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Maze to care: the process of pathway to initial care of young adults aged 18-25 with their first presentation of a mental disorder

Sayumporn Webster
University of Wollongong

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**MAZE TO CARE:
THE PROCESS OF PATHWAY TO INITIAL CARE OF
YOUNG ADULTS AGED 18-25 WITH THEIR FIRST
PRESENTATION OF A MENTAL DISORDER.**

**A Thesis submitted in fulfilment of the
requirements for the award of the degree**

DOCTOR OF PHILOSOPHY

from

UNIVERSITY OF WOLLONGONG



by

SAYUMPORN WEBSTER

PhD. Candidate (UOW), MComH, Dip HSc, CPH, RM, RPN, RGN, (Syd)

DEPARTMENT OF NURSING

2004

ABSTRACT

This study explores the lived experiences of a group of young people prior to coming into contact with mental health services for the first time. It asked, what was the pathway like for these young people, what happened to them and how did they experience and interpret that, and what was the extent and nature of delays in accessing care?

The study uses the grounded theory method and encompasses Glaser and Strauss' (1967) constant comparative method in the uncovering of the grounded theory, Strauss and Corbin's (1990) work in the analysis, and Glaser's (1978) work on theoretical sensitivity to guide data collection and analysis. Grounded theory focuses on how people view their experiences, how they interact and how these processes change (Wilson and Hutchinson 1996), and hence is an appropriate way to investigate the phenomenon.

The purposive sampling consists of eight males and twelve females whose ages ranged from 18 to 23, from one Sydney Area Health Service. Twenty three semi-structure interviews were conducted over a fifteen months period. Analysis was undertaken concurrently, and the computer software application NVivo was used to manage the data.

'Finding a way' represents the core category and is the basic social process by which young people experience the pathway to care. Finding a way can be conceptualised as a four-stage process. The stages which emerged from the data

included a) **first sign** in the early stages of the illness, often greeted with denial and incomprehension, and self medication with alcohol and other drugs; b) **recognition** of the symptoms as a sign of mental illness, indicating that one needs help; c) **understanding**, discovering information about the illness and its impact on themselves and others; and d) **resolution**. At this point, effective care is successfully and, for most, voluntarily accessed. People progress through each process at different rates and for some, the journey to resolution may be short-circuited in earlier stages by particular incidents or exacerbations of their illness, leading to involuntary commitment to involuntary care.

A fifth category, **barriers and facilitating factors**, refers to those processes and factors which impede or speed the progress to care and which can occur at any stage of the process.

A model, called the 'Maze to Care', was developed from the findings. Unlike others, this model focuses on the pre-care rather than the post-care environment and reflects the perspective of the consumer. It can be used to direct attention to social and systems interventions which would enhance the capacity of young people and their families to recognise the symptoms of mental illness and access appropriate care.

CERTIFICATION

I, Sayumporn Webster, declare that this thesis, submitted in fulfilment of the requirements for the award of Doctor of Philosophy, in the Department of Nursing, University of Wollongong, is wholly my work unless otherwise referenced or acknowledge. The document has not been submitted for qualifications at any other academic institution.

Sayumporn Webster

18 February 2004.

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CHAPTER ONE

INTRODUCTION AND OVERVIEW

1.1 Introduction

The aim of this research study is to explore the experiences and perceptions of young people with mental illness before they successfully access care, in other words to document from their perspective the ‘pathway to care’. It might be thought that this aim had already been achieved, as there are many studies looking at the pathways to care. However, those studies tend to focus more on what happens after the consumers have come into contact with health professionals in the health care system, that is, diagnosis and treatment (early intervention) (Sheppard and Benjamim-Coleman, 2001; Rickwood, 2000; Hunter, 1999; Kosky, 1998; McGorry, et al., 1996; Vaglum, 1996).

Another understanding of the term ‘pathway’ refers to the developmental course of the mental disorder itself, its signs and symptoms (National Crime Prevention, 1999; Kohn, 1997; Dadds et al., 1997; Felner et al., 1995; Silverman, 1995; Loeber et al., 1992) and the factors which precipitate its onset (Sullivan et al., 2000; Whisman et al., 2000 and McGuffin et al., 1996). However, in this study, the researcher is concerned rather with what happens to young people as they begin to experience symptoms, how they make sense of them, where they go for help and what delays them or assists them in finding it.

The researcher has termed this pathway the '*Maze to Care*' because, although it ends with the consumer entering the system and receiving treatment, it involves many complexities and false turns along the way, including abortive attempts to find care from various health professionals and others.

