominant social groups (Healy 2000, Jackson & Stewart 2000, Mullaly 2002). Dominant social groups can ascribe negative social identities to those who are 'different' and thus categorised as 'other'. This explains the marginalised position of women with a mental illness as explored through the literature in the previous chapter.

As stated earlier, my assumption in working with women with a mental illness is the significance of oppressions such as gender and subjection to a dominant medical paradigm. Postructuralism informs this dichotomy approach which portrays women in

these contexts as subordinate only, by enabling a broader understanding and seeking of diversity. Therefore when I reconsider my observations of women's identity in these circumstances I begin to construct a different picture. Whilst still accepting oppression in these circumstance and the marginalising aspects of this I can acknowledge the differences such as those afforded by for example, age, race, locality, education, income and so on.

This goes even broader for example when I consider issues of powerlessness for women alongside women's participation in mental health consumer groups which can be very powerful when raising voices and getting issues addressed. Another circumstance is that some women will experience stigma and discrimination in a community whilst others feel accepted. These are just some examples that assisted me to think beyond the notion of dualities and consider the value of a critical poststructural feminist perspective.

The second stage of linking my theoretical assumptions to the principles of the research design was a return to the literature to enable a further drawing out of understandings related to the complexities of power relations and identity as experienced by women in mental health care.

### **3.3 Understanding multiple oppression**

In the previous chapter the literature identified that women's oppression within society is replicated in mental health systems. The experience for women subject to mental health care is linked to processes of power through multiple intersecting oppressions such as gender, the dominance of medically oriented treatment services and the intersection of rural disadvantage.<sup>2</sup> These experiences significantly contribute to how women are socially defined by their mental illness.

Mullaly (2002) explored the concept of oppression in its many forms and describes an intersectional model of multiple oppression where these oppressions may be distinct, but not unrelated. Mullaly (2002:151) discusses how these oppressions overlap:

*... an intersection is the location where a person's race, for example, will meet with his or her class, age, or any other component of the person's identity.*

Mullaly argues that intersecting oppressions build on the oppression already experienced. While some oppressions may mediate the effects of others i.e. an individual may be in the position of dominant or subordinate depending on the context, overall, the intersection is mutually reinforcing and overlapping (Mullaly 2002). For women in mental health care intersecting oppressions are exposed through analyses of the medicalisation of women's distress, the role of experts, the processes of power in the caring relationship and the marginalisation of the rural concept.

In exploring these dimensions I recognise the heterogeneity of both individual and group experiences and acknowledge that not all women residing in rural areas with a mental illness will experience these multiple oppressions, nor will one individual woman experience these at all times. However, these are relevant concepts for consideration and decision making in the development of the methodology for this research.

### **3.3.1 Medicalisation of women's distress**

Statutory authority and considerable privileging invested in the medical establishment gives power to providers to medicalise and individualise despair and distress in women in a way that frames this as mental illness (Gerrand 1993, Horsfall 1994, Russell 1995, Williams et al 2001). However, in any discussions it is important not to deny the experience or expression of women's emotional distress but it is argued that with the *'expert' advice of psychiatrists ... women are consistently guided to think about their emotional distress in pharmacological and psychotherapeutic terms*" (Fullagar et al 2002:4-5).

Many feminist writers have argued that several aspects of women's experiences fall outside the prevailing biomedical psychiatric paradigm and these factors are socially

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<sup>2</sup> It is acknowledged that a number of other dimensions of oppression also intersect such as age, class,

constructed (Brown & Harris 1978, Carmen et al 1981, Dennerstein et al 1991, Cox 1994, Horsfall 1994, Mowbray et al 1997, Kohen 2000, Bondi et al 2001, Martin 2003). Those which are especially relevant to women include poverty, disempowerment, socialisation processes, role conflicts and trauma emanating from violence. The context of women's lives is a significant indicator of the development of mental illness and these same life circumstances impact on the individual support needs for women (Dennerstein et al 1991, Cox 1994, Mowbray et al 1997).

Socioeconomic factors are relevant in the development of mental ill health. The most disadvantaged and marginalised groups in our communities have been identified as experiencing the poorest mental health (Payne 1991, Mowbray et al 1997, Kohen 2000). Socioeconomic factors such as low income are linked to issues of poverty and deprivation and women disproportionately suffer from these (Payne 1991, Kohen 2000).

Women's multiple work roles may significantly increase their stress and symptomatology (NHMRC 1991, Piechowski 1992, Mowbray et al 1997, Lee 1998). Research indicates that women in paid employment generally continue to take a higher level of responsibility for unpaid domestic labour (Lee 1998). In Australia women tend to be concentrated in poorly paid occupations and 39% of employed women work in part time jobs compared to 7% of men (ABS 1997, Lee 1998).

An often unaddressed issue for women that has a high correlation to the development of mental illness is that of sexual abuse and violence (Dennerstein et al 1991, Herman 1992, Gerrand 1993, Graham 1994, Mowbray et al 1997). In a research study exploring the psychiatric service experiences of women who have been sexually abused Graham (1994) found an overwhelming message of emotional and mental pain arising from the women's experiences of sexual assault.

A discussion of the medicalisation of women's distress portrays how the difficulties in women's lives give rise to distress which is subsequently framed as 'illness' within a

medical paradigm. This conceptualisation exposes women to the role of experts and this is now explored.

### 3.3.2 The role of experts

Mental health care has developed as a hierarchical system that reinforces medical dominance through care and treatment processes (Horsfall 1994, White 1995). Hierarchical systems and powerful medical dominance shapes psychiatrists and other medical carers as ‘experts’. A critical perspective suggests that professionals control the client/patient by their capacity to define who and what a client/patient is and should be (Hugman 1991, Harper 1995, Mullaly 2002).

The positioning of mental health professionals in the role of ‘expert’ replays broader social and cultural relations that exist to perpetuate power structures (White 1995, Williams & Popay 2001). The social cultural conditions institutionalise and support the dominance of the medical model in mental health care and reinforce the role of ‘expert’ through statutory authority invested in these structures. This is played out at the microlevel where the power invested in the role of ‘experts’ enables this group to categorise subordinate groups or individuals as ‘other’. According to White (1995) this institutionalised power through the state positions ‘experts’ in ways that enable them to speak and interact with people that reproduces a subject / object dualism. This process:

*‘places people on the other side of knowledge, on the outside. These ways of speaking and acting make it possible for mental health professionals to construct people as the objects of psychiatric knowledge, to contribute to a sense of identity which has ‘otherness’ as its central feature.’*

White 1995:112

This ‘otherness’ perpetuates discrimination and marginalisation of women who experience mental distress and places them at risk of highly medicalised interventions. Medical interventions are based upon positivist, scientific approaches that preclude the life experiences of women, perpetuate the sense of women as objects and enhance the power of the ‘expert’ as the provider of care (Scambler et al 2001).

Diagnoses and treatment in mental health care are mediated through a dominant medical ideology that confirms the role of psychiatrists and medical staff in the role of ‘experts’. Whilst the efficacy of treatments and outcomes in mental health are often contested, the requirement for women to submit to these is less challenged (Orme 2001).

Harper (1995) argues that women are culturally prepared for compliance and the acceptance of ‘expert’ constructions of their experiences through complex social structures. This is supported by Halasz (1994:8) who asserts that women may be silenced against a male oriented scientific knowledge base which is supported and reinforced by the power of scientific rationalist thinking which claims possession of ‘*true knowledge*’. The power invested in scientific knowledge and ‘experts’ reinforces powerlessness for women.

In this section I have outlined the oppressive connotations of ‘expert’ and the power inherent in the framing of ‘other’. The literature also demonstrated the significance of the caring relationship and the complexities of power in this interaction.

### **3.3.3 Processes of power in the caring relationship**

From a critical perspective the caring interaction reflects a dichotomy of power in the professional – client relationship where professionals have privileged access to power through broader social structures whilst clients are seen as opposite with significantly less access to power (Jones 2001, Mullaly 2002). The dominance in the relationship is reinforced through professional status and knowledge. Hugman (1991) argues that the power of the professional is based in the control of language and the knowledge that rests with that professional. He presents gender as being interwoven with issues of hierarchy, occupation and racism in the structures and practices, the theories and the language of the caring profession.

Hugman (1991) argues that there is also a gender distinction in the way that the biomedical approach is used and that the needs of service users are constructed by caring professions. Women service users tend to be treated less favourably than men in

the degree of support they may be given, and women's behaviour is often viewed differently to that of men within professional theories (Hugman 1991).

Although social workers are not part of the medical establishment they are connected with professional authority by association and through privileging with a professional status (Mullaly 2002). Professionals are invested with power through a number of means such as education and status which reflects the privileged social position of this group.

Healy (2000) contests the notion of a dichotomy whereby professionals are presented as all powerful in opposition to the powerlessness of clients by arguing that a dyad approach fails to grasp the dynamism and diversity of practice. The critical poststructural perspective recognises the '*inescapability*' of power whilst challenging the oppositional concept of a dichotomy which ignores the diversities within each category of worker and client and denies that a number of positions are possible (Healy 2000:74). This perspective allows for different understanding of the processes of power within the professional client relationship to emerge.

The literature in the previous chapter portrayed the complexity of the rural experience for women with a mental illness and this is further explored through a critical analysis of rural life.

### **3.3.4 A critical analysis of rural life**

The concept of 'rural' has been defined in various ways but the most common approach has been through geographical constructs. This has been challenged by Judd et al (2002) who defines rural as place, as composed of complex and interdependent geographical, social, economic and cultural entities. For Cheers (1998) and Briskman (1999) an understanding of the rural concept is often misconstrued as 'non-metropolitan' which places a focus on an urban rural dichotomy. This places 'rural' in the position of 'other' and on the margins.

In rural analyses several writers have concluded that power and resources are centralised in the urban sections of Australia. In general, rural issues are often on the

margins of mainstream political agendas and the metropolitan perspective dominates research, service delivery and service model development (Cheers 1998, Briskman 1999, La Nauze & Weeks 1999). Rural communities can feel excluded with centralised service systems that treat their needs as homogenous with urban communities rather than acknowledging the diversity and complexity of rural areas (Cheers 1998, Briskman 1999, Fraser et al 2002). Thus differences between urban and rural are not easily recognised in the development of services. This approach also fails to recognise the heterogeneity of the rural environment where specific rural, regional and geographical characteristics often distinguish one rural area/community from another (Briskman 1999, Fraser et al 2002).

From a poststructural perspective a focus on the dichotomy of urban and rural can draw attention away from, and obscure, structural differences in terms of gender, race and social class (La Nauze et al 1999, Briskman 1999). Teather (1998) explores how women are now more prominent in rural considerations but historically there was a process of 'overlooking women'.<sup>3</sup> She asserts that despite changes, there is a continuing intransigence of gender relations in rural Australia, a traditional resistance to feminist values despite the changing identities of women and contends that women who challenge the rural norms are often socially rejected and ostracised. This argument was discussed in the previous chapter where attention was drawn to the stereotyped views of women in conservative rural communities.

There is an increasing analysis of the gendered nature of rural life and a number of factors experienced by rural women have been suggested as leading to greater stress for women in rural areas. These include a lower level of education, lack of child care, geographic isolation and economic and occupational disadvantages leading to higher levels of poverty and the need for public assistance (Dennerstein et al 1991, Alston 1997, Human Services 1997a, Cheers 1998, Cooney 1998, Dixon & Welch 2000, McLaren et al 2001).

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<sup>3</sup> This is particularly in relation to women's historical involvement in the rural development of Australia.

The rural experience is characterised by complexions of centralised services, inadequate recognition of differences, gendered perceptions and gender inequalities.

The multiple oppression as discussed in this section present a contextual picture of the marginalisation and alienation of women with a mental illness. This understanding led me to the next stage in my considerations of the research design.

### **3.4 Towards the methodology**

In a process of reflection on the contextual issues of marginalisation and alienation for women I continued to consider the implications of an understanding of power relations for the development of the research design. As I understand gender to be a key concept of understanding in mental health care I therefore also drew upon feminist writings on methodologies such as those of Reinharz (1992) and Stanley and Wise (1990) to develop some principles for the design.

The principles I developed for the methodology include:<sup>4</sup>

1. Use of subjective to give voice
2. Intent of working towards equalising the power in the research relationship
3. Acknowledgement of diversity
4. Transformative and change focused
5. Considerations of the distressing experiences of women

These principles will now be discussed in more detail.

#### **3.4.1 Use of subjective to give voice**

Traditionally the usual perspective of mental health care and service experience has been from the professional or 'expert' related interpretations of the realities of

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<sup>4</sup> Other enduring principles attached to feminist research that have influenced this design include those as listed by Grbich (1999:53):

1. The need to centre the social constructedness of gender
2. An acceptance that women are oppressed, although there are differing views to the responses to this oppression.
3. A presentation of research results that addresses issues of power, honesty and ownership.

psychiatric service users. The voices of people using the services have traditionally been excluded as:

*'Mental health patients are frequently only seen as the passive objects of study, whose individual characteristics and feelings are mostly variables to be 'controlled out' in order to ensure valid results.'*

Rogers, Pilgrim & Lacey 1993:6

However, the 'expert' related view has been challenged through critical and feminist analyses and the rise of the consumer movement in mental health. A critical feminist analysis places the experiences of marginalised groups at the centre, challenges positivist approaches and understands the experiences of the world as being framed by social cultural contexts of gender, race and class.

The positioning of subjectivity is important as a way of giving voice and is consistent with the consumer advocacy movement in mental health which rejects 'expert' related views. This movement promotes the significance of understanding individual experiences of people with mental illness from the consumer perspective (Rapp et al 1994, Brooks 2002, Lammers 2002).

Through the rise of the consumer movement a process of inclusion and acknowledgement of consumer voices and experiences is considered central to mental health research (Chamberlin 1997, Wadsworth 2001). According to Wadsworth (2001:8):

*'... psychiatric service users have points of view which are valid and reasonable per se. ... It is poor science for the researcher (or provider) to insist on their own version of reality. In this sense 'reality' is most clearly socially constructed.'*

It is important to listen to subjective experiences as knowledge rests with the subjects rather than being an objective truth (Stoppard 2000).

### **3.4.2 Intent of working towards equalising the power in the research relationship**

The influence of the theoretical perspectives led me to consider a research design which ensured the research process did not replicate medical dominance. I consider that an understanding of relations of gender, power and dominance are crucial to the design and therefore I wished to develop a methodology consistent with this understanding.

Although there is no single feminist methodology, Reinharz (1992) discusses how a feminist research methodology includes the principle of the involvement of the researcher as a person within a non-exploitative framework. To achieve this there should be shared information, openness and clarity of communication. To develop a non-exploitative framework attention is paid to the process of the research as much as the outcome. Process is also important in the negotiation of meaning as Rice & Ezzy (1999:53) explain:

*... meaning in interviews means that the relation of teller to listener is as important as the content and structure of the tale itself.*

I therefore sought a method that would enable me to acknowledge women's experiences rather than presenting them from an expert orientation.

### **3.4.3 Acknowledgement of diversity**

I considered it important to use a method that would enable the women to tell their own stories and to provide an opportunity for rich, thick descriptions of the meanings as understood by the women to emerge. In the telling of these stories I hoped that the diversities and complexities of women's experiences would be revealed.

### **3.4.4 Transformative and change focused**

Critical research and many feminist streams have an emancipatory intent. Hemingway & Parr (2000:154) define emancipation as:

*... transformation of human capacities from possibility to actuality'. This activity opens up spaces for development, in which people are able to explore, test expand, enhance and reflect on their capacities.*

Critical theory is motivated by a change focus in relation to social processes and practices that are exploitative and discriminatory. Although research and practice are situated in specific societal, cultural and material contexts, developmental and emancipatory activity is possible through an emphasis on the power of agency to transform society (Mullaly 2002). Human agency is defined as reflective of micro-processes of people's lives and the everyday choices they make. Human agency enables people to '*open spaces within which they expand their capacities, explore the lives they wish to lead and build the communities in which they wish to live*' (Hemingway et al 2000:159).

#### **3.4.5 Considerations of the distressing experiences of women.**

As a practitioner in the mental health field I am aware of the distress associated with mental illness in women's lives, particularly those with a severe and enduring mental illness who live with varying levels of distress on a daily basis. Therefore in developing the method for this research I considered it important not to lose sight of the experience of distress in women's lives.

This situation is considered by Pilgrim & Bentall (1999) who argue that a middle position of critical realism to mental health problems is helpful as it ensures a proper caution about historical and cultural relativism whilst still acknowledging the realities of misery. They suggest that it is best to approach research in mental health with a flexibility that allows for a holistic understanding that attends to both the social determinants of misery and involves exploring the individual's personally attributed meanings.

In seeking a suitable research design that matched the principles as discussed and explored the meanings of experiences I became familiar with the phenomenological method.

### 3.5 Refining the method

Phenomenological method focuses on the individual's construction of their life-world and emphasises that people's actions are best understood and revealed when they are situated in the meanings that constitute their everyday world (Lauterbach 1992, Rieman 1992, Moustakas 1994, Creswell 1992, Wadsworth 2001). This is a process of understanding individuals and uncovering the rich meanings they attach to experiences by entering into their field of perception in order to see life as the individual sees it (Bryman 1996 cited in Creswell (1998:275).

Cosgrove (2000) discusses the concepts in phenomenology and argues that an essential benefit of a phenomenological method is that it privileges a conception of agency. That is, it emphasises the importance of the lived experience, facilitates the interpersonal realm in the constitution of identity and is capable of providing information on how and in what ways women are able to resist dominant paradigms. Given the strength of a phenomenological method in emphasising the richness and complexity of experience I decided to incorporate this into the research design.

However, phenomenology is asocial and does not connect or situate the structures of meaning within the socio-political realm. Therefore, this decision came with a personal caution to continue to explore methods or processes to acknowledge the social, cultural and structural grounding of experience. This was important given the argument presented through the literature that social, cultural and structural inequalities are contextual and embedded in the lives of rural women with a mental illness.

In the process of exploration and consideration of appropriate research designs a number of studies using a phenomenological method in mental health research were found.

Karp (1996) in a phenomenological study to understand the concept and meanings of depression, disconnection and illness discussed how it is imperative to understand the human experiences from the subjective point of view of the person undergoing it. To really learn the meanings that people attach to their illness experiences and to

understand their coping mechanisms, their relationships and the influence of depression, approaches from the 'inside' are required. Phenomenological approaches respect the complexity of human behaviour and demonstrates that it takes '*different shapes in different cultural worlds*' (Karp 1996:19).

McInnes & White (2001) used a phenomenological approach to explore the concept of loneliness as it related to older adults with mental health problems especially depression. This approach was adopted as the research sought to understand the meaning as determined or constituted by the subject where '*the individual is constituted by the situation as well as constituting it*' (McInnes et al 2001:130). It was concluded in this study that the perspective of the participant and the context of their emotional pain and suffering in their experience of the phenomena requires the rapport and relatedness inherent in phenomenological research methodology.

Later as the research progressed I also found research by Onken, Dumont, Ridgway, Dornan & Ralph (2002) which explored concepts of recovery of people with a mental illness through a phenomenological approach. This was seen as a useful, exploratory approach consistent with an area where '*not enough is known about the experience and life process of recovery*' (Onken et al 2002:13). In this process the knowledge gained was grounded in an understanding of the day to day experiences of people with psychiatric experiences and their life world.

As research is not a static process, nor are participants passive objects of study, the research design was developed to incorporate the principle of transformative and change focused elements.

Action research emphasises change and improvement of practice in the context where the research takes place and it begins with the stated intention of improving practice as well as producing additional knowledge. A feature of action research is personal and collective self-reflection with the collective process oriented to action. It has been conceptualised as a way of investigating professional experience which links practice and the analysis of practice into a continuously developing sequence (Morton Cooper

2000). Friere (1972) argues that linking knowing and learning through an ongoing cycle of action and reflection, leads to the development of a critical awareness about the world participant's live in (cited in Rice & Ezzy 1999). Critical theory often provides the underpinning; participation is emphasised and people work towards improving situations or practices (Morton-Cooper 2000).

Maguire (1996) argues that action research in practice and theory has often ignored the gender factor in oppression. To address this it is important that women are also on the agenda of research even though the meaning of 'woman' differs according to place, situation and time (Rice & Ezzy 1999).<sup>5</sup>

The values and methods as discussed in this chapter have been incorporated into the research design. The perspectives of critical poststructural feminist theory and feminist methodology have influenced the adoption of phenomenological and action research methods to meet the objective of giving voice to women in psychiatric rehabilitation.

### **3.6 Conclusion**

This chapter has discussed the development of the theoretical perspective which informs the methodology. This was explored through a discussion of the construction of identity and the nature of multiple oppression in relation to women's mental health care in the rural context. The developed theoretical perspective is critical poststructural feminism with the methodology informed by feminist and critical research principles. These led to an exploration of phenomenological and action research methods for the research design.

The next chapter on the methodology will explore how these concepts have been operationalised in the research process.

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<sup>5</sup> It is acknowledged that ethnicity, class and age also influence the experience of being a woman, and that the use of 'women' as a unifying group is problematic. However, the focus is on bringing women out of the margins.

## Chapter 4: Methodology

The objective of this study was to explore the experiences of women using psychiatric disability rehabilitation and support services (PDRSS); in particular the home based outreach programs, in the Loddon Mallee Region of rural Victoria. A critical poststructural feminist perspective has informed the development of the research design and the principles of feminist methodology have been drawn upon to develop the method. Consistent with these principles a design which incorporated phenomenological and action research methods was adopted.<sup>1</sup>

This chapter outlines the research design and discusses the research process. This is developed through the following areas:

- Research design
- Procedures of the research
- Verification and trustworthiness
- Ethical considerations
- Limitations of the methodology
- Presentation of the results

### 4.1 Research design

In developing the research design my consideration was to '*give voice*' to women participating in rural psychiatric rehabilitation services. To more fully understand women's experiences a dual perspective method was adopted. This incorporated listening to women and workers in PDRSS in rural Victoria, although the women's words and direct experiences retain primacy in the research. This dual perspective adds further meaning to the women's experiences by firmly placing these in the context of care. The inclusive process with workers centres the experiences of women, removes them from the margins and facilitates a change inducing process with workers through their group reflections of the experiences of women participants.

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<sup>1</sup> These were explored in depth in the previous chapter.

In implementing a dual perspective method I anticipated that this would generate significant amounts and variety of data. It was not my intent to homogenise the voices of workers with those of the women participants but rather to add to the knowledge of women's experiences.

The methods of data collection involved:

- a phenomenological method to gather data from individual in-depth interviews with women participants
- an action research method using focus group interviews with practitioners.

As the purpose of the research was to give voice to women and uncover the meanings they attach to their psychiatric rehabilitation experiences a phenomenological method was developed. Phenomenology is a process of uncovering rich meanings attached to experiences. I considered this an appropriate method with the use of individual interviews for data gathering purposes with women. Individual interviews were also used as a means of protecting the privacy and confidentiality of the women.

The individualised phenomenological method allowed for in depth data gathering and an opportunity for each of the women to share their personal narrative. The process of individual interviewing allows for in-depth interaction, facilitates inquiry and enables a:

*trusting relationship to develop so that respondents will provide information which is honest and thoughtful.*

Lammers 2002:97

Whilst a dual perspective has been incorporated into the research design it is acknowledged that there are significant power differentials between women participants and workers. Given this, I considered it important to incorporate a change inducing focus to the research therefore the action research method used with workers was based on an assumption that workers were open to both hearing and reflecting upon, the experiences, concerns and issues of the women.