The term 'maze to care' is not a new one. It was used by Hiersteiner (1999) to describe the experiences and dilemmas of women, long-term consumers of mental health services, who were attempting to access counselling networks. The term accurately describes the experiences of this study's participants as will be shown in subsequent chapters.

1.2 The study

This study attempts to gain an understanding of how care is obtained in the early stages of mental illness by exploring the experiences and perceptions of young people with mental illness, before they access care successfully. The pathway to care is documented from the young person's perspective, using a retrospective qualitative approach.

In this study, 'care' refers to specialist mental health services, where the participants felt their particular needs were being met. The mental health services in question were three community mental health centres where the participants accessed the services of the available professionals. Many of the participants had previously accessed different types of medical care; mainly GPs but also Emergency Departments in public hospitals, private clinics and counsellors.

However, for a variety of reasons which this study explores, these participants were unable to find a resolution for their mental health problems from these care interventions. It is not suggested that primary care providers such as GPs cannot be effective for the diagnosis and treatment of many mental health problems, but the literature suggests (chapter two) there are significant problems in this area.

The pathway metaphor conjures up a picture of a visible, organised and defined route to providers who have the mandate to treat, care and be responsible for such young persons, but pathways to effective care are often unclear and difficult to negotiate, especially for young people and their families (McGorry et al., 1991). The study found that, in practice, the route is rarely simple. A young person may experience the distressing circumstances of an initial episode well outside the health care system. The symptoms may be unrecognised, or recognised by others from a wide range of backgrounds, for example, friends, teachers, parents and police. This implies that the symptoms and how they are dealt with are a challenge not only for the individual, but for the health care system as well.

The study participants' experiences provide some insight into a young person's journey to mental health care and provide some answers for the following questions. What happens to young people as they begin to experience symptoms? How do they make sense of them? Where do they go for help? What impedes or assists them in finding help?

Staggering statistics show that 14 per cent of children and adolescents and 18 per cent of adults will be directly affected by a mental illness, and 62 per cent of Australians with a mental illness do not receive treatment at all (SANE Australia, 2003). The study is based on the belief that understanding how care is obtained in the early stages of the illness is critical for early detection and intervention. Mental health care aims at treating people with mental illness early, as studies have shown that the earlier the treatment the more successful the outcome (McGorry, 1998; McGlashan, 1996; Loeber et al., 1993). This raises the question - how do we get the mentally ill to make early successful contact with the health care provider/system? This is an important question particularly in reference to young people (17-24 years) as they have the highest prevalence rate (27 per cent) of mental disorders of any age group in Australia (Commonwealth of Australia, 1998, p. 10). Neglect the mental health needs of young people group and high social costs and significant economic costs will result. Some of these costs, such as distress, are intangible while others are only too easily measured - increased suicide, increased drug and alcohol misuse, homelessness and interruption to psychological, educational and social development (Davis et al., 2000; Moscarelli et al., 1991).

1.3 Aims of this study

The aims of this study were to:

- to explore the experiences of a group of young people who have recently come into contact with the mental health services for the first time. The study identifies events and situations critical to these individuals in their initial

decision to seek care, factors that helped or hindered this decision and the support or otherwise they received from family and friends during this time.

The grounded theory approach is used to investigate their 'reality';

- to develop a 'pre-care model' that explains what happens *before a young person accesses the health service*, so that the access point of treatment can be shifted towards early recognition, and intervention can be situated within the philosophy of the young person.

1.4 Research questions

- What was the pathway like for these young people, as they struggled to understand what was happening to them?
- What was the extent and nature of delays in diagnosis and treatment?

1.5 Significance of the study

- With earlier intervention comes the possibility of providing support and treatment that may *prevent* young people from losing their social and vocational roles or their plans to achieve them. Therefore, this study may help fill gaps in our knowledge.
- The reasons for young people not accessing help, support or intervention earlier, and delaying until they are in an acute state, are explored in order to identify support strategies that can be put in to place to promote a young person accessing the health service. This would be a useful guide to health professionals in general.
- Identifying the significant factors that impact upon accessing support or

intervention in the earlier stages, may provide evidence for changing the nature of service provision.

- Results may help guide future health care policy development in the improvement of access to mental health services and assist the long- term goal of a more positive access outcome for the young person with mental illness.