This belief is consistent with ‘conditions of change’ as outlined by Wadsworth (2000:8)

- People first being able to identify a discrepancy between how things are and how they could or should be.
- People believing things should be different/better (wanting change and improvement)
- People believing things could be different/better (being able to imagine change and improvement).

The use of focus groups with workers is consistent with key concepts and activities of action research, which include participation, education and both personal and collective self-reflection (Grbich 1999, Morton-Cooper 2000). Action research ‘*is a quest to understand and improve the world by changing it*’ (Grbich 1999:206).

According to Morton-Cooper (2000:61):

*‘when practitioners come together to discuss a problem they often touch on a range of potential explanations, and after discussion takes place some may change their views, others may hold trenchantly to their original positions, but all will be aware of different perspectives on the same problem.’*

In the next section I provide more detail on the procedures used in this research.

## **4.2 Procedures of the research**

A series of procedures were used to implement the research design which included:

1. Recruitment of participants
2. Interviews with the women
3. Transcription and data analysis
4. Focus group interviews with workers
5. Transcription, data analysis and thematic linking between data sources
6. Feedback to participants

These steps are now detailed below.

#### **4.2.1 Recruitment of participants**

The initial step was to seek formal permission from agencies providing PDRS services to enable access to participants who were clients and workers of these services. This process ensured that all the relevant Services were cognisant of the research project and that all of the women selected for interview were well supported and met the required criteria.

In the Loddon Mallee Region there are five agencies that provide PDRS services<sup>2</sup>, however only two of these are funded to provide home based outreach services.<sup>3</sup> Access to service providers was facilitated by my knowledge of, and participation in, the service network over a 5 year period.

Once permission was received from the agencies I distributed written information on the research project to service workers across the Region.<sup>4</sup> The intent was to inform workers and potential participants about the research project to ensure informed consent.

A purposeful criterion sampling strategy was used to enable access to women who experienced home based outreach support. According to Creswell (1998), in a phenomenological study the participants must be individuals who have experienced the phenomenon being explored and can articulate their conscious experiences.

#### ***The following criteria were used for selection of individual participants:***

- Women who were currently receiving home based outreach support services in the Loddon Mallee Region

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<sup>2</sup> These agencies are St Luke's Anglicare, Richmond Fellowship, Golden City Support Services, Loddon Mallee Housing and Mallee Family Care.

<sup>3</sup> These agencies are St Luke's Anglicare in the Loddon Campaspe sub region and Mallee Family Care in the Mallee, Southern Mallee sub-region of the Loddon Mallee Region.

<sup>4</sup> Refer Appendix 5: Research Information Sheet.

- Women who have been receiving this service type for a period of three months or longer.
- Women who range in age from 18 – 65 years.<sup>5</sup>
- Women who have adequate support structures in relation to their mental health needs.<sup>6</sup>

The next step entailed the forwarding of information to service workers and they were asked to distribute and discuss this with potential participants. The information forwarded included:

- a Letter of Introduction to the Research Project<sup>7</sup>
- Participant Consent Form<sup>8</sup>
- Interview Guide<sup>9</sup>

This initial approach by workers to the women was to provide them with an outline of the project and seek their interest in participating. It was only after the women had consented to participate that the interviews were organised. The purposeful process of identification and the seeking of consent approval by workers prior to my contact with the women considerably lengthened the data collection process. However this was an important ethical consideration to protect the privacy of the women with whom the workers discussed the research project.

#### **4.2.2 Interviews with the women**

The initial research plan was to involve a sample size of up to ten women, however as the process of the research evolved there were nine women who participated in the research.<sup>10</sup> Eleven women had initially agreed to participate in an interview, however

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<sup>5</sup> At the time of the data collection this was the mandated age range for persons using PDRSS in Victoria.

<sup>6</sup> This was an ethical consideration to ensure the safety of the women participating.

<sup>7</sup> Refer Appendix 6: Letter of Introduction

<sup>8</sup> Refer Appendix 7: Participant Consent Form

<sup>9</sup> Refer Appendix 8: Interview Guide

<sup>10</sup> Having a smaller number of women than initially intentioned participate in the individual interviews did not negatively impact on the research. The intent was to gather in-depth information to understand the essence of the women's experiences and rich data was gathered from the nine participants to enable this analysis to take place.

two of these did not proceed. One woman later changed her mind and decided not to participate and a second woman was hospitalised just prior to her interview.

As an ethical consideration there was a “cooling off” period between the initial consent with workers and the conducting of the interviews to enable women to withdraw if they wished. This involved a reconfirmation of consent immediately prior to the interview commencing where the women were requested to sign a second consent form.<sup>11</sup>

The organisation of interviews was a complex process given the broad geographic area in which the research was conducted. The process of recruitment was through service workers and it was only when the women had consented to participate that the worker notified me. Initially it was planned that the next stage in the process would be for me to directly contact the individual woman and organise the research interview. However this was problematic given the large travelling distances across the Loddon Mallee Region. Where there was lengthy travelling involved with the conducting of the interviews the workers organised the interviews from that area in a block.<sup>12</sup> I then travelled to the area over the designated days and conducted the interviews.

During the interviews the women were given the choice of choosing a pseudonym for use in the research reporting. Some women took advantage of being able to make this choice and thought carefully about the ‘name’ they would use. Others declined and wished me to choose a name for them. The majority of women saw this as useful tool to protect their confidentiality whilst two of the women saw no reason to use a pseudonym. These two women specifically requested that their own names be used in the reporting. It is important that the research process allows participants to feel in

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<sup>11</sup> The same Consent Form was used for this second layer of consent, refer Appendix 7. This multilayered approach to consent was a requirement from the Victoria University Ethics Committee to ensure the women had a cooling off period between their initial consent and the actual conducting of the interview.

<sup>12</sup> This was a purely practical approach given the size of the Loddon Mallee Region and the large distances between population centres. This process meant that workers were more involved with the organising of interviews than originally intended but the interview times were still responsive to the times the women had available. Care was taken not to disadvantage the women in terms of choices of times for the interview.

control of the process as much as possible and for the researcher to view the process as a tool for empowering the participants (Patton 1990, Reinharz 1992, Sherman & Reid 1994).

It was initially planned to hold the interviews in venues other than the participant's own homes as it was felt by the Victoria University Ethics Committee that the participants may have felt less free to exercise their right of withdrawal if the interviews were conducted in their own home. This was discussed with the participants at the time of organising the interviews but four of the women requested that their interview be conducted in their own home. These women chose their own home for the interviews as they felt more comfortable in their own environment. Five of the women were interviewed in an office venue.

On reflection it was sometimes difficult conducting the interviews within the office environments as these service centres usually operate PDRS day programs and consequently they are often busy places with many people participating in activities. Even though the interviews took place in separate rooms to program activities there were often interruptions with both staff and consumers looking for others by checking the rooms. Although this had potential privacy considerations for the women they were unconcerned with the interruptions and often introduced me and shared information on the research project with the person.

Given that this research was conducted with women who experienced a psychiatric disability there were special considerations given to the potential for harm resulting from the interviews. Part of the process was to have strategies in place for the immediate support should a participant become distressed. A number of risk minimisation strategies were also implemented during the interview process.

As part of the criteria for participation all of the women were existing clients of PDRS services where they had access to regular service support and ongoing contact with a service worker. Prior to the interviews I ensured the availability of supports for the

women from workers should any of the women became distressed during the interview process. Fortunately this was not required during the course of the interviews.

To ensure that there were no harmful effects, I implemented a number of strategies during the interviews. These included:

1. '*Checking things out*' with the women at different stages in the interview for example, asking them if they were feeling comfortable with the areas of discussion and seeking their consent to continue the discussion.
2. Implementing debriefing in the concluding stages of each interview. This included a discussion with the women to ascertain if there were any issues arising from the interview that they wished to discuss with their support worker.

At the time of the interview the majority of the women who took part in the research had participated in PDRSS for extended periods. This ranged from three months to four years and a large number of the women used both home based outreach services and day programs from the PDRSS.

All of the women were aged in the 20 – 60 year age bracket with the highest number in the 40-50 year age bracket at the time of the interview.<sup>13</sup> Many of the women were living in public housing although a small number lived in their own owned home. All but one of the women was in receipt of a government pension or benefit as their main income source All of the women received in-home support from their PDRSS worker.

All of the women were receiving ongoing treatment and support for their mental illness. For some of the women this was provided through the clinical staff at the AMHS, through their general practitioner, or both of these. Therefore not all of the women had a case manager in clinical mental health services, although for many of the women the case manager had initially been involved with referring them to the PDRSS. Some of the women volunteered information on their diagnosis whilst others chose not to reveal this.

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<sup>13</sup> The age range of the women who took part in the research reflects the age range of participants in PDRSS's which provide adult services for people in the age range of 18-65 years.

Qualitative data was gathered by semi-structured, in-depth individual interviews with the women. The interviews were exploratory and a discussion of experiences and meanings was encouraged. This approach enabled greater spontaneity and responsiveness between the women and myself. The interview format provided minimal prompts that assisted the areas of discussion.<sup>14</sup>

The interview guide that was used was intentionally broad to open up the discussion for experiences to be explored. My initial thoughts were that this material would provide information on women's needs and how effective the services were in meeting these needs. However, as the interviews proceeded I began to realise that the stories that were emerging were much broader than those of the women's needs and the effectiveness of psychiatric rehabilitation services in meeting these needs. I found that the women were actually using the interviews to construct broader stories than I had anticipated. These stories were contextualised by their life experiences, their struggles with coping with a mental illness and how they constructed the meanings of these experiences.

Holstein & Gubrien (1995:4) explained this:

*Respondents are not so much repositories of knowledge – treasuries of information awaiting retrieval – as they are constructors of knowledge in collaboration with interviewers.*

I also noticed that the women used the interview opportunity to elicit information from me as they wished to know if their experiences were similar to those of other women. This led me to incorporate some non-confidential information sharing regarding women's experiences during the process of the interview if the women requested this.<sup>15</sup>

These twists and turns made for an interesting research process and demonstrated the active nature of the women's engagement in the process and the productive exercise of power in the research relationship. The openness of the interview format and the style

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<sup>14</sup> Refer to Appendix 8: Interview Guide for the areas of discussion that guided the interviews.

of interviewing enabled the women to take more control in the process and facilitated an emergence of the constructions of their stories that were important to them. I decided that this process was significant and it was important for me to continue to facilitate opportunities within the interviews for the women to take a lead. This process demonstrates the evolving and ongoing nature of the methodology in this context and the value of researcher's awareness and openness to developing processes. Gustafson (2000) argues that it is important to examine any contradictions between intent and the actual process of discovery as this is part of a commitment to feminist scholarship.

#### **4.2.3 Transcription and data analysis**

The individual interviews were audio taped and transcribed using the women's own words. This was useful as phenomenological research produces rich and thick information on the phenomenon being explored (Creswell 1998) and verbatim transcriptions allow for the narrator's intended meanings and significance to be more easily recognised.

There are various ways to analyse qualitative data but all involve a process of organising and converting the data whilst searching for meaning. McInnis & White (2001) suggest that phenomenological data analysis involves a process of extracting significant statements from each description, formulating the statements into meanings and clustering the meanings into themes. Consistent with this the method of analysis that was adopted reflected the steps in Giorgi's method of phenomenological analysis (Hedelin & Strandmark 2001, McInnis & White 2001)

1. Read through the entire description given by the participants to ensure that a general sense of the whole had been gained.
2. Separate the text into themes with a focus on the phenomenon being researched.
3. Examine each theme to try to gain an understanding of the subject's experiences and to discern those that are most revelatory to the phenomenon under discussion.

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<sup>15</sup> As part of my reflections on this process I decided to include a discussion on the research relationship as part of the findings of the research in Chapter 5.

The process of representing the data and drawing this into themes involved a number of interpretative stages where I considered the material on multiple occasions. Agar (1980 cited in Creswell 1998:143) describes this as the need to '*immerse yourself in the details, (whilst) trying to get a sense of the interview as a whole before breaking it into parts*'. The process of '*breaking it into parts*', or drawing out the themes was a cyclical process using both the audio material and the transcripts in an endeavour to search for significant statements, meaning and emphases as directed by each of the women. This was followed by further reflections to thematically construct the material according to the statements, meanings and emphases. A coding system was then used to identify the meanings and emphases as they arose from the individual data.

From this process the individual analyses were consistently developed and these were later drawn together where the data coincided with those of other women. Creswell (1998) refers to these as categories of information and this process enabled collective themes to emerge from the individual data sources. This thematic analysis represents the commonalities of experiences as presented by the women.

In addition to this process of drawing the material together thematically I considered it important to identify and note any material that was considered different or variant to the themes. This approach was consistent with De Vault (1996:32-33) who argues that it is important in feminist methodology to reveal '*the diversity of actual women's lives*' and be cautious of '*investigations of particular groups of women's lives in terms that are falsely universalised*'.

During the analysis period the primary data was discussed with the Principal Investigators<sup>16</sup> which provided the opportunity for cross-validating the findings and allowed for a greater depth of understanding of the data.

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<sup>16</sup> Ms E. Starbuck and Ms V. Egan, the Principal Investigators, were the only other persons given access to the transcripts.

#### 4.2.4 Focus group interviews with workers

Data gathering from workers involved two focus group interviews<sup>17</sup> with 14 service providers.<sup>18</sup> The focus groups were held after the data from the individual interviews had been transcribed and analysed to identify the dominant themes from the discussions. Focus groups are a form of qualitative research with groups, they are based on topics supplied by the researcher who allows information to arise from interaction within the group and the data produced are transcripts of the group discussion (Sherman & Reid 1994).

A sample of service workers for the focus groups were recruited from a number of PDRS services<sup>19</sup> and from the same sources as the individual interview participants.<sup>20</sup> The participants of the focus group were self-selected and their verbal permission was sought for participation. The interviews were audio taped with the permission of the participants.<sup>21</sup>

Both focus groups consisted of a mix of gender with females forming the majority of participants (9 females and 5 males overall). These participants all had extensive experience in the PDRS field. Four of the participants predominantly work in management roles overseeing PDRS programs while the remaining ten workers had direct client service roles within the participating agencies.

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<sup>17</sup> An additional consideration for the focus group method was to ensure the opportunity for a sample of service worker to be recruited from across the Loddon Mallee Region and across agencies providing PDRS services. Given the large geographical size of the LM region it was relevant to hold two focus groups to facilitate participation.

<sup>18</sup> This number includes the researcher who is also a practitioner in the PDRS service field. One worker took part in both focus groups but for these purposes she has only been counted as one participant. The two focus groups were each held in separate towns in the Loddon Mallee Region and both were held at office sites.

<sup>19</sup> Workers from three agencies providing PDRS services participated in the focus groups.

<sup>20</sup> One of the focus group participants worked within a PDRS service agency that provided day program activities but did not provide home based outreach support.

<sup>21</sup> There were not the same considerations of confidentiality or safety with practitioners as there were with the individual interviews with women participants. Service providers were more likely to have had contact with other focus group participants and any degree of exposure of information or values was not likely to be more than is expected in the course of a normal professional development or in-service training program.

The areas of discussion in the focus group interviews were taken directly from the themes that arose from the individual interviews with the women. I initially guided this process by presenting the themes from the women's stories however the workers in each focus group developed their discussion in relation to the themes from the women's experiences that they particularly wished to discuss or explore. This process maintained the centrality of the women's voices and experiences, enabled workers to hear the perspectives of the women and facilitated a reflective process with workers. To protect the women's confidentiality no identifying material was used in the discussions.

This approach facilitated a shared discussion of the themes arising from the women. Workers actively engaged in the process and used the discussion as an opportunity to reflect on women's diverse experiences, broaden their knowledge and make connections with their practice. This was a reflexive process where workers explored their own practices. This is consistent with an action research approach where one part of the research goes on to implement action in another part (Wadsworth 1993, Morton-Cooper 2000).

Involving service providers through focus groups was an enlightening process and many of the workers expressed their appreciation of the reflective opportunity. This process facilitated the information from the women's stories to move out of the domain of individual experience to a position where this could stimulate thinking for workers and open up opportunities for ongoing reflection and discussion of experiences.

#### **4.2.5 Transcription, data analysis and thematic linking between data sources**

All of the tapes from the focus groups were transcribed and the data was again drawn together by themes and patterns. In this process the areas of consistency or divergence with the themes that arose from the women were further identified.

Themes from both the individual and focus group interviews were identified by a series of colour codings which were used to cross-match the findings. This method allowed

for the themes from both sources to be developed in relation to each other and to easily identify discussion areas. A matrix of findings from the data was developed and this demonstrated the thematic congruence between the individual interviews and the focus group interviews.<sup>22</sup> This dual process further clarified and added validity to the analysis (Patton 1992).

The data analysis was not a linear process but an evolving one that constituted me returning and rereading the data many times. The enormous amount of data gathered from the dual perspective method created dilemmas for me on many occasions as I grappled with ways to deal with such a massive amount of information, perceptions and experiences. I therefore engaged with an ongoing process of reflection that enabled more in-depth understandings and fresh insights to emerge over time. This process continued as the writing developed to ensure this accurately reflected the data.

**4.2.6 Feedback to participants**

Letters outlining the progress and direction of the research project as well as information on the themes that were emerging from the data were sent to all of the women and worker participants. For each of the women this also included information on where their individual contributions connected to the themes as developed and how I intended to use this. All of the participants were invited to comment or contact myself directly if they wished to discuss the project or their individual material.<sup>23</sup> However, none of the participants chose to follow up with me although workers at various times have taken the opportunity to discuss the progress and results from the research.

**4.3 Verification and trustworthiness**

Creswell (1998:201-3) explores how a number of writers have examined and challenged issues of verification of qualitative data. This includes an acknowledgement of the multiple perspectives regarding the importance of verification in qualitative data as well as definitions and procedures for establishing it. These perspectives range from

<sup>22</sup> Refer Appendix 9: Matrix of themes from data.

<sup>23</sup> I also included stamped self-addressed envelopes with the information provided to the women.

attempts to parallel verification processes used in quantitative research (Le Compte & Goetz 1982) to others such as Lincoln & Guba (1985) who have developed alternative terms to establish the ‘trustworthiness’ of a study (cited in Creswell 1998:197).

In interpretative methodologies such as phenomenology one way to demonstrate rigour is to clearly demonstrate how the interpretation was achieved (Rice & Ezzy 1999). In a qualitative study this can be demonstrated by including substantial parts of the primary text in the research report. In the presentation of the results of this research I have incorporated substantive writings that reflect the participants’ information and advance evidence of different perspectives on each theme.

Consistent with a critical reflective paradigm I also acknowledge my role as the researcher in the interpretative process. Although openly presented, the data has been distilled through me as I consistently interpreted and re-interpreted the information. Throughout this thesis I have endeavoured to expose the influences and processes of interpretation by clearly locating myself in the research. This process increases the credibility and validity of the material and conclusions drawn from the research (Lincoln & Guba 1985, Gustafson 2000, Seibold 2000).

As there is no consensus on standards or verification processes Creswell (1998:201-3) has developed a framework from a review of the literature of verification procedures. Creswell recommends that qualitative researcher’s engage in at least two of these procedures in any given study. Several of the verification processes from Creswell’s (1998) framework were adopted in this research:

1. *Peer review or debriefing provides an external check on the research process much in the same spirit as inter-rater.*

A process of peer review for this research was established with the research supervisors. This facilitated discussion and reflexion of meanings and themes with the

supervisors, which allowed for a greater depth of understanding and interpretative discussions of the data gathered from the participants.<sup>24</sup>

2. *Clarifying researcher bias from the outset of the study is important so that the reader understands the researcher's position and any biases or assumptions that impact on the inquiry.*

Consistent with a feminist methodology my approach in this thesis has been to expose both my position as a practitioner in the PDRSS sector, as a Service Director in the rural area in which the research took place and the theoretical perspective which influenced the research design and analysis. This openness acknowledges my position of influence along with my educational, organisational and theoretical biases and assumptions that I bring to the research process.

In acknowledgment of biases and influence I have taken a reflexive approach that has enabled me to be self-conscious, critical and questioning of my assumptions.

According to Gustafson (2000) this process arises from an awareness that values and beliefs penetrate the research process and that all knowledge production is structurally, culturally and historically located. My reflexions are presented at various points throughout the thesis but more particularly in Chapter 5: Views from the verandah: Locating the researcher. In this chapter I openly acknowledge the integral role of the researcher in the method and the lens through which I have conducted this research.

3. *In member checks, the researcher elicits informants' views of the credibility of the findings and interpretations.*

A process of member checking was implemented to verify the research data as discussed in 4.2.6 above. During the course of the interviews several of the women requested a copy of the thesis and this will be forwarded to each of the women on completion. Copies will also be made available to the Agencies from whom workers participated.

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<sup>24</sup> Initially I had intended to develop a research reference group however my work commitments and the lengthy period (over several years) of the research project precluded this.

4. *Rich, thick description allows the reader to make decisions regarding transferability because the writer describes in detail the participants or setting under study.*

The experiences and meanings gathered from this research process provide a rich and thick description, however these descriptions are specific to the participants and it is open to the reader to consider their transferability to other settings.

#### **4.4 Ethical considerations**

Ethical issues were a significant consideration in developing the methodology for this research. The process reflected the values of '*proper conduct*' such as confidentiality, privacy, self-determination and a concern for the wellbeing of participants as put forward by Marlow (2001). These values are consistent with the Victoria University *Code of Conduct For Research* as well as The Australian Association of Social Workers *Code of Ethics*. Ethics approval for the research was gained from the Victoria University Human Research Ethics Committee.

The key ethical considerations driving the research design were concerns for the mental health and wellbeing of the women and any related fears or perceptions that their participation in the research would impact on the services they received. Attention was given to the sensitivities and vulnerabilities of the women in connection with the nature and experiences of mental illness and to their status as service users of PDRSS's.

There were also concurrent ethical considerations for worker participation although this degree of concern was less than that for the women participants as the nature of the exposure for workers was no more than might be expected in the course of a normal professional development or in-service training program.

The key ethical principles implemented for this research included:

- *Avoidance of mental harm to the participants:*

This was ensured by not interviewing women in crisis, by always providing full information and explanations, and ensuring that support for the women from an

experienced PDRSS worker was available should this be required.<sup>25</sup> Although appropriate supports were in place these were not required by the women.

- *Voluntary participation and informed consent*

A staged information sharing and consent process<sup>26</sup> was implemented to ensure each of the women participants was providing an informed consent for their participation. To implement this PDRS workers were key recruiters in the process.<sup>27</sup> Within this recruiting process I recognised the power differentials between women and their workers and the potential this had for workers to exert influence for women's participation. To address this I discussed the project fully with participating agencies and workers to reinforce the importance and nature of voluntary participation in the recruiting process for the women.

I also highlighted information on voluntary participation and the right of withdrawal in the information material that was distributed for the research and again in the consent forms.<sup>28</sup> The issue of consent was also discussed individually with the women both during the pre and post interview periods.<sup>29</sup>

Participation for workers was also voluntary and recruitment occurred through discussions with managers of relevant services and advertising of the focus groups through the participating agencies. Through this process I was conscious of my senior position in the sector and more particularly within my own organisation<sup>30</sup> and of the

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<sup>25</sup> This is further elaborated in section 4.2 of this Chapter.

<sup>26</sup> For further information and clarification of the consent process refer to Section 4.2 earlier in this Chapter.

<sup>27</sup> Although I am also a worker in the PDRSS sector, my position as a service director precludes my having direct client responsibilities therefore I was not directly involved in any of the recruitment processes with the women.

<sup>28</sup> As an added precaution a dual process of consent was implemented. The recruiting worker initially discussed the nature of voluntary participation and the consent process with potential participants. For those women wishing to proceed the recruiting worker ensured that a consent form was signed. Following this there was a minimum period of one week until the interview was to be conducted as a cooling off period to enable the women to reconsider their participation. Before the interviews commenced I also discussed the consent process with each woman and I requested the signing of a second consent form immediately prior to the interview commencing.

<sup>29</sup> This included a discussion in the concluding stages of the interviews and in the process of feedback to participants as discussed in section 4.2.6 of this chapter.

<sup>30</sup> I am a service director with St Luke's Anglicare.

potential for influence on worker participation. I acknowledge that influence in this way cannot be fully eliminated however workers were free to participate and the voluntary nature of this was reinforced. I did this by acknowledging the influence of my position with service managers and potential worker participants and explicitly discussing my concerns to ensure voluntary participation.<sup>31</sup> In addition the focus group meetings were organised well in advance and separately to other service meetings to ensure that workers were well informed and able to clearly distinguish between service related meetings and the research focus groups.

- *Confidentiality and anonymity:*

A series of measures were specifically implemented to protect the privacy of both the women and the workers.<sup>32</sup> Full anonymity could not be ensured as recruitment for the women occurred through individual workers, however a number of steps were taken to ensure that no identifying material was used.<sup>33</sup> This included the use of pseudonyms both for the women and the workers.<sup>34</sup> I also gave careful attention to the use of quotations through the research report to ensure these were non-identifiable for the participants.

Issues of confidentiality were respected through the research process and reporting. Seibold (2000) describes this as an essential ethical requirement especially considering the revelation of highly personal aspects of participant's lives during the interviewing process. To ensure ongoing confidentiality access to the primary data is restricted and the material will be safely stored for a period of five years from the completion of the thesis or any publication date.

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<sup>31</sup> I implemented these discussions of the nature of voluntary participation both prior to the organisation of the focus groups and before commencement of each group.

<sup>32</sup> These measures are fully explained earlier in this Chapter.

<sup>33</sup> Other issues impacting on the anonymity of the women such as when the interviews were conducted in an office environment are explored in Chapter 5.

<sup>34</sup> As noted earlier in this chapter some of the women specifically requested that their own name be used rather than a pseudonym. This was respected although I have chosen not to highlight the names of these women in this thesis.

#### **4.5 Limitations of the methodology**

A key critique is that the feminist research principles are not always easily achieved. This includes the equalising of relationships, the minimisation of differences; and the sharing of power and knowledge in the research process (Reinharz 1992, Creswell 1998, Grbich 1999). I acknowledge that these ideals are not easily achieved, however it should be noted that these principles have guided the research process and the research was conducted within a framework of endeavoring to achieve these goals.

The scope of the research limited representation of participants across age, ethnic and cultural diversity or other rural areas; therefore it is not representative of the population of women using rural PDRSS's. This impacts on transferability issues but it is argued that in a phenomenological approach the intent is to learn of the lived experiences and although these may change across individuals/groups the knowledge gained assists with broader understanding.

#### **4.6 Presentation of results**

The results of the research have been grouped according to themes which reflect the meanings of women's experiences of participation in rural psychiatric rehabilitation services.

Although the intent of the research was to focus on the meanings of rural psychiatric rehabilitation for women, the women participants placed this in the context of their broader experiences of mental health care. This is not an uncommon process in qualitative research in mental health and the broadening may even be a useful process as Lammers (2002:99) suggests:

*Investigation that places factual information in context with the experiences of the respondents offers the opportunity to view the whole picture and takes account of many other elements that have helped shape or construct the environment for the individual.*

The data from the research did not distinctly fall into discrete areas therefore there will be some overlap across the themes and all are interrelated to present the full rehabilitation experiences of the women and the reflections of the workers.

#### **4.7 Conclusion**

This chapter has provided a detailed account of the methodology, which involved a dual perspective method to explore the phenomena of women's participation in rural psychiatric rehabilitation services. This process involved listening to both women who experience a mental illness and workers providing rehabilitation and support. The purpose was to give voice to women's experiences and explore an otherwise little known phenomenon. The inclusion of workers was intended as a change inducing process to raise awareness and promote reflection on women's experiences.

In this chapter I have implemented a reflexive approach as a feature of the methodology. Through the reflective contributions I have acknowledged the evolving nature of the methodology and my integral role as the researcher in the research process. To continue this reflexive process I have further developed the methodology in the subsequent chapter to incorporate a broader discussion. This discussion explores the influences on my sensitivity in both the collection and interpretation of the data. Through this process of incorporating a reflective chapter I endeavour to expose the prism through which the findings are reflected.

The following chapter where I clearly locate myself in the research is an integral component of the methodology but I considered that this material deserved a separate chapter as a way of drawing attention to the complexities of research.

## **Chapter 5: Views from the verandah: Locating the researcher**

This chapter provides a first person account of my location as the researcher in the research process. This process of incorporating the researcher's reflections is consistent with a number of theoretical perspectives including critical poststructural analyses (Healy 2000) and feminist research which encourages the involvement of the researcher as a person (Reinharz 1992). This critical reflective practice approach to the research draws attention to the complexities and contradictions of research and of the processes of power.

My experiences of the research process are explored through the dimensions of:

- The value of locating the researcher
- Reflections on the research relationship

### **5.1 The value of locating the researcher**

The incorporation of the reflections of the researcher is not a new approach but one that has been advocated by several writers. Healy (2000) discusses the relevance of situating the practitioner in the practice context under investigation as a way of making explicit the connections between the theory, practice and research dimensions of social work. In Healy's (2000:69) view this situating of the practitioner connects the practice to the theorising and increases sensitivity to 'othering' practices on which critical social work theories are based. This approach challenges conceptions of a dichotomy between researcher and participant and brings the complexities and contradictions of the process into focus.

Seibold (2000) asserts that social researchers are becoming increasingly aware of how the researcher's self is an actual part of the research process. This integration of the self into the process provides a connection between an internal context related to the researcher's personal frame of reference and the external context involving the research topic, theoretical framework or paradigm. It exposes the influences on the decision making processes during the fluid and evolving nature of qualitative research

where the processes may be subject to change as the study progresses.

Although there is no single feminist method many feminist writers locate the research process within the social cultural context and argue that the process is of equal value or importance as the content (Stanley & Wise 1990, Reinharz 1992, DeVault 1996, Cogan 1998). Feminist methodology argues against distancing or objectifying participants or procedures although it is acknowledged that these values are difficult to measure and not always fully achievable. Research processes should be non-exploitative, clearly locate the researcher in the research process and acknowledge the power implications so as not to replicate social inequalities (Greed 1990, Stanley et al 1990, Reinharz 1992). This process of locating the researcher makes feminist researchers accountable.

Each of these perspectives were influential in my considerations of incorporating a process of reflexivity into this thesis. My intent was to mirror a process as explored by Greed (1990, pp. unknown) who explained she was:

*'... studying a world in which I myself am part, with all of the emotional involvement and accusations of subjectivity that this creates. I do not attempt to keep my surveyors at arm's length and do research 'on' them as my subjects whilst maintaining a dominant position, as is common in much traditional 'objective' research.'*

In the process of incorporating my reflections I acknowledge the processes of power and the significant inequities between women who participated in this research and myself with my role as manager of a large rural welfare agency. My identity was acknowledged with the women and through the process my focus was on the provision of an open and honest approach with shared information and continuing openness to the women's questions during the research process.

The discussion in the next section draws attention to some of the implications and complexities of practice research.

## 5.2 Reflections on the research relationship

The relationship between researcher and participant has gained much attention in the literature which highlights the value of building rapport between researcher and participant in the process of gathering information (Oakley 1981, Smith 1988, Minichiello, Aroni, Timewell & Alexander 1991, Reinharz 1992, Creswell 1998, Grbich 1999, Rice & Ezzy 1999).

Smith (1988) describes the research process as a relationship in itself whilst Oakley (1981) discusses relationship concepts in the research process:

*'the goal of finding out about people through interviewing is best achieved when the relationship of interviewer and interviewee is non-hierarchical and when the interviewer is prepared to invest his or her own personal identity in the relationship.'*

Although some view this as an idealised account due to the inequality in the relationship (Minichiello et al 1991), there are important steps to developing a non-exploitative relationship with the participants in the research. Reinharz (1992:267) considers *'relations of respect, shared information, openness and clarity of communication'* to be reasonable goals in the process.

The intent of this research process was to develop an interactive approach with the women so that they became partners in the research. In the process of the interviews information was shared and participants were encouraged to ask me questions relevant to my experiences and role as a researcher and manager. The individual women interviewed utilised this opportunity to explore the purpose and direction of the research, my interest, background, work role and the dissemination of the research results. I saw the process of encouraging and answering questions as an opportunity to reduce the barriers and social distance between the women and myself.

Laslett and Rapoport (1975:968) describe an interactive research process, as being beneficial and it allows the collection of more information in greater depth than would otherwise be possible. This is developed by the researcher:

*'being responsive to, rather than seeking to avoid, respondent reactions to the interview situation and experience.'*

For the majority of women the interview was the first time they had met me and it was important for me to take the time to establish rapport, especially when dealing with sensitive issues in women's lives. A key part of the introductory process with the women was an explanation of my identity as the researcher, a worker, a rural resident and as a woman. This process included a discussion of my personal life experiences relevant to the research and work experiences in the PDRSS sector and how these led to a wish to explore the meanings of women's experiences. The process of explaining my personal and professional experiences facilitated sharing, demonstrated respect and assisted in relationship building during the research process.

Acknowledging my experiences was a way of reducing the 'distance' between the women and myself. Guba & Lincoln (1998, cited in Creswell 1999:76) discuss how this process enables the researcher to move from being an 'outsider' to being an 'insider' by minimising the objective separateness between the researcher and those being researched.

In the process of the first few interviews I realised that the women were using the interview as an opportunity to explore how their individual experiences related to those of other women. This was a process of the women using the research relationship to gain knowledge from me that would enable them to construct a personal understanding of whether their own experiences were individual to them, or whether there were shared experiences or commonalities with those of other women. After reflecting on this I decided to incorporate information on women's experiences provided from earlier interviews into the interview process. This was in relation to issues raised and did not include any information related to the personal circumstances of the women.

This level of sharing enabled the women to reflect on the experiences and issues as raised by others and to consider their responses to similar themes. For some of the women this process assisted them to normalise their own experiences and develop a

sense of mutuality with the experiences of other women. This led to some of the women expressing relief that they were not alone in experiencing difficulties. This process was part of an interactive interview style that builds upon the knowledge of both the researcher and narrator (Smith & Noble-Spruell 1986, Reinhartz 1992, Graham 1994).

This was a collaborative approach that assisted in avoiding objectification of the women's experiences. In the interview process the women used this as an opportunity to reflect on varying responses and to consider where their experiences converged or diverged from others. This approach placed me in the study as a conduit of information sharing and enabled the women participant's to reflect on both the multiplicity of experiences of women and the value of exploring women's stories through research.<sup>1</sup>

This questioning process emerged from the active engagement of the women in the research interview and my variation in the method was a direct response to this. This process indicates the complexity of the researcher – interviewee relationship and the value of moving beyond a simplistic dichotomous understanding of how power is exercised in this context. Rather than being an oppressive use of power it was a productive use and enabled a new opportunity to emerge.

The research process also identified the complex dimension between research and organisational issues and the influence of my identity as a worker and manager in the PDRS sector. One of the women knew, and had had contact with, myself in a management role (through meetings and combined consumer – worker social gatherings) and she explained that this knowledge of myself helped her to be open and relaxed in the interview. Although it may be argued that this biased the interview process and the data collected from this participant, in reality it facilitated the process. It also acknowledged the complexity of work in rural areas where populations are fewer and workers are more visible in multiple roles.

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<sup>1</sup> This is consistent with a feminist research approach where the goals are to establish collaborative and non-exploitative relationships, to place the researcher within the study and to conduct research that is transformative (Creswell 1999:83).

Another woman used the opportunity of my manager role to discuss a complaint about the services she was receiving. She made the connection with my management role in the Agency with whom she had a complaint and she chose to discuss her issue as part of the interview. This woman did not feel the need to separate this aspect of her participation in services from the context of the research process. Through the raising of the complaint I was required to respond to this situation.

When this woman began to discuss her complaint it presented me with a dilemma as this created a crossover of roles or identities between manager and researcher within the research process. As the woman discussed her complaint I considered the options and responses that were available to me. These included firstly containing my response to a researcher approach, or secondly moving to a position of informing her about how to follow through with the complaint or thirdly to actively engage with the complaint in my management role. I chose the second pathway of informing and discussing the grievance processes available for her to raise her concerns whilst encouraging her to follow this through.

In my reflections on this process I began to consider the exercise of power in this situation and the changing shape of identities. Mullaly (2002) describes the multiplicity of interactions in relation to power in relationships, in particular how the dominance of who holds the power changes across circumstances. Whilst I don't consider that I was subordinate in the situation discussed it clearly demonstrated to me the changing shape of power and how this is exercised. Grand narratives such as the representation of service users / research participants as powerless and workers / researchers as all powerful denies the complexity of experiences (Healy 2000). This understanding contradicts that of Minichiello et al (1991) who view the research relationship as productive of inequality due to the structure and controlling of the process by the researcher.

These reflections from the research process confirm the need to be honest about your involvement and purposes and openly acknowledge the contextual issues relevant to

the research. This exploration opens up alternative ways of conceptualising both the use and nature of power in the research process.

The next section of the thesis presents the results that emerged from this research. The findings have been selected and presented through a critical poststructural feminist perspective. This perspective enables a focus on an analysis of power in relation to women's experiences of rural psychiatric disability rehabilitation and support services.

## **Chapter 6: Reflections of struggle: hardships and strengths in women's experiences**

In this chapter I begin the presentation of the results from the research and this continues through the subsequent chapters. The findings were grouped according to themes and the structure for the presentation of the results reflects these themes.

The themes have been grouped according to the focus as presented by the women through their narratives and these include:

- Reflections of struggle: hardships and strengths in women's experiences
- Long way from anywhere: the rural dimensions
- Construction of the caring relationship.
- Interlinking system of care in rural areas

This research used a dual perspective method with the gathering of data from both women participating in rural psychiatric rehabilitation and workers who provide these services. In presenting the results I have honoured the different perspectives provided by the individual women and by workers.<sup>1</sup>

In a phenomenological approach it is the essence of experiences that is explored. The idea of presenting a notion of 'essence' is challenged by critical poststructural feminists who contend that it is more useful to move towards a recognition of diversity in relation to social work practices (Healy 2000). However, in acknowledgement that little is known of women's experiences in these circumstances there has been some drawing together of the findings to describe an overall sense of essence of the women's experiences. In doing so I recognise that there is no single category of 'woman', 'rural' or of 'psychiatric rehabilitation' experiences and I have no wish to attempt to universalise women's experiences.

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<sup>1</sup> In the presentation of the results some strategies have been used to identify and distinguish between the perspectives of the women and those of workers. The women's stories have been given prominence in the presentation and the perspectives of workers have been clearly identified. Refer to Appendix 10 for a profile of the participants and the identification process to distinguish the experiences of women participants from those of the workers.

One of the key principles guiding this research design was an acknowledgement of diversity, therefore in the presentation of the findings I have endeavoured to draw out the contradictions or inconsistencies as these present as well as commonalities in experiences. However, the dual perspective method produced a rich amount of information, perceptions and experiences and it is beyond the scope of this paper to discuss all of the complexities that have arisen. Therefore as the focus of this research was on an exploration of the women's experiences the analysis has been directed towards uncovering the meanings of these experiences.<sup>2</sup>

A variety of both commonalities and divergences have been drawn from the data, however there are more differences among the individual women as a mixed group compared with that between women and workers. This is not surprising given the differences in priorities and experiences across the two groups. Overall there appears to be a higher level of agreement amongst workers and their material is more consistent although there are several instances of a diversity of understanding.

Although the data from workers is not consistently homogeneous, the level of agreement among workers is not unexpected given the socialisation processes of education, organisational impact and culture. Thus workers are more likely to have been influenced by taken-for-granted categories and beliefs given their expected educational level, experiences and role with PDRS Services. Montell (1999) argues that particular beliefs and categories underlie conscious attitudes including the way people respond to and interact with each other in group interviews. This interaction in itself provides rich and complex data.

The appearance of greater consensus and consistency amongst workers may also have been influenced by the group process which provides less opportunity for individual input when compared to a research design incorporating individual interviews. In the group context ideas are built upon each other and further developed through an

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<sup>2</sup> In developing the methodology I anticipated that the dual perspective would generate significant amounts and variety of data. Any exploration of the convergence or divergence between, for example the workers as a group can be left to the province of future researchers.

interactive process that is not available when gathering data individually from research participants.

In the process of the interviews the women spoke richly of their experiences of mental health care and several expressed their motivation for taking part in the research project. Kate's expression was typical of the women:

*I don't mind talking about these things, as long as it helps other women and gets more services.*

Some of the women were more articulate than others however each individual woman's narrative demonstrated their capacity to reflect on their mental health issues, the conditions of their lives and the nature of the support services that they were receiving.

This chapter presents the first of the themes as discussed earlier and the material reflects a sense of profound struggle and difficulty in the lives of women who experience a mental illness. The stories also reflect their courage and strength in learning to manage the complexities in their lives and regain control.

In listening to the women's narratives it became clear that their mental illness experiences were integral to the understanding and meanings of their experiences in rural psychiatric rehabilitation. Therefore the results as presented reflect the integrated experiences of women in relation to the dimensions of their mental illness and rehabilitation experiences.

Through the discussions with the women a number of themes related to hardship and struggle emerged and these include:

- Difficult lives: experiences of illness and hardship
- Managing the illness and regaining control
- Achievements of the journey

## 6.1 Difficult lives: experiences of illness and hardship

The women's stories revealed the complexities of their experiences and an array of hardships. These difficulties related to the conditions of their lives with some of the women attributing the development of their mental illness to these difficulties. All of the women described distressing experiences of mental illness and many of them spoke of the negative impact of living with an enduring mental illness.

The stories were portrayed as a 'struggle' through distressing experiences that led to a loss of capacity for the women to independently manage. The illness experience created fear and was disempowering of the women as they had to mediate difficulties in accessing adequate services and supports to meet their needs. Overwhelmingly the essence of the women's experiences was a sense of chaos and loss of control as they related their struggles in developing an understanding of their experiences.

A theme from the women's stories related to isolation although there were variations in the experiences of this by the women.

### 6.1.1 Distressing experiences of isolation

The experience of mental illness was devastating and the women explained their experiences of periods of psychosis, fear of voices, paranoia and episodes of hospitalisation. There were recurring themes of isolation associated with distress and fear and for many of the women the experience of illness was isolating.

For Jean the self-imposed social isolation was a part of her illness experience and she explained how this impacted on her confidence:

*I was very unwell ... I was feeling very down ... I wasn't getting out of the house very often at all. I didn't feel like going anywhere, or meeting anyone, or seeing anybody. I would just go to the shops and back and get what I needed and then go home again. I thought I won't go and see so and so today, I will just go home again, I just feel so sad.*

*When I was unwell I was driving under sufferance ... I wasn't driving one kilometre further than I needed to. I just didn't like driving at all and that was unusual for me because I have always liked driving. I used to do meals*

*on wheels ... I gave it up because I had lost my confidence. That was one of the first things to go, and then the sport went.*

Grace explained that her mental illness manifested as voices creating fear and distress which socially isolated her from others:

*I started seeing things and hearing voices ... I still get them ... they're loud even on the medication. I could be doing something and I get so engrossed in what the voices in my head are doing or saying that I forget that there's people around me.*

*When I was really crook I thought everyone was rough at the hospital, I thought they were all after me. I walked down the street and here was all these people driving past and saying "ha ha ha" ... to frighten me or whatever.*

With Alice the experience of illness and treatments was isolating as it led to physical tiredness and a loss of motivation to meet with others or to participate in activities.

Alice explained this:

*I don't have the energy to go out, the medication makes you tired ... I can't be bothered going out to meet with people ... I'd rather just stay here.*

For Karma the experience of isolation was connected to her experience of mental illness but also to an unresponsive social and economic environment which failed to adequately meet her needs. Karma explained her circumstances which led to extreme difficulties in her life:

*I had no one to turn to when I was unwell – I was isolated and alone. When I was really unwell and not able to work I lived in a car – not a very safe place, especially when you are psychotic. I was working when I first became unwell but over time it became harder for me to keep my job. I started seeing a counsellor and although it was a financial burden it was important. The counsellor was helpful but that was only for an hour a week, and I needed to be able to keep working to be able to see the counsellor.*

*The counsellor was very helpful and she sometimes reduced her fees but it was still hard. When I became more unwell I wasn't able to keep working which meant I had no money to see the counsellor and things just got worse. It was hard to know where I could get help.*

*Gradually over time my friends all just drifted off ... I guess they couldn't cope with my anger and upset anymore. I couldn't afford my flat and things*

*just kept getting worse. It was the most difficult time of my life ... I'd become even more alone ... in the end I didn't trust anyone.*

Jenny also discussed her unresponsive social environment which for her was linked to labeling, stigma and negative perceptions of mental illness. In response to this alienating environment Jenny withdrew and isolated herself further. Jenny explained:

*I was diagnosed with schizophrenia. I don't like to tell everybody ... just as soon as you tell say that ... doctors and everyone else they think that it ... I don't know ... they treat it with dread ... they pass it on to me that it is something to be ashamed of. I have rejected the idea for so long that I am schizophrenic, but now that I realise that I am I have to face life with that in mind.*

*It is just a label, but labels can have lots of negatives. Every time a schizophrenic does something wrong it gets put in the paper ... schizophrenia ... so people dread you, think you are going to shoot them or something like that. ... I dread telling people ... I try and let them think I am normal.*

The women discussed the issue of isolation in a variety of ways that portrayed a picture of distress and separation as the women struggled to manage their lives. For some of the women the sense of isolation was compounded by an unresponsive social environment which left them feeling 'even more alone'.

Some of the women also courageously discussed issues of violence and abuse amongst their experiences.

### **6.1.2 Dealing with violence and abuse:**

Through discussions of their experiences some of the women referred to stories of violence and abuse (childhood and adult). Kate explained her experiences of violence which she believes led to the development of her mental illness:

*He would break into the house and belt me up ... I had lots of broken bones, a fractured skull ... I wouldn't give him money for drugs. It broke me ... mentally, it did screw me up, the body broke. I have anxiety and panic attacks ... I can't go down the street on my own still today.*

Kate's correlation of violence and mental illness was supported by Sally (worker):

*Mental illness can be a devastating experience ... it can lead to paranoia, anxiety, phobia ... a whole range of symptoms. Women's experiences of abuse are high and just trying to deal with this may have led them into the system.*

In the focus group discussions there was an agreement among workers that experiences of trauma were significant precursors for women in experiencing mental illness. Veronica added that the '*mental health system can add to the traumatic experiences of women*'.

The experience and impact of violence and trauma was devastating for those who had experienced this. These experiences added to their layers of distress and difficulty. The women also discussed other struggles in their lives.