1.6 Background

In the past two decades, the mental health of young people has become a major public health focus. Depression is the most commonly reported mental health condition in young people and it is the largest underlying single risk factor to suicidal behaviour (Sawyer and Bowes, 1999).

The factors contributing to the mental health problems of young people are numerous and complex. Recent overseas and Australian research has indicated that up to 90 per cent of young people who suicide have demonstrated symptoms of mental illness, or serious mental health problems, before their death (National Health and Medical Research Council, 1997).

It is now recognised that most of the mental health problems and mental disorders develop through complex causal interactions, and it is seldom possible to identify a single principle cause, for example, of depression. The exact nature of the causal interactions affecting mental health problems and mental disorders are often unknown (Commonwealth Department of Health and Aged Care 2000), this

means they are often undiagnosed by health professionals and the disorders progress to the crisis and chronic stages.

The distinctions between mental health problems, behavioural or psychological disorders, and diagnosable levels of psychiatric illness are not always clearly drawn in the literature (Sawyer and Bowes, 1999). This highlights the difficulty for the unskilled health care worker in diagnosis and treatment of the disorders, and may lead to a young person continuing undiagnosed.

Young people with mental health disorders have a better outcome if treatment begins in the early stages of development. Mental health disorders are difficult to detect as they have multiple causality and are multi-faceted. This research will provide information, including a pre-care model, to promote the early access of the young person to the health care system thereby promoting earlier and possibly more successful intervention, and thus promoting the health and well being of the community.

1.6.1 Definitions of mental health problems

This study was not concerned with the particular diagnosis of the participants, but with their experiences over time as they attempted to deal with their problems and access the type of care which they considered to be appropriate for them. The inclusion criteria only specified that the potential participants had to have come into contact with one of three participating community mental health centres

within the last three months (see section 3.3.1.1). In fact, it turned out that the diagnosis were psychotic disorder, depression, mania (bipolar disorder) eating disorders, substance use disorders and acute reactions were suffered by the participants. Thus, while this thesis uses ‘mental illness’ as a short hand, it should be borne in mind that some twelve participants had a mental health disorder and, for five of them, this had legal consequences (see section 4.5.2). Mental illness and mental disorder are defined below.

Mental illness in the psychiatric context refers to a change in the pattern of thinking, feeling or behaviour from which is usual for the person, as a result of an abnormal mental process or disorder (Simpson 1997). Examples of mental illness are major mood disorders and schizophrenia.

A mental disorder is a diagnosable illness that significantly interferes with an individual’s cognitive, emotional or social abilities. There are different types and varying degrees of severity of mental disorders. Examples of mental disorders include depression, anxiety, substance abuse, psychosis, and bipolar disorder (Simpson 1997). Mental disorder is evidenced by the presence of abnormal phenomena which, in itself, is not a diagnosis, but a list of symptoms and signs that occur in many clinical contexts (Simpson 1997). The diagnosis is underpinned by the Diagnostic and Statistic Manual of Mental Disorders (DSM-IV) (Simpson 1997). However, the legal definition of mental disorder allows for compulsory assessment and detainment (scheduling) for treatment under the New South Wales

Mental Health Act 1992, if the disorder of mood or perception or volition or cognition is of such a degree that it poses a serious danger to the health or safety of that person or others or seriously diminishes the capacity of that person to take care of him/herself. (Australian Health Ministers 1992).

1.7 The Australian health care system

Australia's health system is a mixture of public and private health service providers. The federal government has the primary role of developing broad national policies, regulation and funding. However, state and territory governments are primarily responsible for the delivery and management of public health services and maintaining direct relationships with most health care providers, including regulation of health professionals and private hospitals.

Federal government funding includes three major national subsidy schemes – the Medicare Benefits Scheme (MBS), the Pharmaceutical Benefits Scheme (PBS) and the 30 per cent Private Health Insurance Rebate (Commonwealth Department of Health and Aged Care 2003). Australians contribute to the health care system through taxes and the Medicare Levy based on their income, (1.5% of taxable income for most people) and through private financing such as private health insurance, (minus the rebate).

Medicare covers all Australians and subsidises payments for GPs and specialists. The Pharmaceutical Benefits Scheme allows access to a high proportion of

prescription medicines at a reasonable cost. While the Commonwealth and State governments jointly fund public hospital services, (and mental health services), they are provided by the States. Public hospital care is free of charge to people who choose to be treated as public patients.

GPS can require a co-payment as the federal government reimburses only 85 per cent of the schedule fee. GPs are free to charge more than the schedule fee, which many doctors consider to be inadequate. There are 'safety nets', which depend on income, for patients with high out of pocket expenses. After the safety net is reached, the federal government will pay 80 per cent of subsequent medical expenses for that year.

Approximately two thirds of GPs 'bulk bill', which means that they do not charge patients at all, but instead claim 85 per cent of the schedule fee directly from the federal government. High volume medical centres typically do this; other practices may only bulk bill children or concession card holders, as GPs receive higher rebates for these groups. However, the location of bulk billing practices is not uniform and not everyone has access to them.

Consumers access specialists, whether public or private, via referral from a GP. However, people who need to see a doctor, but who cannot afford the co-payment, can access medical care through the Emergency Departments (EDs) of public hospitals, where there may be a significant waiting time. This diversion to EDs

also occurs after hours, when GP services are unavailable. There are presently some pilot studies which co-locate GPs at selected public hospitals to deal with this issue of access (Mann 2003). The utilisation of EDs instead of GPs is seen as ‘cost-shifting (from the Federal to the State Government) and is the cause of friction between the different levels of government (Whiteford et al., 2000).

According to the federal government, the 30 per cent Private Health Insurance Rebate supports people's choice to take up and retain private health insurance and hence decreases pressure on the public hospitals (Commonwealth Department of Health and Aged Care 2000). However, the rebate of thirty per cent has been criticised as subsidising the more well off members of the community. Further, for many critics, there is no evidence to suggest that the burden on public hospitals is any less because of the rebate. The privately insured are not required to disclose their status when admitted to public hospitals and large ‘gap’ payments discourage them from doing so. Private hospitals, including private health clinics, are accused of ‘cherry-picking’ patients; this means they look after the least sick and hence the most lucrative (Whiteford et al., 2000).

1.7.1 Care for the mentally ill

Health care for people with mental illness has shifted from psychiatric institutions to mental health services provided in the general health sector, such as psychiatric units in general hospitals, together with a range of community-based services across health, housing and community service sector groups. The community-

based services are intended to support individuals and their families. These and other changes in the system of mental health care may have been necessary but are not sufficient to attain improved outcomes (Goldman et al., 2002; Bickman, 1996), which will require additional resources. The Australian mental health policy is often depicted as world leading, but both those using and those providing the services have claimed that the system is characterised by restricted access, variable quality, and poor continuity of care, lack of support for family and overt or covert human right abuses (SANE Australia 2003).

The National Mental Health Report 2002 identified Australia's total expenditure in 1999-2000 for health care as \$2.6 billion; this represents approximately 6.6 per cent of national total gross recurrent expenditure. Only 6.5 per cent of this health budget is allocated to mental health services (SANE Australia 2003) which is much less than other countries such as the UK, Canada and New Zealand which spend 10 per cent or more.

The major structural reform within the mental health service system in the 1990s was to transfer resources from 'stand alone psychiatric hospitals' to new community services. The closure of the stand-alone psychiatric hospitals had a marked impact on expenditure, resources and services. This is a process referred to as 'mainstreaming' or de-institutionalisation by bringing mental health services structurally into the general health service system, with the development of community services integrated with inpatient care in general hospitals.

With the restructuring of mental health services in 1992, the National Mental Health Strategy and policy direction framework were developed (Commonwealth Department of Health and Aged Care, 2000). The strategy has the support of all States and Territories, and has been fostered under Commonwealth administration. It now includes a National Mental Health Policy; the setting for goals and targets; a statement of rights; two successive 5 years National Mental Health Plans, and a set of standards for mental health services. The first National Mental Health Plan was framed in broad strategic terms. One of the main issues identified within the Strategy was de-institutionalisation through the development of community services.

However, bringing about of these changes was supported by Commonwealth financial incentives through the National Mental Health Plan, which provided important funding to promote specific service developments - even while much of the New South Wales State Health budget was being 'savaged' (SANE Australia, 2003). Growth in State and Territory expenditure was only 19.8 per cent per capita (increased from \$ 68.22 to \$ 81.76 per capita). New South Wales and Victoria had very low increases of 18 per cent and 4.4 per cent per capita respectively. New South Wales spends only \$77 per capita compared with \$85 in Victoria, \$86 South Australia and \$96 for Western Australia. Only 29 per cent of mental health resources in New South Wales were directed toward community-based care, and less than 2 per cent of resources were allocated to non-government community programs aimed at supporting people with psychiatric

disabilities in the community (Commonwealth Department of Health and Aged Care, 2000).