### **6.1.3 The landscape of living with an enduring mental illness.**

Some of the women discussed their difficulties in sustaining accommodation when their lives were feeling chaotic. Alice explained that prior to getting a house through the PDRSS she had just kept moving:

*as I didn't have any money, my boyfriend had thrown me out ... I couldn't go home again. I had to have an interview to get this house ... it was terrible really, my head kept spinning after moving in and that.*

Several of the women expressed parenting difficulties and a fear of their children being placed in care when they were unwell. Karma described her experiences during a period of hospitalisation:

*When ... (child) was six years old I had a major psychosis and spent 3 months in hospital. During this time she was placed into foster care ... I didn't have anyone to look after her. I didn't like this ... I was very angry about it ... I was scared they'd keep her there permanently.*

*In the end ... thank goodness ... they kept me in touch with her. Now when I look back on it I can see that she was well cared for ... I didn't always feel that way though ... I was so angry about what was happening.*

Karma also experienced frustration as her finances were managed through the State Trustees. As Karma had been very unwell for lengthy periods the State Trustees were managing her finances and she wished to regain this control:

*I want to get back control of my own money now ... I wanted to buy some new clothes, warmer ones for the winter for ... (child) but they won't free up any of my money. I've been learning to manage my money with ... (worker) and I've got some saved now ... I try and talk to them but they just won't free any of it up. I get really angry.*

Workers in their discussions acknowledged and validated the range of difficulties in the lives of women with a mental illness and Sally (worker) felt it was important that workers '*don't add to the distress in any way*'. Lee (worker) discussed the nature of power in relation to the experience of mental illness:

*If you are diagnosed with a mental illness you are often told what to do, where you can live ... people can start to make decisions for you ... people can lose control over their life.*

The women had a diversity of difficult and distressing experiences which led to a sense of powerlessness and loss of control.

Although all of the women experienced significant hardship their stories also reflect resistance. A theme of the stories was a sense of moving through and regaining control by learning how to manage their illness and this is now explored in the next section.

## **6.2 Managing the illness and regaining control**

Whilst the women's stories are full of adversity and difficult life issues these are paralleled by stories of their optimism and developing sense of managing their illness and difficult life circumstances. Through the experience of their mental illness and rehabilitation, the women explored how they had reshaped themselves as '*managers*' of their illness experiences.

For Jean managing meant regaining control by learning how to '*manage around*' her illness.

*I have learnt to manage around it ... I now approach things a little bit differently ... I've got to plan and organise things. Now I feel good ... I've done a lot of work but not without effort. I can't be normal like I was ever again but I can be close to it ... as I learnt more I wanted to shift my focus to feeling more well and going on and travelling on forward.*

For Kate managing meant taking control over her care:

*I insisted on the consistency and the right people to visit ... I let them know what I needed. I am able to tell them when I want a visit and when I need other things. It is important for me to do this so I can manage.*

Cathy (worker) linked the regaining of control to the recovery process:

*Recovery is many different things to people. Sometimes it can be developed through caring and supportive relationships ... sometimes through learning to manage things differently. It's a complex process that involves women being able to say what they need ... being able to have their needs heard. Recovery is about getting the control back.*

The women's stories indicate a movement towards regaining control however as described by Cathy (worker) 'it's a complex process'.

In addition to feeling more in control of their lives many of the women discussed the achievements of their mental illness journey and described how they have been able to overcome their many adversities.

### **6.3 Achievements of the journey**

As the women discussed their life difficulties they also recounted how they were managing things at the time of the interview. Through this discussion several of the women explored circumstances of change in relation to their achievements in overcoming their adversities. Some of the women directly attributed their achievements to their participation in the psychiatric rehabilitation service, whilst for others it was achieved through a mixture of supports from clinical workers, friends and community members.

Karma explained that a significant achievement for her was her capacity to overcome her anxiety:

*I never used to be able to get out ... too anxious ... I am gradually learning to do things and I am really proud of myself that I have caught the bus nine times by myself now ... (PDRSS worker) has talked to me and taught me how to deal with the panic.*

Maintaining stable housing was an important achievement for Alice:

*I have been here (living in the same accommodation) the longest ... I think about two years now. This is the longest I have been able to stay anywhere.*

For Jean developing confidence in her capacity to manage has been a significant achievement:

*I am a lot more confident than I used to be. I don't worry so much about hopping into the car and driving as I was doing there for a while, thinking that I was going to break down and how would I cope with that if I did ... and now I can say to myself 'don't worry about that until you do'. Sometimes I used to just do this physically out loud so I could get around it.*

Some of the women felt they had now developed a friendship network through participation in programs and a small number of the women had returned to study as they achieved a level of stability in their life circumstances.

Workers discussed the importance of achievements in maintaining hope for women with a mental illness. Veronica (worker) explained that '*sometimes seemingly simple things like being able to talk to someone, spending time with others, learning to trust*' were big achievements for women and provided a '*context for healing*'.

Teri (worker) discussed how obtaining and maintaining stable housing was a positive experience for women.

*I think that most women's experience with HBO is positive for them, you know this is my home, there is pride in their home – 'I can become unwell but I know my house will still be there. I am not going to be at risk of being evicted'. If the housing is going OK lots of other things can develop in a positive way for people with a mental illness.*

Although the narratives of the women reflected significant hardship, trauma and disadvantage, there was a sense of the women moving forward and regaining control in their lives. The process of regaining control was developed through their capacity to learn to manage their illness, symptoms and supports and actively participate in their rehabilitation process. This enabled the women to rebuild their lives.

## **6.4 Discussion**

The findings present a narrative of change and development. This understanding was developed from the women's stories as they recounted their extreme life difficulties which presented a story of powerlessness and loss of control but also the process of moving towards regaining control. The women were proud of their journey and they

highlighted a number of their individual achievements which suggests they are proceeding on their journey towards recovery.

I found that the women experienced distressing episodes of isolation as a result of their mental illness experiences but the women were also challenged by an unresponsive social environment which failed to adequately meet their needs. The literature suggests that the experience of isolation associated with mental illness adds to the distress and isolating experiences for women although these are not exclusive to women (Brown 1996, Cagne 1996, Davidson et al 1997). The isolation that was discussed by some of the women was part of their illness experience where these women were responding to their distress and symptoms which impacted on their capacity to manage or cope with daily activities.

The women's experiences were consistent with descriptions of high levels of distress and loss of self-confidence associated with mental illness as discussed by Davidson et al (1997). The literature suggests the experience may be compounded for women as women develop in the context of relationships with others and feel a sense of disconnection more acutely (Miller 1976).

For others among the women the isolation experience was made more complex by an unresponsive social environment. This included economic constraints of not being able to access adequate care, an environment that was unable to adequately meet their support needs and negative experiences of labeling and stigma. Similar disempowering experiences have been discussed in a number of ways by many writers who suggest that the difficulties experienced by women reflect contextual and psychosocial difficulties (Dennerstein et al 1991, Cox 1994, Mowbray et al 1997, Kohen 2000).

The isolating experience of stigma as discussed by Jenny also reflects a landscape of distress and the experience of 'othering' in the form of diagnostic labeling and separation from others by the fear of stigma as discussed by White (1995). Power operates through the use of language and psychiatric diagnoses signify individuals as

‘other’ (White 1995, Stoppard 2001). ‘Otherness’ perpetuates discrimination and marginalisation and precludes the life experiences of women. (Scambler et al 2001).

Issues of violence were recounted by some of the women and it was found that this compounded their difficulties. Other difficulties such as accommodation instability and a loss of control through children being placed in care and external financial management added to the significant hardships for the women.

The literature indicates that there is a high correlation between the context of women’s lives, especially experiences of violence and abuse, and the development of mental illness (Herman 1992, Graham 1994). I found that participants had developed an understanding which reflects their rejection of a purely biomedical and individualising approach that places the problem within the individual rather than the sociocultural context (Stoppard 2000).

There are many descriptions in the literature which connect the experience of mental illness as impacting on all aspects of a person’s life leading to feelings of disempowerment and loss of control (Gerrand 1993, Spink 2000, McLaren et al 2001). This loss of control meant that some of the women had difficulty in sustaining accommodation and the literature has shown that the housing needs or circumstances for women with a mental illness are largely unknown. However it is known that many women may be living in unsuitable or unstable accommodation and the findings reflect this (Robson 1995).

It was found that the measures of control as experienced through statutory authority in the women’s lives was disempowering. It is not uncommon for women with a mental illness who are parents to be fearful of losing custody of their children. Mullaly (2002) describes how this is a powerful social control mechanism which reinforces the power of the medical establishment to control women’s lives. Similarly with financial authority to manage a person’s economic life.

I found that the women participants in this study had a diversity of experiences related to the negative experience of mental illness and the oppressive social cultural context of their lives which led to a sense of powerlessness and loss of control.

The women's stories indicate a development from feelings of not being in control towards regaining control through a variety of means whether by managing the illness or managing the care. Stoppard (2000) found that women resist stereotyped notions of passivity and can play an active role in their care and treatment and these findings support this claim. The women developed strong coping skills and learnt to manage their illness, symptoms and environment. The process of women feeling more in control of their symptoms and illness and the development of effective personal coping strategies is consistent with a recovery paradigm (Anthony 1993, Brooks 2002).

The movement towards regaining control as discussed by the women indicates a level of resistance by them in response to their feelings of powerlessness and lack of control. The women responded to their significant difficulties by learning new ways to 'manage' and reshape their personal identities. Mullaly (2002) describes resistance as a form of power that can manifest in everyday ways to assist people to assert what remains of their autonomy.

The women recounted stories of their resistance in their journey towards regaining control. This was achieved by moving towards self-agency by learning to manage their illness and their care. The women were active in this process rather than the stereotype of women as passive recipients of care (Stoppard 2000). This movement indicates levels of resistance by the women. A number of their individual achievements were highlighted by the women which demonstrates the continuation of their journey towards recovery. Although there was heterogeneity across the group of women in relation to their experiences there was a commonality of resistance and change.

Through the process of moving towards self-agency the women were able to reshape and redefine their personal identity. This heightens the need for practitioners to look beyond dichotomous understandings of power which portrays women in a constant

state of powerlessness (Healy 2000). It would be more useful for practitioners to be alert to stories of change in women's lives.

The women's stories reflect contextual and psychosocial difficulties. The literature argues that negative conditions impact on the outcome of mental health issues for women (Mowbray et al 1997) however the women in this study have been able to move towards recovery despite their difficulties.

## **6.5 Conclusion**

This chapter has examined the landscape of extreme difficulties in the women's lives which precipitated feelings of powerlessness and loss of control. These difficulties compounded the women's distress.

The women had a diversity of experiences related to the negative experience of mental illness and the oppressive social cultural context of their lives. The women were able to move from a position of not being in control towards managing their illness. The women resisted stereotyped notions of passivity by learning to manage their illness, symptoms and environment. Through the resistance process the women were able to regain control and reshape their identity. It is important for practitioners to look beyond dichotomous understandings of power which portrays women in a constant state of powerlessness.

The next chapter will present the rural dimension of the women's experiences.

## Chapter 7: Long way from anywhere: the rural dimensions

This chapter explores the dimensions of women's experiences of participation in psychiatric rehabilitation in rural Victoria. This research took place in the Loddon Mallee Region which comprises a large rural area in the north-western part of the state and covers approximately one quarter of Victoria.<sup>1</sup>

The Loddon Mallee Region covers a broad geographic area and consists of a number of large regional cities, towns and small rural communities. There are two major regional cities Bendigo and Mildura, but the Region also has a number of towns of varying sizes, with some as small as under one thousand people making up the population.

Many of the women who participated in this research reside in smaller towns and communities in the Loddon Mallee Region whilst only a small number of the women reside in larger regional centres. Workers who participated primarily delivered services from the larger regional centres but a number also delivered services in smaller towns and rural communities.

The themes which emerged from the data reflect the multilayered nature of experiences in rural areas. These themes include:

- the negative impact of limited access to transport
- the complexities of privacy, stigma and service delivery in rural communities
- the availability<sup>2</sup> and accessibility<sup>3</sup> of services
- the value of creating community connections

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<sup>1</sup> The research was held in the Loddon Mallee Region as I am a practitioner in this rural area and have well developed links to other PDRSS services. Refer Appendix 2 for a map and information on the Region

<sup>2</sup> In this context 'availability of services' is taken to mean the volume and type of services relative to client needs (Young, Dobson, Byles 2001).

<sup>3</sup> The term 'accessibility of services' is defined as location of services relative to transport, distance and cost (Young et al 2001).

## 7.1 Rural transport

A significant theme of the rural experiences related to rural transport issues with an acknowledgement by both women and workers of the disadvantages of living in rural areas with limited transport availability.

Amongst the women there were several variations on the theme of rural transport. Some of the women had their own private cars, but for many of the women access to transport was an issue. The women living in larger regional centres discussed their access to and use of public transport and this was readily available for them. However, many of the women reside in smaller rural centres where only limited transport is available. For these women their main mode of transport was that offered by workers, or by walking. Chris explained that her transport option was to *'to get around by walking and it is the same for my friends who use the day program'*.

The limited options led to a reliance on workers for transport for daily living activities. Grace described this reliance:

*The worker picks me up and brings me here (PDRSS). I do my shopping at ... and then she (the worker) takes me home. I can't get around otherwise.*

Transport limitations impacted on the availability and accessibility of services for the women. Chris acknowledged the urban rural differences: *'there is more availability of services in the city because of transport.'* Jean felt fortunate that she has her own car which enabled her flexibility to access services distant from her own rural community. This widened her choices and opportunities for access to services.

Limited public transport options increased the isolation of some of the women by restricting their social activities and negatively impacting on their capacity to maintain contacts with people other than those who attend the same service. Mary explained *'you can't get around to see many people ... there are no buses or anything.'*

For Chris the significant limitation was her capacity to visit her daughter who lives in another rural town in the region. There is no transport availability between these towns

other than by private car. As Chris does not have a car her contact with her daughter is restricted.

Workers acknowledged the limited transport options and discussed how this increased the difficulties for people who are isolated in the community. This included women on farms or in smaller communities where there was no available public transport.

In summary there was consistency from both the women and workers that transport was considered a significant disadvantage particularly for women living in smaller towns and communities where public transport was not available. This disadvantage related to being '*able to get around*' for daily living activities, for maintaining social connections and to access services.

A second theme which emerged from the findings related to a fear of stigma in rural areas and this will now be explored.

## **7.2 Diversities of privacy and stigma**

A theme amongst the women was the difficulty in protecting their privacy particularly in smaller communities. Amongst the women who were from smaller communities there were differing views about whether the services should be located within their small community as opposed to being provided by a visiting service from another town. For some of the women this was related to fear of stigma and the wish to protect their anonymity and privacy.

Many of the women expressed a wish to maintain their privacy and not have their mental illness publicly known. Jean explained that even though she has a supportive community of friends around her, she still wished to maintain her confidentiality because of her fear of discrimination, '*it is hard in rural communities to show that you are unwell.*' Equally though, due to the size of the community, it was difficult to hide. Jean explained '*because they are all people that you know, it is hard to hide that you weren't well.*'

A few of the workers acknowledged this dilemma and Patrick (worker) explained he was:

*aware there are some people who won't disclose to their neighbour, they won't disclose to the community about what's going on and they may have had bad experiences of not being accepted or understood.*

This was supported by Matthew (worker) who discussed the diversity of experiences in small communities:

*As far as stigma goes, in a large area you are fairly anonymous whereas in a small town ... we work with individuals that have problems with the fact that they don't get accepted, they suffer a lot of anxiety and paranoia just walking down the street. In such a small community everyone knows and notices. That can be a double edged sword because you have people that are genuinely caring and don't have the stigma attached to it, that can offer support but there is still always going to be this peripheral group where the stigma is strong'.*

Paradoxically, Sally (worker) explained that whilst the size of the community makes people more visible it also means the community '*don't have a faceless mass of people*' when you are working towards building community acceptance as '*you can make an impact on a smaller community, a positive impact*'.

Anne (worker) explained how people wishing to keep their mental illness confidential impacted on service delivery: '*sometimes it may just be too difficult and the support will be about assisting the person to access support outside the community, especially if it is a really small locality.*'

To maintain their privacy several of the women felt that it would be more appropriate if the services were provided either as a visiting service (from another town) or located in another town where they could access these. These women were concerned that they would be more identifiable as having a mental illness if the worker who was locally providing their service also lived in their community. For Jenny, having psychiatric rehabilitation services in her own town would mean that others in the community would know the type of supports and services that were available and they would recognise the workers who might visit her from these programs. It was important for her to '*not have everyone know that I am ill*'. She also felt it was easier to trust workers from another community:

*because they come from ... and if they did tell anybody it would only be the mental health authorities or someone that should know. With the others (local services) they (workers and community members) know that you are ill if you are there.*

Workers discussed privacy issues in small communities and some agreed that it was more difficult because of the visibility of people in small communities. Lee (worker) explained, *'the whole community is watching to see who is visiting ... that is small town stuff'*.

However, Jennifer (worker) felt that local service delivery could work well and provided an example where the capacity to utilise local supports had been very helpful for someone she had been working with. Jennifer (worker) explained this:

*This person engaged to deliver the service worked outside the community but was from the community where the support was offered. This was positive as it was because the worker was known to the community that it helped the client to be supported by the community rather than an outsider coming in and trying to do some of the roles. It was helpful that the worker understood the community.*

Several workers discussed the significance of the size of the community in regards to service delivery. Teri (worker) explained *'in larger areas people can be more anonymous but this is not the same for smaller communities. Any stigma is more apparent in smaller communities because people have nowhere else to go.'*

Some of the workers disagreed with this and Sally (worker) felt there were people *'who are genuinely caring, but in smaller communities those who are discriminating can seem more apparent.'*

This theme presented multilayered and diverse views both within and across the two groups of participants with a number of intersecting categories created through the stories. These included:

- the distinction between the geographic construct of small / large communities
- a distinction between people being caring in the community / stigma in the community. There was some connection between these categories and the size of the community.

- categories of visibility / anonymity: this was linked to the geographic construct of size with visibility more linked to small communities and anonymity to large communities. However, issues of visibility whilst being negative for the women in term of identifying them as having a mental illness, can create an opportunity for workers to link with the community to build community acceptance.
- a distinction between visiting services / locally provided services: the issues of privacy and fear of discrimination because of identification issues were linked with the locally provided services category. There was a contradiction from a worker with this as the worker being known to the community can bring some benefits.

This theme presented a broad diversity of views in connection with services in rural communities, particularly in smaller towns and communities. Privacy was a concern for the women as it is difficult to disguise the illness but there was also an imperative to do so because of the fear of stigma from the community. These issues impacted on the delivery of services and there were a variety of views among workers as to whether these should be provided from within the local community or as visiting services from another town.

Some of the women considered the issues of accessibility and availability of services were more important than privacy concerns.

### **7.3 Availability, accessibility and location of services**

Several women who reside in small communities distant from larger centres where the services are located, expressed concern regarding the availability and accessibility of visiting services. Kate expressed her anger at visiting services, *'these people have to come all the way down here and they can't stay long ... 'oh we have to get back', it is not good enough.'*

Some of the women felt disadvantaged and angry as the distance for workers to travel limited the availability of support services for them. These women wished to have the services provided and located in the same town in which they lived so as to provide more availability, accessibility and flexibility in the supports according to their needs.

Kate explained that it would be great to have *‘someone who started their day in the town and was around when you needed them.’*

Many of the workers discussed the resource difficulties of providing a range of programs and supports in smaller communities. This was expressed as a general frustration among these workers as this meant there were fewer opportunities to provide *‘different’* activities and less time to spend in the smaller communities because of the travelling distances. Often the geographic areas covered by services contained a number of small communities and with limited resources this often means some communities are unable to receive services. Meg (worker) explained:

*In our area there are quite a few small communities and we just can’t provide services across the whole area. We’d like to be able to spend time with people but there are lots of demands. Services don’t get any extra funds because they are delivered in rural areas ... people can be really disadvantaged because they can’t get a service, even a visiting service or otherwise in their town.*

In summary some of the women were angry and frustrated at the limited availability of services and workers due to the visiting nature of the service rather than being locally provided. This frustration was mirrored by many of the workers who discussed the practice issues of not being able to provide adequate services or variability in services across the geographic area due to resource issues. Having services provided as visiting services impacts on the availability and accessibility of services for women.

Workers broadened the discussion of rural practice to include an exploration of the value of creating community linkages.

#### **7.4 Creating community connections: rural practice issues**

Some of the workers built on the themes of the rural experiences of women and linked this to rural practice issues. These related to the acceptance of people with a mental illness in rural communities, the need for workers to educate the community and to assist people to re-develop strong community linkages.

Workers discussed how the size and ‘ruralness’, that is, the distance of the person’s community from larger centres, impacts on the available linkages for people in their

community. Other factors such as how the illness has affected the person and how their illness or illness behaviour has been perceived in their community are also relevant when working with people to re-create links in their community. This was explored by Michael (worker):

*The more rural and remote you get and travel, the more difficult it gets in terms of working with someone in a small rural area. This relates to people who may be fearful of disclosure within their small communities, at times when they may have been quite unwell they may have alienated the local community by their behaviour, or they may be angry and critical of the local community because of what they see as a lack of support.*

In these circumstances Teri (worker) saw a key role in 'educating the community ... we need to provide information, education, support carers and assist family members to support the person with a mental illness',

Some of the workers agreed on their role of informing and educating the community whilst facilitating community support opportunities for clients. Sally (worker) described her optimism in the capacity of the community to support people as:

*people that you link back into the community ... the community at large are really, really welcoming. It is a matter of education ... if you take the time to support people in dealing with it they will actually support that person back. It is almost like that sense of community is something we need to be building around people.*

Although agreeing on the need for community education Peter described the difficulties both for the community and for the person with a mental illness in accessing community support, 'It is hard for the community to support people and it is usually a minority who are doing this'.

Matthew (worker) described the context of difficulties of acceptance for people with a mental illness which was related to stigmatised understandings within a smaller community. In this situation the worker was able to implement community education to address access difficulties for people:

*It is important how you approach the community ... did some education programs in the Community House at ... and she started off looking at the myths of mental illness and the name calling that goes on. Out of this group came, 'I call them crazies', 'I call them psychos' ... so she was dealing not with the converted but the perpetrators of stigma and this was really*

*interesting because that was to be one of the linkages for people in that area. It created a really interesting session and the group reflected on what they were carrying and their own values and judgements. It lead to another session where they really shifted differently with that and realised they were one of the barriers, so they were actually spurning people rather than welcoming them and they were in an environment that was supposed to be welcoming of all of the community. Given this you can understand why someone wants a visiting service.*

The discussion in the focus group continued on the theme of community acceptance and smaller communities to explore other factors contributing to this. Some of the workers discussed how the residency status of the person was relevant to acceptance. That is, whether the person with a mental illness had been a long term (born there) resident, or someone who had not had the opportunity to establish strong links within the community.

Workers discussed how it is harder for a person with a mental illness that has moved to a smaller community, to fit in and be accepted in that community, rather than someone who has lived there all of their life.

Jennifer (worker) who herself lived in a small rural community considered the differences: *'I think it is supportive of someone who has been in the community all of their life and it is like part of you. You work with them like you do your own family whereas it would be different with a transient person'*. This was supported by some of the other workers who agreed that it takes time for a sense of community to develop and build and Anne (worker) felt this is *'more naturally forming for long term residents in smaller rural communities'*.

Overall there was agreement among workers that community inclusiveness and support might be an issue in general for people who move into a smaller community. Some of the workers felt this was linked to historical connections with the community with Jennifer explaining, *'you are not a local until the third generation'*.

However, Cathy (worker) disagreed with historical connection being a single factor and stated that this *'this varies according to the community and individual'*.

In summary, rather than seeing 'rural' as a homogenous category, the workers differentiated between regional cities and 'rural areas' with the size of the rural community and distance from regional centre identified as significant factors.

The discussion from workers identified key issues relevant to people being accepted in their community. These included:

- the size of the community
- the 'ruralness' or distance from a regional centre
- the perceived behaviours of the person with a mental illness
- historical connections with the community i.e. period of residence

However this understanding was multilayered and variable as each of these 'issues' were interlinked. For example, if a person exhibited perceived negative behaviours they were still more likely to be accepted in the community if they were born within that community. This was not seen as homogenous though as this varied according to the particular community.

In a broader sense the acceptance for people with a mental illness is also linked to contextual issues of stigma related to mental illness within the community as raised by the women earlier in this chapter.

Workers discussed how some of these issues could be addressed by community education to assist with building community support for people with a mental illness. However, community acceptance and support for people with a mental illness was linked to other environmental factors. Workers had different views on whether communities in general were supportive and helpful or whether it was only a minority of people within the community who were helpful.

## **7.5 Discussion**

The findings as presented in this chapter indicate the complexity and inequalities for women living with a mental illness in a rural area. The findings highlighted a number of issues relevant to women's rural mental health experiences and the service context. Through the participants stories it was found that:

- women living in smaller towns and communities where public transport is not available are structurally and socially disadvantaged
- there is a double bind of living with a mental illness in a rural area for women with significant issues of privacy and visibility
- structural inequalities impacting on the availability of services in smaller rural communities.
- workers explored practice opportunities in relation to community education to assist with building community acceptance for people with a mental illness.

I found that there was a consistency across both the women and workers that the lack of public transport presents a disadvantage, particularly for women living in smaller towns and communities where public transport is not available. The findings present a picture of structural inequality which created difficulties for the women in their capacity to be independent. This is particularly relevant in the Loddon Mallee Region as this is a sparsely populated and large geographic area within the state.

The women's stories highlight the issue of maintaining social connections where there was no available public transport and this is consistent with the literature. Both Cheers (1998) and Woodhouse et al (2002) suggest that the travelling distances and lack of public transport in rural areas precludes women from actively participating in activities, services or their community. This compounds the difficulties for women as the capacity to maintain social connections is relevant to the experience of mental illness as social relationships act as an important buffer in the face of adversity (Brown & Harris 1978, NHMRC 1991, AIHW 1998). This is relevant given the discussion in the previous chapter where it was found that isolation was a distressing experience for the women

The findings raised issues of dependence by the women on workers for transport. From my practice experiences this reliance is an ongoing difficulty in rural services.<sup>4</sup>

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<sup>4</sup> I am also aware that workers in urban PDRSS also make transport available for their clients however I consider there are distinctions with the rural context in relation to the availability of alternative transport options.

This presents an additional burden on services and worker time and places workers in a position of power in relation to the women who are reliant upon them for transport. This reliance has implications for the processes of power in the worker-client relationship where the workers have access to resources that are denied to the women (Mullaly 2002).

In a critical understanding the positioning of professionals privileges them with institutional power to either afford or deny access to resources for those in less privileged positions such as clients (Hugman 1991). In relation to transport reliance this privileging can be understood as a dimension of 'power over' exerted by workers.

In the rural context where public transport is minimal, a reliance on workers reinforces professional power and potentially creates issues of compliance for clients. Although there is controversy in the meanings attached to compliance (Murphy & Canales 2001) in these circumstances compliance may be defined as situations where clients are less likely to challenge the professional power of workers due to variations of dependency upon services. Issues of professional power are compounded if clients are dependent upon workers for transport for day-to-day activities beyond their usual use of the PDRS Services.

Transport dependency in this context is also likely to negatively constrain the activities of the women as they are reliant upon the structure and constraints of the worker's time to enable them to carry out their necessary daily activities. Thus any reliance further limits the activities of the women and challenges their capacity for self-management.

A critical poststructural analysis facilitates a further exploration of the issue of professional power in the rural transport context and enables positive aspects of transport provision to emerge. Although it is acknowledged that transport dependence has potentially negative consequences it can also be constructed as beneficial in certain circumstances. In the rural context where there are significant issues of isolation for women with a mental illness (McLaren et al 2001) a reliance on worker

transport effectively means that clients spend more time with the worker which assists with the relationship building and social support. This additional contact time enables a depth of interaction to occur beyond the usual program contact. This can act as a valuable buffer for the women as the rural transport limitations which are products of structural inequalities and disadvantage, reduce women's capacity to maintain social connections and potentially compounds issues of isolation.

In this context the level of interaction with workers can positively assist with reducing social isolation for women. Social support brings levels of satisfaction and enhances wellbeing (Lu 1997), particularly for women as many writers have argued that women develop in the context of connections with others (Miller 1976, Gilligan 1982, Miller & Stiver 1993).

In exploring issues of service transport a number of paradoxes have presented. Although the worker-client interaction is an unequal relationship; the receiving of support through the provision of transport and additional worker contact time can be beneficial. Whilst restrictions such as the limitations on worker time and availability for transport negatively impacts on the women's capacity for self-management the provision of transport positively assists the women in meeting their daily living needs and thereby supports them in overall self-management activities. These paradoxes would be worth exploring further with women although it was not the focus of this research.

However, there are a number of variables in this discussion such as the amount of transport time, the level of interaction with the worker and the nature of the worker-client connection. This connection can vary as often in rural and regional areas workers will share transport responsibilities so that clients are not necessarily regularly engaging with the same worker for transport.

Issues related to rural transport provision, reliance or dependency and the exertion of professional power lends itself to a multidimensional understanding of the nature and exercise of power in rural PDRSS's. For PDRSS workers the context of professional

power may not be fully understood as '*individuals or groups who exercise power may be unaware of doing so ... and social workers may even reject the idea that they exercise power*' (Hugman 1991:33). It is therefore relevant for practitioners to be alert to the implications of professional power in their practice.

I found that the theme of privacy and stigma as presented by the women portrayed a complex picture of the rural experience and highlighted a diversity of perceptions both within and across the separate groups of women and the workers.<sup>5</sup> Overall I found that issues of privacy and confidentiality were key concerns for many of the women as they were fearful of their illness being known in the community because of the potential for stigma and discrimination. However, being a member of a small community also meant higher visibility, therefore it was difficult to '*hide*' the illness but there was a greater imperative to do so because of the stigma.

This experience of alienation and marginalisation highlights the nature and tensions of a double bind of having a mental illness and living in a small rural community. Fear of stigma and non-acceptance effects the shaping of individual identity and a sense of powerlessness by the internalisation of shame, guilt and fear (Olsen 2002). This experience would add to a sense of isolation and alienation. It is a paradox that when these women wish to be the least visible they become most visible due to the structure of their environment. Although the literature indicates the sometimes paradoxical nature of the rural experience these findings presents a new understanding of the meanings for women of living with a mental illness in a small rural community.

I found that for many of the women there was a significant fear of stigma and discrimination from their community. Much has been written in the literature about the significance of stigma for people with a mental illness and Miller (1993) argues that there are gender differences in these experiences. Miller contends that women experience stigma as a disconnection and the women's fear of being identified as having a mental illness supports this.

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<sup>5</sup> It is beyond the scope of this paper to fully explore the complexity as presented in the material therefore the focus is given to the experiences and perceptions of the women although the diversity among workers is noted.

The rural context adds additional dimension to the women's experiences of mental illness. It was found that women with a mental illness are more visible in smaller rural communities which exposes them to rejection or possible threat of rejection by the community if they don't conform to the norms of that community (Cheers 1998, Martinez-Brawley 2000). This work provides a signpost for understanding the experiences of the women and their fear of others in the community knowing of their mental illness. The anonymity and confidentiality that the women sought is harder to achieve in the smaller communities and this is a consistent theme in the literature.

The women's perceptions, fear of stigma and their unwillingness to disclose their mental illness within their community may be associated with the conservative nature of rural communities as discussed in the literature. Many writers present rural communities as conservative, less informed or open to enlightened attitudes than urban areas (Dixon & Welch 2000, Jorm et al 2000) and therefore less likely to be accepting of diversity including those with a mental illness (Fuller et al 2000).

Perceptions and understandings are mediated by the contextual circumstances and from critical perspective the women's expressed fear of stigma could be understood within the context of a conservative, traditional masculine culture that prevails in rural areas (Wainer & Chesters 2000). This serves to disadvantage women by reinforcing notions of accepted behaviour and marginalising those who are seen as 'different'. The women's fear of stigma and non-acceptance in the community may be understood within the context of conservative values where there is less understanding of the sociocultural context of women's lives or of the nature of mental illness.

A further analysis of the data revealed a complexity and diversity of tensions and distinctions between intersecting categories of privacy, stigma, size of the community, acceptance by the community and the nature of service delivery which together make up the rural experience for the women. These tensions and distinctions included:

- Differences in experiences related to the geographic construct of small / large communities with a heightened awareness of the potential for stigma within smaller rural communities.
- A diversity of views regarding the nature of service delivery in rural areas. This was linked to views on whether services should be provided as visiting services or locally provided within the community. Issues of privacy were a concern with locally provided services and some of the women discussed that this may lead to them being identified by members of their community as having a mental illness.
- Distinctions were made between visibility for people, particularly in small communities and the opportunities for anonymity for people within larger communities such as regional towns.
- For workers there was the tension of visibility for the women against the opportunities to build community acceptance in smaller communities.
- An additional tension for workers was the benefit of locally provided services as the '*worker was known to the community*'.

These tensions and complexities highlight the social cultural context for women living with a mental illness in a rural area and supports the concept put forward by Judd et al (2002) of defining rural as 'place', that is, composed of complex and interdependent geographical, social, economic and cultural entities. The geographical construct of rural is inadequate given the diversity as discussed by the women and workers participating in this research.

This complexity also underscores the use of a concept of 'rural' as a single category and supports the argument by Briskman (1999) and Fraser et al (2002) that there is significant heterogeneity within the rural environment where specific characteristics can separate one rural area or community from another. Focusing on rural as oppositional to urban also fails to recognise the significant diversity of rural practice.

A key theme that emerged from the data related to the accessibility and availability of services in rural areas and the difficulties of these being provided as visiting services. This indicates structural inequalities impacting on the availability of services in smaller rural communities. I found that there was a level of anger and frustration at the

inequalities experienced by some of the women and the workers through the limited availability of services and the visiting nature of services in many smaller rural communities. This group wished to have the services locally provided and saw visiting services as an inequitable resource issue.

Visiting services are often provided to less populated communities and within the Loddon Mallee Region the majority of mental health services including PDRSS are located in areas of high or medium population density which effectively means the development of visiting services rather than these being substantially located within each community. This allows some measure of services to be available for smaller communities but conversely it also restricts accessibility and availability to services for people living in these smaller communities.

If we look at this situation of visiting services in combination with the transport disadvantage as discussed earlier it compounds inequalities in service access and contact with workers. This is consistent with Strong et al (1998) and Dixon & Welch (2000) who argue that a range of resources and services are not as accessible or obtainable in rural areas. Therefore women living some distance from services would have a greater need for access to suitable and affordable transport in order to facilitate their use of services.

Paradoxically whilst some of the women wished to have visiting services to maintain their privacy and protect them from stigma in the community, others among the women described it as a disadvantage to not have services locally provided.

Cheers (1998) argues that outreach or visiting services make opportunities available within rural communities, reduce access costs for clients and provide the capacity for more personalised face-to-face contact, but at the same time they require additional travelling resources from the service organisations. However, as suggested in the findings, visiting services are often only available for limited periods and although they are an effective way of providing some services in smaller communities it still

leaves a measure of disadvantage for women living in rural communities who wish to access PDRS services.

These findings indicate the layers of complexity in the life of rural communities and the need for practitioners to develop individualised approaches where possible for women accessing their services and to be cognisant of the need for understanding the local contexts of services.

In the focus groups workers took the opportunity to expand on the themes of women's rural experiences and discuss a range of practice issues related to community acceptance of women with a mental illness. As part of their discussion workers explored practice opportunities in relation to community education to assist with building community support for people with a mental illness. This suggests that participation in this research facilitated a reflective practice process for workers as hoped with the adoption of an action research methodology. This was intended to provide workers with an opportunity to reflect on the women's experiences.<sup>6</sup>

The discussion from workers identified key issues relevant to people being accepted in their community. These included:

- the size of the community as workers believed there were more stigmatised perceptions of mental illness within smaller communities
- the 'ruralness' or distance from a regional centre
- the perceived behaviours of the person with a mental illness
- historical connections with the community i.e. period of residence for the person within the community. Someone who has been born within the community is more likely to be accepted.

I found that the workers did not see 'rural' as a homogenous category as they differentiated between regional cities and 'rural areas' with the size of the rural community and distance from regional centre identified as significant factors. This

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<sup>6</sup> It would be useful to know if this process led to any ongoing reflection for the workers however, it is not the purpose of this paper to explore this.

findings is consistent with the earlier discussion related to stigma and the conservative nature of rural communities.

This finding is supported by literature which indicates that small towns and communities are microcosms of society and as such the inter-relationships for people living in that community are often based on '*a clear understanding of where each person stands in society ... in relation to relationships, reputation and history*'. These factors may influence the person's acceptance, emotional supports and networks within the rural community (Bell & Newby 1972:23, cited in Martinez-Brawley 2000)

## **7.6 Conclusion**

This chapter has examined the rural dimensions of the women's psychiatric rehabilitation experiences and has highlighted the importance of the social cultural environment in shaping women's experiences. It was found there was a double bind of living with a mental illness in a rural area for women with the paradox of issues related to the provision of transport by workers in rural area. A second paradox connected to issues of privacy, fear of stigma and visibility in small rural communities was explored. An additional paradox of visiting services versus locally provided services was also revealed. All of this points to the importance of an understanding of the heterogeneity of the rural concept.

The next chapter will examine the women's construction of the caring relationship and its role in the psychiatric rehabilitation process for women.

## Chapter 8: Construction of the caring relationship

This chapter explores the dimensions of the caring relationship between women and their PDRSS workers. It identifies how these particular women constructed the relationship and mediated their rehabilitation and support participation through their experience of relationship.

The themes that emerged through the women's narratives reflected the dimensions of the caring relationship. The themes are:

- Caring relationship
- Use of relationship in the rehabilitation process
- Dimensions of the relationship
- Change of worker
- Gender of the worker
- Silencing through relationship
- Relationship as a mediator for healing and regaining control

The theme of the women's experiences was the significance of the rehabilitation relationship both as a promoter of healing and a means of connection with others in the context of their mental illness and rural environment.

### 8.1 Caring Relationship

All of the women spoke of the importance of the rehabilitation function of the relationship with service workers. Many of the women discussed how they had experienced a caring and supportive relationship based on trust, respect and acceptance. The rapport developed in the relationship facilitated the rehabilitation process. The women also shared some examples where the relationship had not been as respectful.

Chris explained that the rapport was an essential part of working together. If this weren't established '*there wouldn't be any point in doing anything together ... it would be too hard ... it would be impossible.*'

The rapport was developed through someone taking an interest in their lives and demonstrating the care by being available to *'talk'*, to *'call in'* or making it known that they are *'there for you'*. For Alice it was important to have her worker *'just drop in to have a talk.'*

Elements of the caring included a safe, trusting and accepted relationship with the worker. Kate explored how it was important for the worker to *'accept me as a person'*. It is also important to be respected and accepted as an individual and Karma explained this as:

*everybody is an individual, not everyone is the same and it is important that not everyone is treated the same. It is important that the worker respects this. He respects me and treats me as an individual ... treats me like a person ...not just someone to go and see.*

Karma went on to describe how the relationship enabled her to *'know there is someone there, someone to fall back on, knowing there was someone to call upon'* and that it was *'important knowing someone was on your side.'*

Karma also described a situation with a previous worker where she felt *'let down'* by the worker. Karma had been hospitalised when she was very unwell and it was a very difficult time for her as she *'felt she had no control'*. During this time a friend visited and told Karma that she was being moved out of her flat, because she had not been able to get to the agent to pay her rent. She had some leave from the hospital and found all of the boxes at her flat ready to be moved. She explained *'this freaked me out and I was so angry with ... (worker) and I didn't want anything to do with her'*.

Kate explained that she wasn't happy with the conversations with one worker as she felt this worker wanted to talk about things Kate was not willing to discuss. Kate explained *'one of them just kept going on and I said sorry but you are going to have to go'*.

The workers who participated in this discussion agreed that the quality of the relationship is important. Patrick (worker) explained *'the quality of the relationship is*

*a therapeutic thing*'. Sally (worker) added that if the rapport is there, women will *'feel safe to tell you things'*.

Veronica (worker) identified how the rapport was developed, *'I think it is part of a woman with woman, you can share that too in a genuine way'*. This was challenged by Patrick (worker) who stated, *'men have got good caring relationships too, it is part of humanness'*.

Workers also discussed the nature of rehabilitation relationships and there was agreement that the way the rehabilitation was delivered was crucial and as relevant as the type of supports that were delivered. Values of respect and empowerment were considered key values in the relationship with clients and Lee (worker) linked this to the context of women's experiences:

*Women may have had bad experiences in the mental health system, so it is very important that we work in ways that are respectful and empower women to feel supported to try new things, to be able to make decisions for themselves.*

There was a commonality among the women in relation to the meaningfulness of rapport in the relationship although the identified key elements of rapport varied in importance for the women. These key elements included the capacity for workers to demonstrate the care by taking an interest in the women's lives, being available and accepting of the women. Although all of the women had experienced caring relationships there were some examples of difference presented by some of the women where they had not felt respected.

Amongst the workers who participated in the discussion there was agreement on the value of the relationship however there was differences between workers on whether this was related to the commonality between women or 'humanness' aspects.

## **8.2 Use of relationship in the rehabilitation process**

The emotional support and caring provided through the relationship facilitated the

rehabilitation process and personal growth for the women. All of the women discussed how a positive relationship assisted them with motivation, capacity to develop skills to deal with anxiety and panic, problem solving skills and their capacity to generally become more confident in managing activities and interpersonal relationships.

Several of the women discussed how the PDRSS worker assisted them with motivation to deal with day to day activities. Grace found it difficult just to *'face the day sometimes'* and workers provided encouragement:

*You only have to say 'oh I can't do that', they'll say 'have a go and if you can't do it then come back and we'll have another go.*

Alice felt her mental illness made it difficult to stay motivated but the workers assisted with this, *'they do motivate you ... cause with the voices it is hard to get out by yourself'*. Kate explained how the visits by the worker assisted her to maintain motivation and keep things in the *'right perspective'*.

Many of the women discussed their experiences of anxiety and panic and how their worker helped them to manage this. Grace found the worker helpful in dealing with her panic:

*At the moment I am having trouble with the telling machines on the wall ... I have been avoiding them like the plague. She's got me into them ... I will go as long as one of them stands with me and I'll punch it out ... but I can't do it on my own ... I get really nervous even with them there. I need (PDRSS worker) to come and help me ... I get a bit breathless ... I can't breathe ... they help me ... stay with me ... talk to me.*

Many of the women also discussed how workers assisted them to develop problem solving skills and deal with life's problems. Jenny discussed the value of having someone to *'bounce things around with ... to help me work things out'*.

Workers agreed as a group that rehabilitation was facilitated through the strength of the relationship which enabled them to encourage and support clients to deal with their difficulties. Sally (worker) saw the use of relationship as a valuable way of motivating and assisting women to try new things. She explained:

*Sometimes people just don't want to go out of their home ... so it takes a lot of*

*encouragement to take them out and get them somewhere. It's about fostering independence and helping people to get out. Often this is done by building a relationship with people, showing people that you care and respect them as a person.*

Veronica (worker) explained that working from a caring and supportive perspective with clients was valuable whilst at the same time it was important to 'give women opportunities to learn how to cope'.

The caring and supportive rehabilitation relationship supported the women as they learnt new ways of dealing with their life difficulties. However, the relationship is also experienced as multidimensional and this will be explored in the next section.

### **8.3 Dimensions of the relationship**

The dimensions in the relationship relate to issues of self-disclosure by the worker and with workers being described as 'a friend' by some of the women. Self-disclosure is defined as the sharing of some of the worker's personal information with the client.

All of the women discussed aspects of self-disclosure by their worker that assisted in the interpersonal relationship building and in skill development. Jean explained that the worker's self-disclosure facilitated trust in their relationship.

*I trust my worker ... it didn't take me very long though. Perhaps because we are in similar ages and background and everything like that.*

For Karma the worker's self-disclosure assisted with her parenting:

*(Worker) told me a bit about his parenting ... he shared a bit of himself and his parenting experiences which helped me to feel ok and to learn more about what being a parent means. It's been really important for him to help me do that.*

Some of the workers discussed the value of limited self-disclosure as a way of building the relationship with clients. This had the effect of normalising difficult circumstances and assisted women to learn more about how to deal with their difficulties. Workers all agreed that self-disclosure should be for the benefit of the women. Jennifer (worker) explained:

*It is the normalising that I use the most 'OK but look at this, this is what*

*happens in my life – we are no different’ People think that it is just something affecting them because of the mental illness, but hey look this is what happened to me.*

Even though there was agreement about the value of normalising life’s difficulties with clients, some of the workers saw limits to self-disclosure and acknowledged the differences between worker and client. Veronica saw the sharing of some personal information as an ‘*opportunity to develop a closer relationship*’, but cautioned that it was important to ‘*share things that are of benefit to the client*’, that it should not be ‘*burdening as the roles are quite defined*’.

Patrick (worker) discussed how even by normalising there are still differences between workers and clients, ‘*like someone on \$320 per fortnight in a flat with most of their income going out on basically surviving ... it is a bit different*’.

Issues of self-disclosure and a ‘close’ relationship can lead to complexities in the relationship. A small number of the women explored the worker – client relationship in a framework of friendship. Jean explained that the rapport with her worker felt like she had ‘*made a friend more than a support worker*’ because ‘*we shared the same sorts of interest and had the same sorts of hobbies and we got along together so well.*’ When Jean was asked what the qualities were that made her relationship with her worker ‘*like a friend*’ she replied:

*It is being able to talk to her, being able to be very open and honest, knowing that she is just there on the end of the phone.*

The similarities between notions of friendship and the rehabilitation relationship were discussed by workers and there was a diversity of responses to this. Some of the workers described feeling uncomfortable with a blurring between friendship and support as Lee (worker) explained:

*The rehab relationship might be more casual and relaxed than maybe other professional relationships, it is a special relationship, but you still have to maintain those boundaries between being a friend and a worker.*

However, other workers differed and were less concerned at being thought of ‘*as a*

*friend*'. Michael (worker) normalised the importance of friendship and described this as *'a significant part of all of our lives, especially when we are experiencing difficulties, so it is not surprising that we are seen as friends by some people'*.

Michael went on to discuss how he agreed that whilst the relationship is not friendship it does have *'elements of friendship'* with the friendliness and caring. This made it more difficult for people to distinguish between friendship and friendliness. Other workers discussed how the context of women's experiences, such as violence and the potential vulnerability of women in difficult circumstances also impacted on how they regarded the relationship.

Amongst the workers who perceived difficulties with the relationship being regarded as friendship discussed how this had the potential to make things difficult for women when workers changed their employment. Veronica (worker) explained that if the relationship is seen as friendship then it might be experienced as a rejection when the worker moves on, *'if a client thinks it is a friendship it becomes very complicated and it can end up hurting the person'*. In response to this Elise (worker) added that it is important to make the distinction between friendship and *'friendliness'* in the rehabilitation relationship, especially when working with women who may be vulnerable.

This theme presented a number of dimensions related to self-disclosure and friendship. The women regarded self-disclosure on the worker's behalf as valuable in assisting them to develop a connection with their worker and to learn new skills. However, the discussion with workers highlighted some contradictions, tensions and cautions amongst the workers. These included:

- the value of self-disclosure / the importance of limitations with this
- the normalising through self-disclosure can mask significant differences in the life circumstances between worker and client
- self-disclosure is normalising / self-disclosure can create perceptions of friendship
- discomfort with the perceptions of friendship / less concern with being thought of

- ‘as a friend’ and acknowledgment of friendship elements in the relationship
- the importance of drawing distinctions between friendship and friendliness

One of the perceived vulnerabilities for women in the context of friendship was the potential for difficulties when there was a change of worker.