In addition, New South Wales has not pursued the expansion of its 24-hour staffed community beds as an alternative to inpatient care. Total per capita beds available in fact dropped by 9 per cent, between the years 1993-2000, mainly through a decrease in general adult services (Commonwealth of Australia, 2002). The lack of bed-based treatment option for consumers has put pressure and demand on acute in-patient units to meet the needs of people affected by mental illness. The lack of beds remains a significant issue in relation to the commitment by the New South Wales Government to develop a full range of community services to replace the historical functions of the stand alone psychiatric hospitals. A deficiency in accommodation options to replace the former role of large stand alone psychiatric hospitals have been linked to the failure of mental health reform initiatives and is the focus of criticism in Australia (The Royal Australian and New Zealand College of Psychiatrists 2002).

One example of restructuring that resulted in a significant change to the nature of psychiatric services is that the consumers are now presenting themselves to mainstream general health care services/providers. For example, the emergency departments in general hospitals have reported an increase of people presenting for management of acute psychiatric conditions (McIndoe et al., 1994; Ryan et al., 1997). The increase varies across Area Health Services, with estimates of increase in attendance ranging from between 0.6 per cent to 10 per cent of all

presentations at individual emergencies department (New South Wales Health Department, Centre for Mental Health 1998).

Studies have reported that the organisational structures and clinical pathways of emergency departments present a mismatch between the requirements of people in acute medical emergency and the needs of those presenting with mental health problems. As well, emergency staff may not recognise all presentations that are associated with a mental health disorder (Bailey 1998; Tehan and Murray 1996). The research also suggests that nurses who have not undertaken specific education and clinical experience are poorly equipped to assess the needs of clients with mental health problems (Bailey 1998) and do not enjoy providing care to patients with a psychiatric diagnosis (Flemming and Szmukler 1992; Toulson 1996).

This situation highlights the plight of the mentally ill in accessing care, as well as the issue that the integration of service elements requires a more coherent mental health program, when operating within a framework of mainstream health care, if emergency departments are to be principal places of care. The service needs to develop flexible and creative solution to address gaps in service provision.

The SANE Australia Mental Health Report (2003) concludes that the two five year National Mental Health Plans for restructuring of the service system (from policy framework through to standards of care) did not represent a failure of

policy but rather a failure of implementation. Poor government administration and accountability, lack of ongoing government commitment to genuine reform, and failure to support the degree of community development required for achieving high quality mental health care outside institutions were put forward in argument of failure of implementation.

1.8 Delay in access

Delays are multi-faceted. Those delays at the onset of care access are associated with poor long-term outcomes. Mental disorders tend to have a chronic and/or recurrent course and are allied with considerable morbidity and mortality (Herz and Lamberti 1995, McGorry et al., 1996). Studies have highlighted that before initial treatment, patients often remain in the community for more than a year with substantial levels of untreated acute symptoms (Macnaughton 1998). Hence, mental health professionals need to increase their understanding of delays to assist individuals accessing appropriate health care, (Herz and Lamberti 1995; McGorry et al., 1996).

The evidence also suggests that, during the first few years of the illness, young adults experience the greatest amount of decline in functional abilities, after which deterioration levels off (McGlashan and Johannessen 1996). Certainly, the first years of illness are critical from a social and psychological standpoint, since mental illness most often strikes when young people are forming key social roles and relationships, and dealing with crucial issues of identity and independence (McGorry et al., 1996). There are several converging reasons why earlier

intervention prior to the acute stage, is critical. There is increasing evidence that early intervention improves long-term outcomes while it is believed that delays in accessing care results in significantly higher direct and indirect cost to individuals, family and society, (McGorry, et al., 1996; Thara, et al, 1994; Birchwood 1992; Loebel et al., 1992).

A mental disorder occurring at any time is a serious 'life event' that can threaten self, identity, valued goals, roles and social status. In many cases, the symptoms first presenting can persist and progress, leading to a 'burden of suffering' and the need for ongoing care, consequently the future of the individual affected by such conditions is placed in jeopardy (Kessler et al., 1995). There are ramifications at every level of society from this 'burden of suffering', such as cost to society, relationship breakdown and self- development.