## 8.4 Change of worker

Several of the women had experienced a change of worker and this was described as an emotionally difficult period for them. In many cases the women had developed a caring relationship with a specific worker and were used to having frequent contact and working together. For the women, the relationship issues made it harder to deal with this level of change.

The emotional difficulty of changing workers was explained by Kate:

*When he left ... it was pretty ... a bit emotional ... cause I had him for a couple of years you see and I felt that I had come a long way. I was starting to feel a bit more myself ... settled. I could just ring him up which I had to do a couple of times. If it had of been 12 months before that I hate to think because he had brought me so far.*

Often when there had been a change of worker it took the women some time to develop a rapport and relationship with a new worker. Grace explained ‘*it was a bit funny changing workers cause we had a good relationship*’.

Workers acknowledged the difficulties for women when there are changes of worker, especially if they have worked with someone for a long time. Elise (worker) explained that it is not surprising that it is difficult for women to cope with this change.

*The closer the relationship ... and the longer you work with individuals ... it can be hard. We spend a lot of time working on building a good relationship that helps women to manage. As workers we support people on a formal basis but we also work in ways that enable us to get to know people very well. Sometimes this can shift from the person seeing you from a worker to a friend. This leads to ongoing issues when there is a change of workers. You have to work with people at an individual level in a way that you can operate ... and we get to know a lot about their lives ... it is not surprising that it is hard for women when we leave.*

Jennifer (worker) discussed the change of worker in a rural context:

*It is difficult working with someone in a small rural town ... especially if they are fearful of disclosure or if they are out of sorts with the local community and there is not a lot in the way of services and supports to be creative. That is a situation where often a close relationship is built ... it is even harder for women in these areas when their worker is leaving or changing jobs. They might feel really isolated again. It is much harder though in smaller areas.*

Anne (worker) explained that the closure process might also be difficult for workers 'because we have got to know people and it means saying goodbye'.

It was difficult for the women when workers moved on or changed especially when they had developed connections with the worker. The tension for the women was the loss of their worker and the emotional impact of this loss. These difficulties were understood and acknowledged by workers who also related the difficulties of a change of worker to the caring nature of the relationship and the level of connection with the women. Contextual issues such as the size of the community, limitations of services and isolation issues were identified as relevant in understanding women's responses.

The women also raised issues of gender through their stories and this is now discussed.

## **8.5 Gender of the worker**

Through the process of the interviews with the women the gender of their key worker was integrated into the discussions. Many of the women had worked with more than one worker and had experienced working with both a male and a female worker during their PDRSS contact.

Grace, Amy and Jean expressed their wish to work with a female worker in the key worker role in the individually provided HBO support but at the same time they felt comfortable to work with a male worker in the day program activities.<sup>1</sup> Amongst a small number of the women there was ambivalence about the importance of the gender

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<sup>1</sup>Women participants were drawn from two Agencies and both of these provide a range of programs including Home Based Outreach (the key focus of this study) and Day Programs. Therefore women will

and these women did not perceive the gender of their worker as being relevant to their support.

Although some women may have expressed a preference for a specific gender in their worker they were not always able to exercise a choice as the services were unable to offer this. For Karma it had initially been important to have a female worker and her first key worker after entry to the PDRS Service had been a female. However, when Karma was faced with the loss of her accommodation during a period of hospitalisation she became angry with her worker and requested a change of worker from the PDRS Service. She was still seeking to work with a female worker but the PDRSS was only able to offer her support from a male worker. Karma explained they *'asked me to try him for a while ... just to give it a trial ... they didn't have anyone else. I didn't like it at first but then I started to get on well with him'*. Over a period of time Karma developed a strong rapport with her male worker.

The stories provided by the women highlighted diversity in their responses to issues of gender of worker. These included:

- gender of the worker was important to them / gender of the worker was not important to them
- some of the women wished to work with a female worker for individual support / the gender of the worker was less relevant in participation in the group programs

However, in general for the women, the gender of the worker was not as relevant as the nature of the interaction in the worker – client relationship.

Some of the women had expressed a wish to work with a specific gender of worker however even though they were often unable to have this request met they were still able to develop an acceptance of the worker through the building of a caring relationship.

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have access to different workers according to the program or activities. However in rural areas, according to the size of the Service and the community, women may also be working with the same worker across a range of programs.

Workers focused their discussion of gender on the capacity of services to provide choices of worker for clients. Meg (worker) discussed this in a rural context:

*There's not a lot of resources to deliver services and in rural areas ... things can get pretty sparse. We'd certainly like to be able to give women a choice but it is not always possible ... it is easier if you are working in (large regional centre) but even then it can still sometimes be hard.*

The opportunity for women to exercise choice in the gender of their worker was limited by the rural service context. The next section is related to the capacity to deal with conflict in the rehabilitation relationship.

## **8.6 Silencing through relationship**

For some of the women the nature of the caring relationship with workers made it difficult to deal with conflict or discuss complaints related to the service delivery. This reluctance was expressed through a wish not to '*hurt workers feelings*'. Mary explained how she felt at times her worker was '*bossy*' but she still felt she was '*nice*' and considered the relationship important. However, she requested:

*Don't tell her I said she is bossy ... I don't want her to know this ... I don't want to hurt her feelings.*

This was less overt with Grace but she was reluctant to raise any negative issues with workers. When asked if she would feel comfortable to ask for more home visits if she felt she needed them her response was: '*Yes, I think so ... no, I don't think it would be OK for me to say*'.

Alice had raised a complaint with the program supervisor about the service as she felt that her worker was not sufficiently attentive to her support needs, '*she just seems to forget about me, doesn't come around enough ... she says she was too busy*'. Alice went on to explain, '*I'm sick of her ... when she gets here she is alright*'. Although Alice felt comfortable talking with the supervisor she chose not to proceed with the complaint. When she was asked about discussing the issue directly with the worker, Alice's response was '*I didn't really like saying anything*'.

This reluctance was not the same for all of the women and when Kate was asked if she was able to discuss difficulties or complaints with workers her response was, *'I don't muck around, I would tell them straight ... I'm not scared to speak'*.

However, many of the women were less assertive in their approach and acknowledged that they would find it difficult to express their dissatisfaction.

This reluctance to raise complaints was discussed with workers who expressed surprise. Veronica (worker) felt this was a gender issue:

*Feeling conscious of not complaining to workers can be a gender issue as generally women don't like to hurt your feelings. It is important that we provide opportunities for women to raise their issues and to let them know that we are glad to hear how they feel.*

Anne (worker) discussed how women may be disempowered through the 'system':

*Women might have to deal with a whole lot of different services and in other services they may not have had any choices, for example in their case manager, so it hard for them to realise that they have a choice. Sometimes the whole mental health system can take away people's choices. Perhaps we need to be conscious of building opportunities into the support for people to say if things are not as they wish them to be.*

Sally (worker) acknowledged the interpersonal issues and the inequality of power of services in providing care:

*Some people genuinely like the worker and they don't necessarily want to hurt them and sometimes it may be that feeling that 'if I am honest I won't get that care again'. It is something that services need to take on so that it is us that is feeling responsible for it not them.*

This was a point of reflection for workers and their comments were summarised by

Patrick (worker):

*I think it is interesting about the complaints and grievances about how a person who may be unhappy or wanted to do things differently but didn't want to approach their worker because they were worried about the way the worker saw it, or may be hurt by that. It is interesting about the sensitivity around the workers feelings. As a flexible service we would hope that people wouldn't be worrying too much about that. We talk about input*

*and how important that is, but it might be saying something about relationship as well - they don't want to offend you and they are also in need of the services. That is actually a detriment to making things better and more responsive to people.*

These findings demonstrate the dimensions of the rehabilitation relationship with some of the women not wanting to 'hurt' workers feelings by raising any grievances or complaints. Even though there were times, for some of the women, when they wished to raise their concerns they felt unable to do so. However, some of the women did not have this constraint and were more assertive in their approach. This was a point of reflection for workers who discussed how women could potentially be disempowered by the dominant system of mental health care.

Although there were difficulties at times for the women the rehabilitation relationship assisted with their healing.

### **8.7 Relationship as a mediator for healing and regaining control**

Through the interviews many of the women explored how the strength of the caring relationship was part of their healing process. Kate described how the rapport in the relationship with her worker was an important part of her 'healing':

*I just locked myself up and made myself worse ... I wouldn't answer the phone but he just kept coming back. I was just lucky that I came across this real beaut bloke that knew things. He used to get things out of me ... he would come at the end of the day. We bonded real well ... swore sometimes ... and he knew that that was just part of my healing and he laughed.*

This was supported by Jenny who felt that the relationship helped her to stay well.

*'The visiting, talking with the worker ... having someone to confide in ... someone I get on well with. The support from the worker helps me stay well ... they certainly do ... isn't that amazing, they are supporting me so that I can stay well.'*

Several of the women expressed a sense of control by expressing how they wished the relationship to best work for them. Jenny was clear that she wanted an active listening process:

*I want to relate one on one with someone who will advise me, then I can*

*leave it and I can go on. I don't want someone just listening ... I want someone who can help me work out what to do. I don't want to just talk for the sake of talking.*

For Kate companionship and understanding in the support were important:

*I am starting to perk up, I still have my problems and what not ... but I know that if I don't get the support where it is needed I will slip back again. A bit of companionship and understanding with the right people that really know what is going on on an individual basis ... that's what I want from them.*

Alice explained that she needed 'someone to just come around and have a chat so I can keep on top of things' whilst Karma has additional support needs with her pregnancy:

*I will need more support as it gets closer and the when the baby comes. If (PDRSS worker) is not there I will still ask and get the support and the system will be in place.*

The women described the relationship as an important part of their healing process and some of the women had reached a position where they were able to define their needs to ensure the support was guided accordingly.

## **8.8 Discussion**

These findings present a multidimensional construction of the interpersonal relationship through which the women mediated their psychiatric rehabilitation experiences. The narratives of the women portray a strong sense of the relationship that is caring and productive although at times dimensions of silencing were also revealed.

The women saw the relationship as helpful and this is consistent with studies explored from a consumer perspective which have found the helping relationship to be rated highly as a positive influence on the recovery process (Sullivan 1994, McGrew et al 1996, Lammers 2002).

I found that the strength of the relationship helped to create an environment for the women to rebuild a sense of self. This occurred through the positive quality of the

relationship and the rapport that was developed which enabled the women to learn new ways of coping with the impact of their mental illness. Through learning to manage the symptoms of their illness such as limited motivation, anxiety and panic and difficult interpersonal relationships the women were able to develop an identity or sense of themselves as '*managers*' of their care.

This shift was developed through a productive use of power where the rehabilitation relationship was used as a motivator for change and development. This was demonstrated through the process of the women learning and developing new skills to deal with their difficulties. Healy (2000) discusses how a poststructural reconceptualisation of power enables the incorporation of both its coercive and productive effects. Foucault describes power as productive in that it constitutes identity and it can be used not only to subjugate but also to produce a sense of self and enhance individual capacities (cited in Healy 2000:44). This understanding enables us to reflect on the rehabilitation relationship in different ways rather than confining this to a dualistic powerful / powerless relationship.

The notion of productive power is consistent with the views of Miller & Stiver (1997) who would describe the dynamics in the relationship as displaying caring and mutuality. Rather than presenting the rehabilitation relationship as a dominant – subordinate one the women reconceptualised this as a form of mutuality.

Miller et al (1997) suggest some ways to work with women to develop the sense of mutuality in the relationship and these include:

- acknowledging women's experiences with authenticity and presence that reflects the difficulties and disconnections in their lives.
- Respect and honour women's coping strategies
- Moving towards equality of power in the relationship

I found that for many of the women the sense of mutuality was conceptualised as friendship. An important element of this was the self-disclosure by workers. Whilst the

women presented a diversity of experiences and perceptions they collectively saw self-disclosure by the workers as an important aspect in the relationship building. This sharing by workers assisted in creating a mutuality and a sense of connection in the relationship which was valued by the women. These concepts of caring and mutuality have been explored by Miller & Stiver (1997) as core elements in the dynamic of change for women and this is consistent with the concept of power as a productive force (Healy 2000).

Through the process of relationship the identity of the women moved as they reconceptualised their rehabilitation relationship as friendship. Given the context of struggle, isolation and the significant hardship of living with an enduring mental illness in rural areas as portrayed in Chapters 6 and 7, it is not surprising that the women saw elements of friendship in the relationship. This presented a challenge for many of the workers and it appears to be contradictory that women are expected to negotiate mutuality in relationships as presented by the self-disclosure of workers and yet maintain a distance and respect the professional boundaries. Even though the connection to friendship was challenging to some workers there was some understanding among workers of the difficulties in women's lives and the context of the relationship.

Regardless of conceptions of friendship the women were respectful of workers and their stories as presented explored the value of mutuality. For Miller et al (1997) the opposite of mutuality is a "power over" situation in a dominant-subordinate relationship that creates violations of relationships rather than opportunities for change to occur. It may be that the notion of friendship expressed by the women is valued as a sense of reciprocity in the caring exchange. This could be seen as a way of expressing the commonalities between the women and their carers rather than emphasising the differences between those who are cared for and those who do the caring (Orme 2001).

Miller et al (1997) see caring as oppressive if there is a denial of reciprocity but reciprocity itself in the worker client relationship can create ambiguities as

demonstrated through the friendship paradigm. Some writers might argue that ambiguities and contradictions are inherent especially when the relationships are embedded in a hierarchical power structure that creates professional separations reflective of broader social structures (Lipsky 1980, Hasenfeld 1983, Jones 2001). However, other understandings are available and as discussed the dualistic presentation of power is too simplistic to fully explain the women's experiences.

It was found that women had difficulty when there was a change of worker and some of the women expressed a wish to only work with a female worker. However given the rural service constraints this was not always possible, but the women were able to develop a connection with their new worker despite not having their choice of gender. It was difficult for the women when they experienced a change of worker as this was seen as a disruption in their connection. Through the relationship connections the women had developed a sense of self worth and growth and they valued the experience. Therefore it is not surprising if they experienced distress and a sense of loss at the change of worker against a background of isolation as previously explored.

The difficulty for the women was compounded by their lack of choice in terms of the gender of a new worker and even though the women were 'accepting' and able to develop strong relationships with their new worker over time, this should not mask the inequalities of opportunities for women. Women are in need of services, and in rural areas they may live in communities where accessibility and availability of services are significant issues therefore acceptance of disadvantage becomes a political issue through the limiting of women's options and responses (Dixon et al 2000).

To further discuss the concept of women 'accepting' their lack of choice with the gender of the new worker it might be that the connections that the women developed with their new workers was based on relational issues and a genuineness for connection as described by Miller et al (1997). Miller et al (1997) argues the importance of gender relational issues as women are more in tune to a sense of connectedness with others and feel a sense of disconnection more acutely. However it

is important not to stereotyping the experiences of women in the caring relationship.

It was found that the women were able to develop a connectedness with their new male workers and this finding challenges the notion of caring as being a woman's issue.

This supports Orme (2001) who argues that the social construction of care as being a feminine activity is challenged by men participating in the care relationship. It is wrong to develop universalistic conclusions about care and the caring relationship, especially with gender; it denies difference and ascribes a female nature to the notion of caring (Orme 2001). All of this leads to the complexity of gendered understandings of care especially with the overlay of mental illness and rural disadvantage.

The women's stories present a sense of silencing and it was found that the nature of the caring relationship made it difficult for the women to deal with conflict or raise concerns/complaints regarding service delivery. The theme of silencing for a number of the women was expressed as a wish not to '*hurt worker's feelings*' and this may be viewed as influenced by:

- the women's wish to maintain connection (Miller et al 1997) or,
- as an interpretation of their experience of powerlessness (Mullaly 2002) and reliance on services especially in the rural context and the lack of choices regarding other services.

However, the construct of not wishing to '*hurt worker's feelings*' as expressed by some of the women lends itself to an understanding framed by a model of connectedness where power is understood as taking different forms in helping relationships (Miller et al 1997). Nevertheless the diversity of the women's experiences and expression of not wishing to pursue complaints lends itself to multiple understanding rather than a universalising approach.

Within a critical conceptualisation there are overlays of power and inequality embedded in the caring relationship (Hugman, Peelo & Soothill 1997, Orme 2001). The construction of authority gives power to providers to include or exclude, provide

or withdraw services. It could be argued that the women's acceptance of difficulties rather than raising their concerns is part of a narrative that acknowledges the power of 'experts' who control access to resources and frame the experiences of women as 'other' (White 1995, Orme 2001). This is an area where further exploration would be useful to deconstruct the meanings for both women and workers in relation to complaints or grievances with the services. The interpersonal relationship requires attention to the conditions of women lives and an understanding of mental illness as a disempowering experience.

However, we cannot position powerlessness as a generalised experience for all women as evidenced by the diversity and complexities of the findings. Just as some of the women were more accepting of the services and disadvantages equally others were raised to anger at the inequities. A catalyst for the anger or distress for the women appeared to be when they were faced with powerlessness such as services not being responsive to their needs, not available or accessible when they need them or when there is a change of worker.

The findings construct multidimensional interpersonal and social relationships and for the women the connection in the rehabilitation process is constructed through the interpersonal interface. This interface is a combination of social relationships and power which are reflected through identities such as gender, disability and rurality. The women make sense of their participation in rehabilitation through the lens of relationships. It was found that power can be used productively and this facilitates the change process for women.

Overall the clients cared about their relationships with workers and they perceived the workers in general to be sensitive to their needs within the economic constraints. There were relationships of respect and trust that have a positive influence on the rehabilitation process.

## **8.9 Conclusion**

This research points to a need for workers to understand the subtlety and influence of power in the caring relationship. There is a need for a reconceptualisation of the worker client relationship within PDRSS's and for the concept of mutuality as a productive use of power to be explored. The key worker client relationship in PDRSS's is one among many but it is one where the client exposes their vulnerability therefore there is a need for workers to acknowledge and challenge power differentials whilst working towards the development of a productive mutuality in the relationship.

The next chapter explores the phenomena of interlinking care in rural areas.

## Chapter 9: Interlinking system of care in rural areas

This chapter examines the phenomena of interlinking care in rural areas as expressed by the women who participated in the research. Although this research was focussed primarily on the women's care within PDRSS's the women chose to describe their care and support as an interlinking system of care that encompassed services and supports beyond that provided by the PDRSS. The women constructed a broader concept of care beyond their psychiatric rehabilitation needs.

The circle of support for the women encompassed organisational care such as that provided by General Practitioners, clinicians and PDRSS workers as well as the informal care and support as provided by friends and the community.

Through discussions of care, a number of themes emerged and these included:

- Collaborative care system
- Participation in a community of care
- Valued care and support network
- Supportive friends and community

The experiences of the women must also be understood within the context of their mental illness experiences and the rural context where services are less accessible or available.

### 9.1 Collaborative care system

Many of the women discussed shared care arrangements that arose from combinations of support, all of which were described as helpful. Several of the women explained how the collaboration between sections of their care network assisted them to feel well supported although there were variations among the women as to which services were providing the collaborative care.

The services mentioned by the women as involved in the collaborative care approach included:

- PDRSS
- General Practitioners
- Clinicians (Psychiatrists, Case Managers and inpatient staff) from the Area Mental Health Service

The collaborative care was an important component for Karma who described how she now feels ‘safer’ with elements of her care network, the psychiatrist, PDRSS worker and General Practitioner, working together.

*Things are very organised now and going well, I have a plan with my doctor, psychiatrist and (PDRSS) worker so that we all know what to do if I become unwell. My crisis plan helps me to feel safe, especially now that I am pregnant. The things that have made the most difference ... the support from my psychiatrist, my local doctor and the worker ... this is important ... I feel safer this way.*

Grace described the collaborative work from workers across programs within the PDRSS (HBO and Day Program workers) and with her Case Manager from the Area Mental Health Service [AMHS].

*For supports I have ... who is my key worker at the day program, ... who is my housing worker and ... who is my case manager ... she comes around as well. She makes sure my dosette is alright. I see the psychiatrist through the case manager.*

*Does it work well with having all of these people? Yes, it seems to, but my case manager ... rings up ... my housing or key worker at the day program, and she comes out here to the day program to see me once a week and has a talk to me. They all know what is happening for me ... it is good like that.*

Grace continued to discuss the importance of her care network:

*Are you feeling well supported with the supports from your doctor, your case manager and your support worker? Yea I am, first time in my life cause I've been on my own since I was 14, and this is the first time. Pity I had to get schizophrenia to get some help.*

Karma also felt it was important to meet her needs and explained that *'it is important that everyone is working together ... that's what I need.'*

Workers discussed collaborative care arrangements and Anne explained that *'ideally we'd all be working together all of the time if that's what the client wants'*. Veronica (worker) shared an example where this had worked well:

*It was a seamless approach where the PDRSS, the case manager and the GP were working in the same direction and because this woman had a lot of physical, emotional and mental health issues it was very important that we all worked together. There was a lot of very positive meetings and some good outcomes. It can be achieved and really it is the best way to be working for the client.*

The women described a network of interlinking care that enabled them to feel *'safer'*, and best have their needs met. The value of coordinated care was acknowledged by some of the workers. The PDRS Service and workers were seen as part of a network of care for the women and this was most beneficial when collaborative care arrangements were operating. The following sections explore the elements of the care network as described by the women.

## **9.2 Participation in a community of care**

All of the women participating in this research had attended both PDRSS day programs as well as receiving individual support through the home based outreach support programs. Many of the women still attended day programs at the time of the interviews, however a small number had actively chosen to only continue with the individual support.

All of the women who were attending day programs agreed that their participation was valuable. Grace explained this participation gave her *'somewhere meaningful to go to instead of just getting up, having a shower and breakfast and nothing to do during the day'*. This was helpful for Grace *'because there's other people there ...I can talk to other people'*.

Jean explained that the individual support through the HBO program is important but it is also helpful to participate in day program group activities:

*It is important to have the one on one contact with the worker ... to still see her on her own. But the support group has also been a great help. With the support group I get in the car and I go out with a group of people and we generally get to know each other and have a bit of an outing that you wouldn't normally have when you are on your own.*

Many of the women described how the day program participation provided them with opportunities for social connection. Mary explained '*it's good being with other people ... make your friends in amongst the other clients*'. Apart from the social connection there was also a sense of acceptance and peer support from other participants in the day program. Grace explained this:

*People here treat you the same whether you are sick or well ... we accept each other ... there are few here we know that have gone into hospital ... and the staff and some of the people here always go down and see them.*

Participation was also an opportunity for the women to be with others who understand the experience of mental illness. Jean found this supportive as she saw herself as being different to '*ordinary people*':

*My family try to understand the illness but they can't get a really good grasp of it. They do the best they can which is good for ordinary people ... you can't expect people who are not going through that themselves ... who are fit and well and healthy themselves ... they don't understand how you feel.*

Jean also explained that participation in activities is an opportunity to relax, and do things together without a focus on mental illness as '*in the support group we don't talk about our illness, we just do things together*'.

Some of the workers discussed the issues of women accessing both day programs and HBO services as each provided different supports. Workers took a similar approach in considering the value of both types of support being accessed and felt that it was useful if Services were able to provide both program types.