Compelling evidence from physical health care models of early detection and intervention (Dunst 1996) and, most importantly, the experience of many consumers and their families (Osher 1998), point to the need for intervention in the earliest stages of developing a mental health illness. The focus of research to date has been on 'early intervention' and 'maintenance' after the first contact with health service providers. Lincoln et al. (1998); Mrazek and Haggerty (1994) and Lincoln and McGorry (1995) concluded that there is limited understanding of consumer access to help, or of the pathway to help experienced by those consumers experiencing a mental health disorder for the first time.

Dadds (1997) argued that many programs for health promotion and treatment for young people are based on the responses and observations of adults. Notwithstanding that these responses and observations are valid, the question arises: are they filling the young person's real needs? The association between delays and good clinical and social outcomes suggests that access to treatment should begin as soon as the illness is suspected (McGlashan and Johannessen 1996; McGorry et al., 1996).

The first experiences of assessment and treatment may strongly influence the young person's future attitudes and adherence to intervention (McGorry et al, 1996). To understand their personal experience is a key goal as such understanding can help to identify barriers, reduce factors such as a reluctance to seek help, and reduce difficulties in the recognition of the disorder by primary care professionals, family and friends, and inaccessible or non-responsive services.

It is recognised that health promotion, with its messages of early diagnosis and treatment, often fails to reach the young population (Werry 1997; McGlashan 1996). From the researcher's personal experience, this is especially true in the mental health field. All too often, a young person's initial contact with mental health services is via police (for drug and alcohol abuse, disturbed behaviour in the community) or presentation at the emergency department of a hospital with evidence of self-harming behaviour. In these usually strained environments the young person is diagnosed and labelled. This problematic situation has

implications for subsequent mental health intervention and care, such as follow-up, as the person with a mental health disorder may not wish to return to such an experience/environment.

Consumers themselves condemn the notion that a mental disorder must be 'serious enough' before action is taken. Reflecting on the time that they were experiencing early signs and symptoms of the mental disorder, some consumers recall that 'nobody would help because it wasn't serious enough' (Champ 1998, p. 56). Carers and clinicians echo the concern that treatment is not often initiated until symptoms are well advanced (McGlashan 1996). These concerns demonstrate the need to identify the early pathway to care for young people.

1.9 Framework for the study

Research into the nature of symptoms and signs preceding the first episode of mental illness has necessarily been retrospective in nature, involving reconstructing the changes in a person who has become ill (Klein et al., 1997; Lincoln 1996; Beiser 1995). This study necessarily does the same, selecting participants who are experiencing their first contact with the mental health service.

A naturalistic research design was employed, using the inductive approach of grounded theory (Glaser and Strauss 1967). The aim was to make sense of the situation without imposing pre-existing expectations. Grounded theory is an

approach based on theory development from data collected, then analysed, systematically and recursively. The researcher seeks to gather data to add to and enhance the existing body of information with the aim of explaining what is happening. A key aspect of grounded theory is the interrelationship between the collection, coding and analysis of data. Theoretical sampling, the label assigned to this process, is 'data collection for generating theory whereby the analyst jointly collects, codes and analyses the data and decides what data to collect next and where to find them, in order to develop the theory as it emerges' (Glaser and Strauss 1967, p 45).

Strauss and Corbin's (1990) method was used in the analysis process (see chapter three). The process included the recording of in-depth interviews and field notes. The constant comparative method of analysis and its coding procedures was used, first comparing items in each category, then drawing up categories and, finally, comparing categories. The endpoint of the research is the development of a grounded theory. The theory can assume the form of a narrative statement (Strauss and Corbin 1990), a visual picture (Morrow and Smith, 1995) or a series of propositions (Creswell and Brown 1992). In the present study, the theory takes the form of a model, entitled the '**Maze to Care**', representing the process young people undergo from experiencing symptoms for the first time to successfully accessing mental health care services.

The study employed theoretical sensitivity (Glaser 1978). There are three interrelated activities which define the research process: articulation of the

researcher's individual belief system (in relation to the research domain), decisions on the theoretical perspective and strategies of enquiry, and decisions on the methods of data collection and analysis. The research design provides the connections between the three different activities. However, under-pinning each of these activities is the nature of the 'biographically situated researcher (who) speaks from within a distinct interpretive community' (Denzin and Lincoln 1994, p.164). The process allows for a balance between one's own knowledge, insight, awareness of subtleties and capacity to identify relevance.

1.10 Structure of the thesis

In Chapter One, the researcher has presented an overview of the study, identified its aims and provided background information.

Chapter Two discusses the relevant literature associated with mental health disorders and pathways to care.