Several workers explained how they saw individual support programs as being complemented by the social support opportunities available through day programs. Sally (worker) discussed the benefits of this for women:

*Women who are linked into groups and have more social contacts require a lot less support in the times when they are ill. They may require extra support but when they are well you can back off because they reunite with their social group in some way and are able to access it and use it for a variety of supports.*

Some of the women had previously attended day program but explained that they now preferred to only use the home based outreach support. Kate explained that although she previously enjoyed the day program activities it no longer meets her needs as *'some of them left and now you just sit around and talk till the cows come home ... now I would just rather have the worker visit me'*.

For Jenny, the day program had been helpful in the past but as she experienced difficulties with privacy she now prefers just to work individually with her support worker as *'I don't want everyone to know I've got a mental illness. ... this one on one is much better for me'*.

There were differences between the women in relation to ongoing participation in the day program alongside their HBO support. Some of the women found day program participation valuable whilst others chose not to participate in these.

Some of the women who continued using day programs discussed how they had not always felt safe or comfortable there. These women explored how workers had supported them to feel more comfortable in accessing the day programs. Amy discussed how she *'was really nervous at first'* as she *'didn't know anyone ... but the workers helped me to meet people there ... people talked to me ... I'm not nervous any more ... I'm fine'*.

Workers discussed women's participation in day programs and acknowledged that it was not always a safe or comfortable place for women. Elise (worker) explored this as a gender issue:

*Traditionally more men have attended day programs and women may find it harder to participate or speak up. It is important that if women don't feel OK we talk to them and find out what is going on. If they are scared of other people, or they don't feel safe then we need to know.*

In the discussions many workers acknowledged the value of activities and different experiences for women in group activities. However workers also discussed the difficulties of providing a variety of activities in rural areas. In the larger regional centres there were more opportunities for participation in a range of interesting activities but this was more difficult in the smaller rural towns/centres. The lack of public transport in many areas also meant that workers have to plan the activities carefully as a considerable amount of time was also taken up with assisting people with transport.

Workers also mentioned cost as a factor when arranging activities for groups as many of the participants in PDRS services are on pensions and benefits. A limited income restricts the range of activities that are possible.

Although many of the women preferred dual participation in HBO and day programs there were differences as some of the women no longer wished to access group activities. For the women who continued to participate in day programs they found value through social connection, acceptance and understanding. There was acknowledgement that day programs are not always a safe or comfortable environment for women, however workers were seen as supportive in assisting the women to feel more comfortable. Workers discussed the complexity of running day programs in rural areas with fewer opportunities, limited public transport and cost issues being relevant.

Many of the women discussed the value of care provided by their general practitioner and by others involved in their clinical care. This included Psychiatrists, Case Managers and inpatient staff of the Area Mental Health Service.

### 9.3 Valued care and support network

A large number of the women discussed a strong supportive relationship with their General Practitioner (GP). This was seen as an important part of their network of mental health care and supports. The relationship with their GP was a key element of the care and this was built through caring and giving time to the women.

Kate explained how the relationship with her GP is an important connection given the context of her abusive circumstances:

*My doctor is just marvellous, my GP, she has known me right the way through, the breathing and relaxation, I'm too aware, I can't switch off so it is no use to me, though I like my music. I have high blood pressure because of anxiety ... she is keeping that at bay. I had a fractured skull; all of my ribs have been broken. She is wonderful.*

When you say your doctor is wonderful what do you mean, what does she do that is wonderful? *Well they did a lot of research because they knew I didn't have ... they knew I wasn't a manic depressive, like I am depressive but no wonder. She has had a bit of a rough time too as far as a chap is concerned ... they had a bit of a play around with the medication ... I'm a bit nervy until we got to the right one.*

So does she take the time to just listen to you? *Oh yes, she's lovely, I'd be in there for an hour, I'd go up to the hospital just a mess and she would come. The migraines ... she's come to my home and give me the needle every four hours ... personal, very caring ... she must have understood what it was like for me and how it was... she saw how I got caught up and it wasn't me ... and I needed trust there too as I don't like men doctors for personal reasons.*

Grace discussed how her doctor took the time to listen to her fears and help her deal with these:

*I was really bad and they told me to go see Dr. ... and I went in and he had a vent in the wall. I was convinced he had a camera behind the vent in the wall, so he jumped up, you know the bed you lay on at the doctors, he jumped up on there, ... worked it open and said 'see there is nothing there, come on up, you come and have a look for yourself'. I had no choice then, as there was nothing there. It was good that he showed me though or I would've been really frightened ... he's a fantastic doctor.*

Workers were in agreement regarding the value of a supportive GP for women but discussed how it was not always easy for clients to access general practitioners due to a shortage of GP's in rural areas. Veronica (worker) discussed that support from GP's may be less stigmatising for people with a mental illness:

*I guess with clinical services there is the stigma attached to it whereas going to see the GP it is a lot more acceptable. Everyone visits a GP but not everyone goes to a mental health service. Many people see it as OK to sit in a local doctor's waiting room ... no one knows what you are there for.*

Workers explored the value of PDRSS workers linking in with GP's who were seen as an important support for people with a mental illness. However, some of the workers discussed the difficulties with maintaining contact with GP's but considered that it was easier if the GP had a specific interest in mental health. Workers discussed in general how there was a low rate of referral from GP's to PDRSS's and Patrick (worker) explained the need to raise awareness of the PDRSS programs with GP's:

*GP's know about clinical services, the regional triage service and case management and they would look to refer there and it is up to the case manager to refer to us. I think our link with GP's is very minor. There are some who understand what is there but most are not aware. Perhaps we need to think more about working with GP's to raise awareness of our services.*

The women had strong caring relationships with their GP's who were an important part of the care network for the women. Workers reflected on their linkages with GP's and explored methods to strengthen the links.

Many of the women were receiving clinical care from the AMHS and a few of the women discussed their care experiences. The positive experiences of care were related to a caring relationship. Some of the women explored their positive care experiences with clinical staff in the context of their vulnerability whilst inpatients. Kate explained this caring relationship:

*Everyone is different, like you may be schizophrenic, you may be manic depressive, but everyone is different. I hated being in the hospital ... the system you were just put in there like a sheep penned up ... here's your medicine, here's your meal.*

*Actually I got close to two nurses ... he came up to the special care for me and that was individuality. He got me going down to the town bit by bit and I used to have an attack and he'd sit me down and pat my hand and give me medication or whatever and just talk ... sometimes we'd go round the block, maybe do a couple of things I had to do like pay bills. He was terrific and I got to know him.*

Jenny also felt vulnerable in hospital and explained the care from a supportive doctor:

*When I was in hospital I was devastated ... and I thought I am never going to be right. I was a mess and I just envied the doctors for their health and one of the doctors just gave me a hug and said 'you will be right again one day, you will be alright again'.*

Karma provided an example of where she felt the relationship with her case manager was not respectful:

*She used to come quite a bit but she would only stay for a short time ... just give me my medications and go. On day when ... (Case Manager) came I opened the door and found she had two people with her ... they were two students. She hadn't told me anything about it so I got really upset and angry. I don't see her anymore. .*

Many of the women experienced a caring relationship with clinicians at a time of vulnerability, although this was not the same experience for all of the women.

The women also discussed the support they received from friends and community members.

#### **9.4 Supportive friends and community**

Several of the women spoke of supportive friends who were understanding, helpful and accepting. For a few of the women the support from friends included seeking assistance from clinicians when the women were unwell. The women described their friends as being accepting of them and helpful in times of need. Jenny described her experiences:

*I have a friend who is schizophrenic too and she was the first to ring me up, she is also the first to dob me into the police (laugh) ... but when I came back from hospital she just treated me like a friend again as if nothing had happened. I sort of feel with the ones who don't know I don't want to tell,*

*the one's who do and still want to be my friends, I am very grateful for them.*

Jean had a similar experience:

*My friends knew what was going on ... they were worried about me. They had put me in hospital to start with ... they had come along one day, a couple of friends, just out of the blue they called on me at home and they found out I was very depressed and blue and everything else. They rang up my GP and put me in hospital. I went from there but that was where I needed to be ... in hospital, for a little while. It is good having friends like that ... people who can help you when you need it.*

Some of the other women explored how connections with people in their community had been helpful for them. For Kate the church community and the friends she developed within this group have been accepting and helpful:

*I'm accepting a lot of things ... little things that people have done ... like camps ... I couldn't afford to go but they (church group) pitched in ... so I could go ... it's shocking cause I couldn't go out by myself ... it's bad enough just being with someone ... and crowds ... but they helped me go on the camp.*

In the focus groups of workers there were significant discussions of community supports that can also be available for women with a mental illness. Some workers explained the sense of community and support where 'you get pockets of people supporting people in small environments' such as a neighbourhood, community or church group. Veronica (worker) explored this:

*Sometimes there is that sense of community, like there is a client who lives in a small block of flats and the neighbours do lots of small things like carry a spare set of keys and help and inform her parents when she is not well. It is like a little community and they know when she is unwell, they support her in a number of ways and when she is well they support her by accepting her. She is valued in that community. She came from being an isolated person and she is now an accepted person. You can see the change in relationship – they (neighbours) come out and greet her and when she is unwell they do lots of extra things whereas in the past they would close their doors and hide.*

Workers discussed how it is harder for people with a mental illness to build a strong sense of community however there are many people in the community who do accept and

support people with a mental illness.

Friends and supportive members of the community were important to the women. The elements of this support included caring, acceptance and help or support when the women were unwell.

This chapter found that many of the women had a well developed circle of supports which included collaborative care arrangements for some of the women, a caring and supportive relationship with a GP or other clinicians involved in their care and a supportive network of friends and community members. Many of the women complemented their individual home based outreach care to access day program activities which provided an opportunity for social connections and the development of peer relationships.

## **9.5 Discussion**

The women's experiences reflect the importance of a circle of supports, both formal and informal, to meet their needs. Elements of the circle provided caring relationships and acceptance for the women. This same circle provided help and assistance particularly when the women were vulnerable due to their mental illness.

The findings as presented in this chapter have examined the benefits of a collaborative care system for the women. This included combinations of care with PDRSS's, GP's and clinicians. The women experienced a caring relationship with clinicians including GP's, Psychiatrists and Case Managers during their periods of vulnerability. It was also found that friends and supportive community members were significant in providing informal support to the women. This informal support provided caring, acceptance and valuable assistance when the women were unwell.

I found that a collaborative, interlinking network of care was beneficial for the women. This provided coordination across programs and services which supported the women to feel '*safer*' and to best have their needs met. This approach enabled the women to feel

well supported especially at difficult periods. This finding is consistent with the literature which suggests that coordinated approaches to care enhance the value of the service system to clients (Reynolds et al 2003). Fleming (2001) supports the value of collaboration and integration across services in rural areas but adds that unfortunately there is usually a paucity of such services.

The social reality for many women with a severe mental illness is the high level of service involvement in their lives in response to the nature and experience of their enduring mental illness. In these circumstances there is the potential for women to feel powerless and ‘managed’ by the care. However the women participating in this study don’t present themselves in this way. The women identify themselves as active members of this network of care rather than being ‘managed by’ the services who are involved in their care. This suggests that this is an active participatory role by the women and contradicts stereotype notions of passivity (Stoppard 2000). The women have resisted a passivity paradigm and constructed their identity as active members of their network of care. Through this process they have developed active coping strategies such as finding supportive people to talk to.

Through the women’s stories of a community of care which involved participation in day programs as well as the individually provided home based outreach (HBO) service it was found that for many of the women it was useful to participate in both program types. The social connections such as those developed through participation in the day programs was valuable in assisting the women to make friends and feel an accepted part of a community. However, there was diversity across the women as some of the women chose not to continue to participate in the day programs for various reasons.

As described by Grace, this participation gave her ‘*somewhere meaningful to go*’ where there is an acceptance and acknowledgement of the difficulties of the illness experience. All of the women participated in the individual support as provided through the HBO program but for many of the women this failed to provide them with the opportunity for social connection. Several of the women made a distinction between the value of the one-

on-one support as provided through the HBO program whilst also acknowledging their perceptions of the value of the group programs for acceptance and peer support. Mental illness is an isolating and distressing experience and peer support enhances personal resources, provides friendship and companionship and enables people to feel part of a community (Brooks 2002). The participation as explained by the women is linked to the experiences of mental illness and the rural context as described in earlier chapters.

The workers mirrored the women's responses regarding the social value of women's participation in the day program and added that the social support can assist in building resiliency. For workers there were difficulties with providing a variety of activities and different experiences given the rural context and travelling distances. In rural areas this is made more challenging with the issues of public transport unavailability as a considerable amount of worker time is taken up with assisting with transport. This was discussed in Chapter 7 where it was found that for some of the women the transport assistance was required to support the women in their daily living activities not just their access to day programs.

A small number of the women discussed their 'comfortableness' at the day programs and it was found that workers were conscious of gender issues and of providing an environment that supported the women to participate. This is an important practice implication given the discussions in the literature regarding the higher participation rates for men in day programs which can leave women feeling alienated or threatened by the predominantly male environment (Cox 1994, Reid 1995, HS 1997b).

Many of the women discussed the care and support provided by their General Practitioner (GP) and it was found that these relationships were an important part of the care network for these women. The women's relationship with their GP was variously described as caring and respectful of the women's needs. GP's are often the first point of contact for people with mental distress (Wilkinson 2000) and they are a valuable connection for rural communities where services are fewer and have less flexibility in their delivery due

to limited resources (Cheers 1998, Brooks 2002). The literature indicates that GP's take on a higher burden of psychological care in rural areas because there is less access to specialist care (Campbell et al 2001). Paradoxically there are some advantages for women in the midst of rural disadvantage in access to specialist services. This was discussed by a worker who highlighted the less stigmatising nature of visiting a GP rather than a specialist mental health service:

*'it is a lot more acceptable. Everyone visits a GP but not everyone goes to a mental health service. Many people see it as OK to sit in a local doctor's waiting room ... no-one knows what you are there for.'*

The fear of stigma and high visibility in smaller rural communities was a significant issue for the women as discussed in previous chapters therefore paradoxically there may be some benefits for women with the limited specialist service availability.

Many of the women felt they had good access to their GP, although workers described access differently and discussed how it was not always easy to access GP's due to a shortage in rural areas. This is supported by the literature which indicates the significant disparity in the number of GP's practising in rural areas in comparison to urban Australia. Young et al (2001) describes the difficulties of GP access in rural areas and found that rural areas are disadvantaged in access to female GP's, after hours care and long waiting periods for appointments. There is also a significant difference in the male:female ratio of GP's in rural area where the majority of female GP's overall practice in Melbourne (83.6%) with only a smaller number (16.4%) practising in the rest of the state (Wilkinson 2000). This indicates significant structural disadvantage for women with a mental illness in a rural area as this effects their capacity for either a choice of GP's or for a choice of gender in their GP.

From my practice experience this difficulty is evident across the rural areas and not confined to the more rural or smaller communities. Often women in large regional centres

such as Bendigo have limited access to GP's as there are insufficient numbers to meet the community's needs. In practice for PDRSS workers this often means that it is difficult for women to gain access to a female GP. At times it is difficult for all clients to access a GP as many have their 'books closed' and they do not take on new clients until their patient numbers are reduced. This often leaves women without adequate access to GP care. This situation also makes it more difficult for PDRSS workers to develop and maintain good connections with GP's although as discussed earlier collaborative care is beneficial for the women. This is an area for rural PDRSS workers to continue to explore.

The women also described relationships of care with clinicians at a time of vulnerability, for example during periods of inpatient care. Much of the literature on professional or 'expert' care describes the professional – client relationship as a hierarchical relationship that reflects the dichotomy of power and the privileging of the professional (Hugman 1991, Mullaly 2002). However, through the women's stories a different picture is provided. Many of the women discussed their experiences with specialist mental health professionals as caring, respectful and empathic. This suggests that a dichotomy understanding doesn't allow for diversity or difference within the category of 'professional' to emerge (Healy 2000). This understanding doesn't minimise the impact of the sociocultural understanding of power as invested in dominant groups, nor does it forget the power inherent in the statutory role of medical clinicians, but it does allow for a broader understanding beyond the powerful / powerless dyad.

This knowledge can alert practitioners to explore and seek ways to understand the complexities of power in the local context. This has practice implications for PDRSS workers as often there is a culture of 'separation' between the clinical role and the rehabilitation role but this finding suggests there are alternative ways for PDRSS workers to understand the processes of power in the medical clinician – patient relationship.

The women discussed the informal supports from friends and community members as part of their circle of care. For some of the women their friends were alert to their needs and

were able to get adequate support for the women when they were very unwell. The women appreciated this caring aspect from their friends. This findings supports the study by Sullivan (1997) where respondents highlighted the value of care from friends who were providing friendship and social support.

Workers discussed the role of community supports for people with a mental illness. This was found to work best when the person became an accepted part of a community. This community can be small such as the immediate neighbours in a block of flats but the significant thing is the support, acceptance and care. Martinez-Brawley (2000) argues that everyone needs to feel some sense of acceptance within their community and a sense of ‘*security*’ is derived from mutuality of community relationships, familiarity of the environment, and from the affection and support of friends and neighbors.

All of these supports would be especially important for the women when they experience an unresponsive social environment such as that discussed in an earlier chapter which explored the dimensions of living in a rural area with a mental illness. These findings also show that not all of the women’s experiences are negative and whilst some people/groups in the rural communities can be stigmatising there are also groups that are able and willing to provide support for the women.

The workers raised a number of examples of where community supports had worked well to facilitate acceptance, support and social connections for women. The literature suggests that there are powerful health effects of social connectedness and a positive social environment can strengthen individuals (Cheers 1998, Vichealth 2002). Whiteford (2001) argues that psychological strength (self-esteem and individual identity) and vulnerability, all factor into functionality and wellbeing and each of these are effected by the social context of an individual. This is a signpost for rural practitioners to continue to work at building supportive and inclusive communities especially in rural areas. There may be a need to re-examine the work of PDRSS from the perspective of social inclusion to ensure a responsive environment is available for women. Whilst doing this it is relevant not to see

this as a problem for women, but to recognise that the problem is to ‘fix’ the community, not the person.

## **9.6 Conclusion**

This chapter has provided a number of stories of connection and La Nauze & Weeks (1999) found that connectedness is enhanced by the interweaving of different spheres of women’s lives. These findings have demonstrated the nature of this interweaving and in the process has provided many clues for services. Within the context of a circle of care the PDRSS’s were able to offer a significant part of the support that is needed for women in distress.

The following chapter presents the conclusions from this research.

## Chapter 10: Conclusion

The focus of this research was an exploration of the experiences of women using rural psychiatric disability rehabilitation and support services; in particular the home based outreach programs. The research occurred in the Loddon Mallee Region of Victoria. The objective was to give voice to women and to uncover the meanings of their experiences.

The argument as presented through this thesis is that women are marginalised and alienated by the social cultural conditions of their lives which impacts on their mental illness and rural experiences. However, women are not a homogenous group and a diversity of experiences exists which demonstrates women's active capacity to mediate their environment.

The literature and findings from this research highlight the importance of the sociocultural context of women's lives as an integrated component of their experiences and identity. The nature of this environment helps shape the identities of the women. However, to see this as a "fixed" environment where women are perpetually portrayed as powerless denies the active strategies implemented by the women in their journey of learning to manage their illness and environment.

The women's narratives of their experiences provide a sense of a journey, of change and movement where they have mediated their environment to move from a position of powerlessness and lack of control to a position of regaining control and power. For the women their psychiatric rehabilitation experience provided a vehicle for change. Through the construct of a caring rehabilitation relationship the women were able to move forward and reshape their identities and in the process become '*managers of their care*' rather than being '*managed by*' their illness experience or services. They were also able to develop a measure of management of their environment by seeking out the services and supports from their community to best meet their needs.

Through their participation in the research the women revealed their active capacity to

reflect on their actions, to consider and explore relationship issues and to indicate how their needs are best met. These women have moved beyond being total victims to their mental illness distress, to their alienating environment and to 'all powerful workers'. Ostensibly the women appear to be in a position of powerlessness or disempowerment due to their gender, disability, reliance on services, the context of rural disadvantage and so on, yet the women don't see themselves as powerless and I suspect would strongly resist such a category. Rather than understanding their position as powerless it would be useful to continue to explore ways that women in psychiatric rehabilitation make use of power to mediate their environment.

This research process has also been a reflective journey to develop an understanding of women's experiences and the processes of power. It was found that power can be a productive force and it can take shape in many different ways. This was exposed through the discussion of mutuality and the nature of the connection in the rehabilitation relationship and journey.

This research offers some alternative understandings of the processes of power in psychiatric rehabilitation and this shared knowledge offers workers opportunities for ongoing reflection. The findings from this research have acknowledged the importance of the psychiatric rehabilitation process for rural women with a mental illness.

In the process of the research a number of paradoxes or tensions were also revealed and these are added as a point of reflection for those in the field. The paradoxes reveal the need for a multidimensional understanding of the nature of power in the rural psychiatric disability rehabilitation and support service context and the diversity of experiences of women with a mental illness. The tensions revealed through this study include:

- Developing strong connections – PDRSS's marginalised
- Provision of transport and professional power – the benefits of workers providing transport
- Support from community – potential for stigma
- Local services – visiting services

- Care relationship – oppressive practice
- Distress of women – psychopathologising of women's lives
- Complexities of being a worker in rural areas – blurring of professional boundaries.

Through their narratives the women have provided many clues for services and workers on how best to support women and these have been incorporated into the discussions at the end of each findings chapter. The responsibility for change and development is now in the province of practitioners.

The women who participated in this research still live with an enduring mental illness as part of an everyday presence yet this research has shown their capacity to reshape their identity and move beyond the divide.

I wish to convey my thanks to the women and workers for enabling us to be the audience for their journey.

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Psychiatric Disability Rehabilitation and Support

Service Types

Please note that these services were formerly known as Psychiatric Disability Support Services.