In Chapter Three, methodological issues, and the process of research using grounded theory, are described, as are the study settings, the participants, ethical considerations and the methods used to obtain and analyse the data. The pre-care model, showing the process from the first sign of the illness to the successful accessing of care, is presented, prior to more detailed discussion of its constituent parts in the succeeding chapters.

Chapter Four discusses the stages in the process to care, and **Chapter Five** explores the barriers which may impede the process at any stage, and factors which facilitate progression. In these chapters, examples of data incidents are included both to illustrate the social reality of participants and to demonstrate the close connection between data and theory. The relevant literature is illustrated in the discussion through out the chapters.

Chapter Six contains the discussion of the research findings and the conclusions. Included in this chapter are the limitations of the study, and suggestions for further research.

Finally, **Appendix A** contains the ethics approvals, the participants' information sheet, the flyer and consent form, and **Appendix B** contains the semi-structured interview guide. **Appendix C** contains correspondence. **Appendix D** contains Paradigm for the categories Recognition, Understanding and Resolution.

CHAPTER TWO

LITERATURE REVIEW

2.1 Introduction

There are two main areas of research concerned with pathways to care. The first looks at what happens once the consumer has accessed care, and includes models dealing with early intervention. The second looks at the developmental pathway of the mental disorder itself. A number of models based on these ‘pathways to care’ studies are currently utilised to guide intervention. They focus on the therapeutic relationship (Beiser 1995), or the support of consumers with mental disorders in the community (Macnaughton 1998; Payne 1992). Their aim is to reduce distress, shorten the episode of care, minimise the required intervention and reduce cost (Davis et al., 2000; Jenner and Van de Willige 2001; Griffith Early Intervention Program 2000).

Models of care that have been already developed for consumers of mental health care include behavioural models, e.g. the Attention Deficit Hyperactivity Disorder (ADHD) model (Dadds et al., 1997; Kazdin 1998); a psychosocial model for drug and alcohol problems (Dakof et al., 2001; Drake et al 1998) a prevention model for conduct problems (Sander et al., 2000; Webster-Stratton 1997); an anxiety disorder model (Roth and Dadds 1999; Spence 1996b); an early intervention and detection of psychiatric disorders model (O’Hanlon et al., 2000; Rickwood 2000; Martin et al., 1993; Vaglum 1996; Silverman 1995; Trickett et al., 1994); and a youth suicide prevention model (Koch and Magary 2001; Hickie and Burns 2001).

These models provide frameworks for care and highlight an emerging awareness of appropriate care of people with mental disorders. However, evaluations of these models highlight deficiencies in the current approach and in the delivery of these models in mental health services (Durlak 1997), and early intervention may not be successful in every situation for everyone (Davis et al., 1999).

The literature looking at these issues from the consumer's perspective is limited, though that which is available gives some useful insights involving the personal accounts of consumers. The research studies in this area included the role of illness recognition in accessing care (Meyer 2001); the person's own belief system (Strauss 1994); their story (Deegan 1996); living with the ambiguity of mental illness (Rose et al., 2002); and how personal interpretation and family factors may impact on the consumer's personal interpretation of mental illness and help-seeking behaviours. (Rogler and Cortes 1993).

Evaluation studies of mental health care have suggested a number of barriers as key areas of intervention, including; stigmatised attitudes towards mental illness (Schreiber and Hartrick 2002; Czuchta and McCay 2001); personal factors such as grief issues (Tennant 2002); social factors such as substance abuse (Cornelius et al., 2001); and cultural factors (Chadda et al., 2001; Minas 1991); services issues such as service inefficiency and health service professionals' lack of mental health knowledge (Hulse et al., 2001; Blake et al., 2001; Potts et al., 2001; Wu et al., 2001); and economic factors including cost (Goodman and Huang 2001; (Leslie et al., 2001; Dickey et al., 2001; Elford et al., 2001).

These are the areas covered by this literature review. The review begins with an overview of the search strategy, and continues with an examination of the current 'pathway to care' literature, the personal accounts of consumers, and a discussion of the current models, and concludes with an examination of barriers to care so far identified by research.

2.1.1 Search strategy

The literature search was conducted through the data-bases Austhealth, Cinahl, Medline, PsycINFO covering the years 1991-2002. Search strategies covered the following terms: mental disorders/young people (aged 15-25), pre treatment, and patient acceptance of health care, health services accessibility, help seeking behaviour, health care seeking behaviour, health care utilisation, self referral and mental health service/utilisation. Literature pertaining to grounded theory, and qualitative studies of the consumer's experience of mental disorders, accessing care, health care seeking behaviours, experience help seeking behaviour, commitment to treatment (psychiatric), health care utilisation, hospital admission, mental health services, and self referral were also covered.