Psychiatric Disability Support Service Types  
(Mental Health Branch 2000:21)

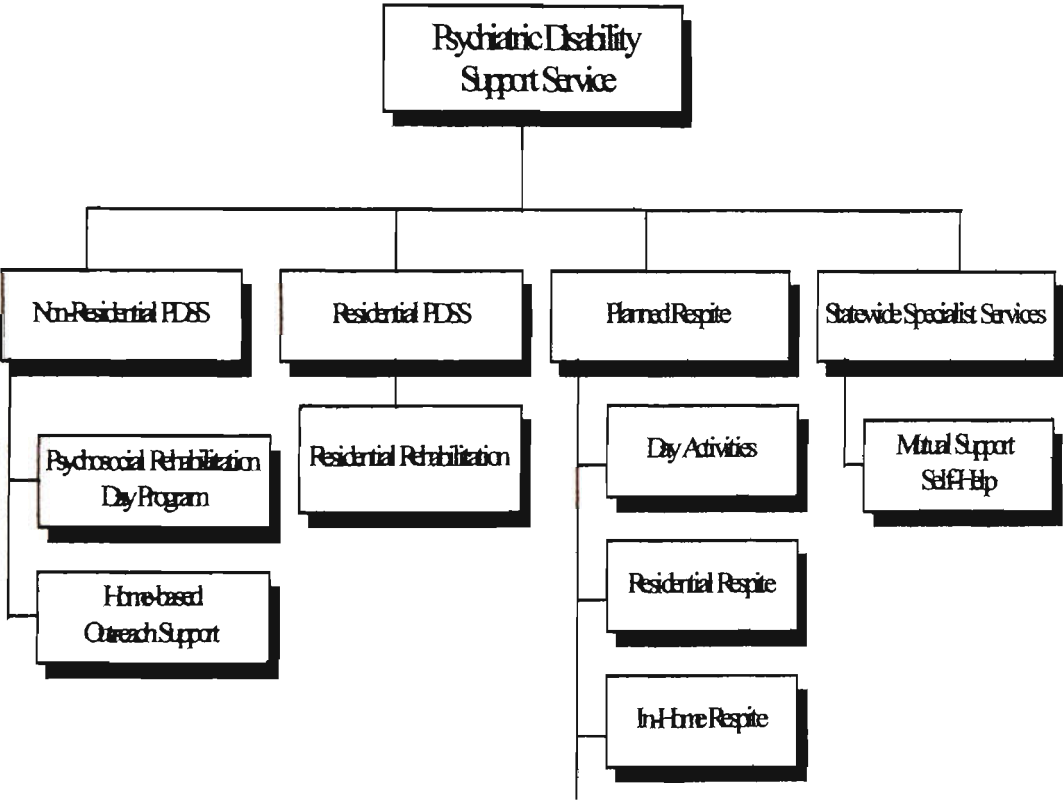
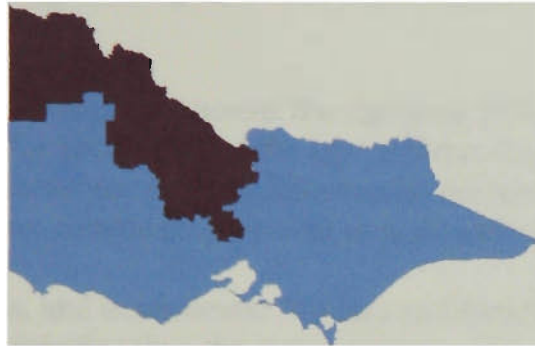


Figure 3: Taxonomy of Psychiatric Disability Support Services

### The Loddon Mallee Region of Victoria



### Loddon Mallee

#### Regional Overview

Source: Human Services (1998) *'Improving Women's Health': A Strategic Plan for Women's Health in the Loddon Mallee Region 1998-2001*, Department of Human Services, Victoria p. 6

#### The economy

The Loddon Mallee Region has the largest geographical area of any of the nine DHS regions and covers approximately one quarter of Victoria. The Region comprises five significant areas, namely the Sunraysia district around Mildura, Bendigo and its surrounding hinterland, the Murray River communities including Swan Hill and Echuca, the sparsely populated Mallee area and the southern urbanised portion of the Region bordering Melbourne.

The major communities are Bendigo and Mildura. Other towns such as Swan Hill, Echuca, Kerang, Ouyen, Wycheproof and Kyneton also act as focal point for services.

A range of factors has contributed in recent years to significant restructuring of regional communities. Rationalisation of transport, the redevelopment of services and changes in the agriculture sector have had an impact on the Region, particularly on smaller communities. A considerable sense of isolation is felt in the far north west of the Region.

#### Population

The population of the region was 269,194 in 1996 and is projected to be approx. 282,000 by the year 2001. The population is not evenly spread across the Region. The southern portion houses the rapidly growing commuter suburbs, whilst the northern portion is sparsely populated. The major provincial centres are experiencing continued steady growth.

In 1996, there were 105,142 women aged 15 years and over in the region. Nearly one in five of these are aged 65 years or over.

The Region is home for some 1,567 Aboriginal and Torres Strait Islander women, and also a small but diverse range of language other than English background communities.

There were 43,664 women employed across the region in 1991, with part time employment accounting for about 19% of the labour force. Community services was the largest employment sector for women, followed by the wholesale and retail sector. In some parts of the region, female employment in agriculture is significant.

The major service centres, and in particular Mildura and Bendigo, have a higher proportion of one parent families than the state average.

### **Health profile**

The key risk factors associated with ill-health in Australia are poor diet, smoking, excessive alcohol consumption, obesity, physical inactivity, raised blood lipid levels and raised blood pressure. Research has shown some socioeconomic differences in the prevalence of risk factors.

The 1993 ABS Survey of Disability, Ageing and Carers estimated that 18.7% of Victorian females had a disability of some kind. The rates of disability increase rapidly over the age of 45 years.

### **Mental and emotional health**

The Region has high rates of suicides, and small country towns are especially vulnerable to high rates, with often devastating effects on communities. Whilst deaths by suicide are more common amongst males, females attempt suicide at a higher rate than males across all age groups.

The ageing of the population means that the proportion of women over 65 years using mental health services will continue to increase.

The central role of alcohol in some social activities in rural communities and the associated potentially dangerous behaviours that result are of significant concern.

### Medical Definitions

A common medical definition of the terms mental illness and disorder refer to the spectrum of cognitive, emotional and behavioural disorders that interfere with the lives and productivity of people (CDH&AC 1998).

Among the broad spectrum of mental illnesses there is a categorisation into high prevalence and low prevalence conditions which are also termed '*serious mental illness*' or sometimes referred to as severe and enduring mental illness.

In the general population the incidence of serious mental illness is high with up to 3% of Australians experiencing a serious mental illness (Commonwealth of Australia 1995:3). These conditions include conditions such as schizophrenia, bipolar affective disorder, severe depression, personality disorders, schizo-affective disorders, obsessive compulsive disorder, post traumatic stress disorder and severe eating disorders (McKenzie 2000).

People are usually required to have a diagnosis (or pending diagnosis) of a serious mental illness for entry to Area Mental Health Services (psychiatric treatment services) and Psychiatric Disability Rehabilitation and Support Services.

For the purposes of this research a functional and social definition of disability as used in Psychiatric Disability Rehabilitation and Support Services is adopted, although this is most mentioned in the literature rather than being a guide to entry to programs.

A psychiatric disability is defined as being associated with, or as a result of, a serious mental illness which affects the ability of the person to perform the activities and tasks of everyday living and to develop and maintain effective personal and social relationships (Department of Human Services [DHS] 2000a).

### Principles of Psychosocial Rehabilitation

Cnaan, R.A., Blankertz, L. & Saunders M. (1992) 'Perceptions of Consumers, Practitioners and Experts regarding Psychosocial Rehabilitation Principles' in *Psychosocial Rehabilitation Journal*, Vol. 16, No. 1 pp. 95-119

1. All people have an under-utilized human capacity that should be developed.
2. All people can be equipped with skills (social, vocational, educational, interpersonal and others).
3. People have the right and responsibility for self-determination.
4. Services should be provided in as normalized an environment as possible.
5. Assessment of needs and care should be differentiated (i.e. based on the unique needs, abilities, deficiencies and environment of each client).
6. Maximum commitment is needed from staff members.
7. Care is provided in an intimate environment without professional authoritative shields and barriers.
8. Early intervention is preferable.
9. Environmental agencies and forces are recruited to assist in the provision of service.
10. Attempts are made to modify the environment in terms of attitudes, rights, services and behaviour (social change).
11. All clients are welcome for as long as they want to be serviced (with the exception of specific short-term high demand programs).
12. Work and vocational rehabilitation are central to the rehabilitation process.
13. There is an emphasis on the social rather than a medical model of care.
14. Emphasis is on the client's strengths rather than on pathologies.
15. Emphasis is on the here and now rather than on problems from the past.

**Women and Psychiatric Disability Support: A study of the needs of women with psychiatric disabilities and the efficacy of rural home based outreach support programs for women participating in Psychiatric Disability Support Services. Psychiatric Disability Support Services.**

My name is **Margaret Brooks** and I am conducting a research project as part of a Masters Program in the Social Work Unit at Victoria University of Technology. The aim of the project is to learn about women's experiences in home based outreach support programs within rural Psychiatric Disability Support Services. I would like to learn more about the needs of women who use these services and the helpfulness of support programs for women.

**Why am I interested in this area?**

I have worked in the psychiatric disability field for a number of years and have often wondered why some programs only have a minority of women using the services. This is surprising given that women are over-represented in seeking mental health supports from generalist health services, represent approximately 50% of service users in specialist treatment services, and have a higher percentage of disability from mental disorders than men. Yet they are a minority in psychiatric rehabilitation programs. This got me thinking about the way services are run and whether they are meeting the needs of women. Are the current services helpful for women?

There has only been limited research into women's own descriptions of their needs and experiences and the helpfulness of services, and even less is known about women in rural areas. Some people have looked at day programs, but no-one has explored home based outreach programs that offer individual support for women. Therefore this research project aims to interview a sample of women about their self reported needs and what they see as the helpfulness of rural home based outreach support programs. To add to this understanding I am also wanting to interview a number of workers to see how well their thoughts and ideas match those of women consumers. This information from women consumers and workers will help services learn more about meeting the needs of women consumers.

**There are several steps to doing this research:**

- I would like to form a reference group of interested service providers/workers and community members in the region to oversee the project. This would mean a commitment to discuss and help make decisions about the research project. This would involve meetings on a monthly–three monthly basis (depending on what is happening with the research) and would continue for the life of the research project (until February 2000).
- I will be contacting all of the psychiatric disability support agencies providing home based outreach support programs in the Loddon Mallee Region. This will be to see if they agree to participation in the project. Participation means that workers would be willing to discuss the project with their women consumers and see if they are

willing to take part, and for workers in these services to think about taking part in a focus group. I am seeking to interview 10 women from across the region, and 6-10 workers for the focus group interview.

- The workers will identify women who meet the criteria for the research project. There will be no pressure for women to take part. The criteria for women consumers to participate in the research are:
  - women who are currently receiving home based outreach support services in the Loddon Mallee region.
  - women who have been receiving this service type for a period of three months or longer
  - women who range in age from 18 – 65 years
  - women who have adequate support structures in relation to their mental health needs.
- When women consumers have agreed to take part they will be asked permission for me to have their contact details. From this contact I will then arrange individual interview times with the women. The women can decide where they want the interview to take place. The commitment for women would be for a 60 – 90 minute taped interview where I will be asking a range of questions related to needs and the helpfulness of services in meeting these needs. Before we start the interview we will discuss how I will protect people's confidentiality, any possible effects of the interview and each woman will be asked to sign a consent form. Possible effects could include someone getting upset or feeling uncomfortable because of remembering things that may have happened to them. If this does happen then I can support the woman through this, or I can arrange for the women to see her worker as soon as possible. However, I have a lot of professional experience in this area and I will be very sensitive to the women in the interviews. My primary concern will be for the well-being of the women.
- When I finish the interviews I will be looking at all of the material collected to help me decide on the themes that came from the women. If I want to quote any of the women I will get in touch with each person to see if they agree to me using their words. When I put all of this together for a report I will not use anyone's name and there will not be anything in the material to identify who said the things.
- I will also be asking workers in services to take part in a focus group interview, and I'll be seeking workers who are willing to take part in the project. They won't necessarily be the same workers who have contact with the women consumers. The focus group will be similar to the individual interviews; I'll be asking what the workers see as women's needs for service and how helpful the services are in meeting these needs. This will follow the same process as the individual interviews – i.e. consent forms, taping, use of quotes etc.
- The process following this will be putting all of the work together to see if what the women consumers say is similar to the thoughts of workers. A research report will be developed from all of this information and this will be submitted for my Masters Program. At this time I will also distribute a copy of the report to everyone who has taken part in the research project.

**If you are interested in participating please feel free to contact me.**

**My contact details are:**

Name: Margaret Brooks

Address: St Luke's

Telephone: (03) 54401100

My name is **Margaret BROOKS** and I am doing a research project as part of a Masters Program in Social Work at Victoria University of Technology. I am wanting to learn more about women's experiences in individual support programs in rural areas. I am interesting in hearing about the needs of women who use the services and the helpfulness of support programs for women.

### **Why am I interested in this area?**

I have worked in the psychiatric disability field for a number of years and have often wondered why some programs have few women using the services. Overall women are a minority in psychiatric rehabilitation programs yet women have a higher rate of mental ill health than men in many areas. This got me thinking about the way services are run and whether they are meeting the needs of women. Are the current services helpful for women?

I am interested in hearing the way women describe their needs and experiences and learning more about what women would see as helpful. To do this I would like to interview 10 women who are prepared to be involved, and who are willing to speak about their experiences in home based outreach support.

Later I would also like to interview a number of workers to see how well their thoughts and ideas match those of women consumers. This information from women consumers and workers will help services learn more about meeting the needs of women.

### **The interviews**

I would seek to interview you once for approximately 60 - 90 minutes. At the interview you may have a family member or friend with you if you wish. I also seek permission to tape the interviews and take notes, however to prevent any identification you will be asked to choose a pseudonym and this will be used instead of your own name. The tapes and notes will be stored safely and will only be available to myself and my university supervisor. These will be kept for a period of five years and will then be destroyed.

**All of the information will remain confidential, and participation in the project is voluntary. Your involvement would be greatly appreciated.**

The interview may raise issues or concerns which can be distressing for you, therefore it is important that you have current access to a support worker. Your participation is voluntary and you may withdraw from the project at any stage.

The information from the interviews will be used to write a thesis for my Master of Social Work, and this may be published at a later date. There will be nothing in the writing to identify you, and a copy of this report will be available to you on request.

I will ask you to sign a consent form (attached) to show that you have fully understood the project. If you are willing to take part your worker will pass your name on to me and I will contact you. **I would appreciate your involvement and thank you for your time.**

Stage One and Two consent form for women participating in:

**Women and Psychiatric Disability Support: A study of the needs of women with psychiatric disabilities and the efficacy of rural home based outreach support programs for women participating in Psychiatric Disability Support Services.**

I would like to invite you to take part in a research project as part of a Masters Program for Margaret Brooks in the Social Work Unit at Victoria University of Technology. The aim is to interview a sample of women who are using rural home based outreach support programs. Little is known about the needs of women using these services or the helpfulness of services in meeting the needs of women with psychiatric disabilities. I will also be interviewing service providers/workers to see how their views match those of women using the services. The project hopes to be able to provide information to service providers to enable them to make the services more responsive to women.

**I acknowledge that:**

- I am currently receiving home based outreach support services, with access to a support worker, and have been receiving this support for a period of three months or longer.
- I am aged between 18 – 65 years.
- The full details of the project and any possible effects of participating in the project have been explained to me. I understand that this is **stage one/two** of the consent process, and that I will be required to sign a further consent form prior to the interview. This will be no less than one week after signing this consent form.
- I have had the opportunity to have any questions answered and I have been informed that I am free to withdraw from this project at any time. If I do so this will not jeopardise me in any way.
- The project is for the purpose of research and not for treatment.
- I consent to the taping of the interview.
- I have been informed that my confidentiality will be protected.
- the results of the research may be published, but this shall not contain my name or any other identifying information.

**Consent for participation:**

I .....  
of .....  
..... Postcode: .....

freely consent to participate in the above research project.

Signed: ..... Date: .....

Witness other than researcher:.....

\*Any question/queries about your participation in this project may be directed to Margaret Brooks, Telephone: ..... If you have any queries or complaints about the way you have been treated, you may contact the Secretary, University Human Research Ethics Committee, Victoria University of Technology. PO Box 14428 MCMC, Melbourne 8001 (Telephone: 03-96884710).

### Interview Guide

#### VICTORIA UNIVERSITY OF TECHNOLOGY

The interviews will be semistructured with the intention of facilitating a broad discussion of the women's perceived needs for service and their experiences of support. The women will be encouraged to 'tell their story' by using their own words. This interview guide will be used to facilitate discussion and to allow responsiveness between participant and researcher.

Similar themes will be used for the focus interview with workers. However other areas for exploration in the focus group may be added as they arise from the data collected from the women consumers.

#### **THEMES: Perceptions of home based outreach services**

##### **Experiences at early stages of contact with the program:**

- Experiences at first contact
- Support needs on first entering the program
- Knowledge of these services
- Information on referral

##### **Experiences over a period of time:**

- Support needs at the current time
- Have there been changes in support needs over time
- Discussion of opportunities and supports offered
- Whether alternatives were offered
- Participation in support decisions
- Helpfulness / unhelpfulness of services
- Continuity of workers and contact
- Gender of the worker
- Nature of the relationship with primary worker
- What has made the most difference?
- Things that can be improved
- What other supports could have been offered?

## Matrix of themes from data

Int.	Difficulties in women's lives	Experience of mental illness	Achievements of the journey	Supports useful	Parenting & mental illness
1	X	X	X	X	X
2		X		X	
3	X		X	X	
4		X	X	X	
5	X	X		X	
6				X	
7	X			X	X
8	X	X	X	X	
9	X	X		X	X
FG 1			X	X	X
FG 2				X	X

Int.	Interlinking care			Rural issues
	GP important	Case Manager	Friends / Community / Church supportive	
1	X		X	
2				
3		X		X
4		X	X	X
5	X	X	X	
6				
7	X		X	X
8	X	X	X	X
9		X	X	X
FG 1	X			X
FG 2	X		X	X

Int.	Nature of relationship with worker	Gender of worker	Change of worker	Grievances & complaints	Using Day Program & HBO
1	X	X	X	X	X
2	X	X		X	X
3	X	X	X	X	X
4	X	X		X	X
5	X	X		X	X
6	X	X			X
7	X	X	X	X	X
8	X	X	X	X	X
9	X	X		X	
FG 1	X		X	X	X
FG 2	X		X	X	

\*FG = Focus Group

## Matrix of themes from data

### Summary of data from interviews

This information is not in any particular order but has been gathered from all of the individual and focus group interviews. This material represents the broad areas of discussion from which themes were developed. Through the process of analysis this complex range of information was distilled into themes as presented in the thesis.

#### Difficulties in women's lives

- Physical health issues
- Poverty, difficulty coping on low income
- Experience of stigma
- Abuse and violence (childhood and adult)
- Separation from children
- Sole parents
- Parenting and mental illness
- Isolation from families
- History of substance abuse to cope
- Difficulties with community acceptance

#### Experience of mental illness

- Hard to get information and know how to access services
- Hospitalisation
- Periods of psychosis
- Separation from children when unwell
- Fear of losing accommodation
- Difficulties accessing the private system with the need for payment
- Loneliness and not feeling safe with living alone
- Tiredness from medications
- Limited motivation to do things or get out or meet anyone

#### Achievements of the journey

- Stable accommodation
- Friendship network
- Able to manage and seek supports
- Increased self esteem and confidence
- Return to study
- Establishing a 'community' of

#### Supports useful

- Finding and maintaining accommodation
- Worker normalising – reality testing
- Information about parenting and support
- Information and support with accessing benefits and financial management
- Practical support – helping with move, getting furniture etc.
- Information about housing and knowing where to go and how to do things
- Support with skill development – catching buses, learning how to manage things
- Advocacy
- Transport
- Flexibility / Capacity to stretch the support is important – small loans to help at difficult times
- Help with motivation
- Support worker visiting and chatting, having a coffee together “*Having someone come in, drop in and talk to you*”
- Made a friend and continued support is helpful to stay well
- Things that have made the difference include having a routine with things planned and the natural growth over time with co-ordinated support.

#### Parenting and mental illness

- Role modeling of worker with parenting
- Worker able to normalise unknown situations for the women
- Difficulty coping when unwell
- Fear of children being placed in care
- Lack of shared care arrangements
- Women needing to feel part of their children's lives

## Matrix of themes from data

supports e.g. neighbours, friends, family, GP, Case Managers and PDRSS worker

### Interlinking care

#### a. GP important

- Crisis plan with key worker, psychiatrist and GP – coordinated support most helpful
- GP an important part of the support network
- GP support that is most beneficial includes: caring, following up beyond the expectations, visiting at home, availability, fitting you in and seeing you when you most need them, acceptance of the illness and symptoms.
- Someone that workers can contact if there is concern for a client
- High number of people that GP's see with a mental illness but few referrals to PDRSS
- PDRSS needing to make their services more known to GP's

#### b. Case Manager

- Value of co-ordinated support between case manager and PDRSS worker
- Case managers able to help people access PDSS
- Some experienced case managers as caring and able to follow things through
- May be some stigma associated with seeing clinical services
- Case managers only see you when you are unwell and they focus on the illness

#### c. Friends/Community

- Having friends know about the illness and supports is beneficial
- Friends helpful when they stay in contact during the difficult times as well as the well period.
- Friendship network is important

### Rural issues

- Availability of doctors: a more relaxed type of service where they fit you in
- GP's more likely to know people
- Smaller rural areas: some had issues with workers and services not being available in their community but for others this was benefit as it helped to maintain their anonymity
- Fear of disclosure of mental illness
- Sense of community important in smaller areas.
- Harder for workers to be anonymous in rural areas
- May be more stigma in rural areas
- Some people more isolated in rural areas
- Communities can be very supportive and workers can help people learn how to support someone with a mental illness.
- Can be helpful for women who access other services in the community.

### Mixture of services

- Majority of women using both housing support and day programs
- Value of peer and group support at day program activities
- Peer support useful but good to still see the support worker individually.
- Group activities gets people out doing things although some frustration about the availability.
- Some frustration with group work and a preference for individual work with the worker.
- Value of having a rounded support approach for women
- Some had difficulties with trust in a group

### Gender of worker

A range of responses:

- Difficulty with having a male worker but became used to this
- Not able to share as much with a male worker

## Matrix of themes from data

### Nature of the relationship with worker

- Relationship with worker: important to get on together
- Strong relationship with the worker: workers encouraging, supportive and accepting
- Takes time to build the relationship
- Respect for individuality by workers
- Identifying areas of common interest helps the relationship
- Capacity for humour valuable: important to be able to have a joke with the worker
- Good to know someone is there, good to have someone to talk to
- Relationship of trust
- Non complaining / non judgmental – worker capacity to hang in there with the client
- Caring important
- Life is lonely and it is good to have someone around
- Feelings of making another friend rather than a support worker
- Important for worker to be ‘genuine’ with consumers
- Some self-disclosure valuable
- Humanness of the worker important
- Difficult for workers to be seen as a ‘friend’ as workers move on.
- Discussion on the difference between ‘friends’ and ‘worker’ but friendliness or elements of friendship important in the relationship

- More in common with female workers
- Preference for female but have learned to work with a male worker
- The gender doesn’t matter: relationship more important
- Prefer to work with a male worker
- Important to acknowledge gender issues with a history of violence and/or isolation.

### Change of worker

- People get used to working with the same worker: attachment/linkages develop
- Relationship issues make it hard to change workers
- Workers need to be aware of difficulties of changes and find ways to support people

### Grievances and complaints

- Feel OK about asking for extra support when needed.
- Feeling OK to say if things were not working
- Looking for more services to be delivered in different ways (particularly day programs)
- Wanted some things to change but sensitivity about the worker’s feelings with making any complaints
- Workers needing to be more receptive to enable people to discuss if they want things to be done differently.
- Workers needing to let service users know that it’s OK to have a complaint as then things can get changed. Important to create an atmosphere for this.

Profile of the research participants

Below is a profile of the women participants in the research. Some of the women chose to use their own name but these are not highlighted or identified in the research.

Pseudonym or name <sup>1</sup>	Age Range	Period of support	Program types used during their period of contact with the PDRSS
Karma	20-30 years	3-4 years	HBO & Day Program
Mary	50-60 years	2-3 years	HBO & Day Program
Alice	30-40 years	2-3 years	HBO & Day Program
Jean	40-50 years	2-3 years	HBO & Day Program
Grace	50-60 years	4-5 years	HBO & Day Program
Amy	30-40 years	1-2 year	HBO & Day Program
Chris	40-50 years	< 1 year	HBO & Day Program
Kate	40-50 years	2-3 years	HBO & Day Program
Jenny	50-60 years	< 1 year	HBO & Day Program

\*HBO: Home Based Outreach Services

A number of workers took part in the focus groups and contributed their reflections to an understanding of women’s experiences.

Focus Group	Worker’s Pseudonyms	M/F
Focus Group 1	Veronica	F
	Lee	F
	Paul	M
	Sally	F
	Matthew	M
Focus Group 2	Patrick	M
	Teri	F
	Elise	F
	Anne	F
	Jennifer	F
	Peter	M
	Michael	M
	Cathy	F
	Meg	F