2.2 Pathways to care

The literature shows that there are many pathways to initial care via health professionals in primary care services (Scharer 2002; Thesen 2001; Bower et al., 2001; Reust et al., 1999; Balestrieri et al., 1994; Gater and Goldberg 1991) and those in mental health services (Hiersteiner 1999; Mcnaughton 1998; Lincoln and McGorry 1995). These studies focus on care after first contact with the services,

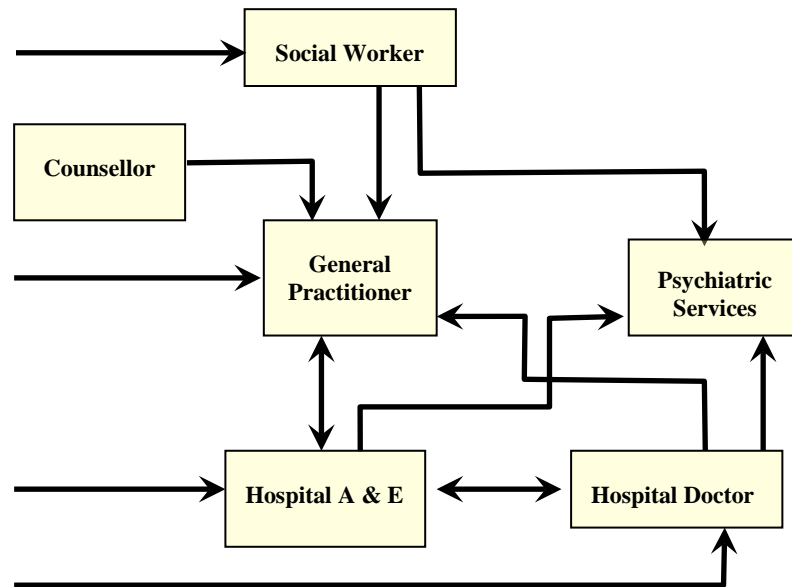
and associate the initial pathway to care with delays in the pathway continuum, which lead to barriers to care. These barriers are discussed in detail later in the review.

Most studies in this area have used a quantitative methodology. They concentrate on the pathways to care of consumers with mental disorders such as depression and anxiety (Flament et al., 2001; Andrews et al., 1999; Roth and Dadds 1999; Spiker et al., 1995); psychosis (Jenner and van de Willige 2001; McGorry 1998; McGorry et al., 1996); and behavioural problems (Sourander et al., 2001; Sawyer and Bowers 1999; Kazdin 1998; Cornelius et al., 2001). Central themes are the difficulty of diagnosing and recognising mental health disorders and delays in accessing initial care (Helgason 1997; Lincoln and McGorry 1995; McGorry et al., 1996). These authors recognise that delays in accessing care are associated with poor long term outcomes.

There is an area of the literature which addresses the ‘referral pathways’ to care in the young people population (Williams and Healy 2001; Lincoln and McGorry 1995; Gater and Goldberg 1991). The first study was conducted by the World Health Organisation in 1988 and proposed a four- year program of research aimed at improving the quality of mental health care access in community settings. The first year of the study produced a ‘pathway diagram’ (Gater and Goldberg 1991) in order to document the complexity and the size of the network of the various pathways to care needed in the community (see Figure 2.1).

Figure 2.1 An example of a pathway diagram showing referral networks

(Gater & Goldberg, 1991).



This study did address a number of ancillary questions concerning the referral access pathway process - for example, it identified the need for specialist treatment (especially in drug and alcohol services) as an additional service. The pathways diagram shows the most commonly used steps on the way to psychiatric care. The program aimed to develop more intensive studies at the important points in the referral pathways.

The study of Gater and Golberg (1991) suggested that the quickest pathway to care is at the casualty department, as the mental health team will see the consumer more quickly. This is due to the urgent nature of problems presenting in casualty, e.g. deliberate self-harm. However, studies of this route show that casualty professionals do not consistently exercise adequate clinical skills, may have

insufficient knowledge of mental health or fail to communicate effectively (Secker et al., 1999; Gray et al., 1999), and may contributing to failure in follow-up care. The same may be true for general practitioners (Millar and Walsh 2000; Garralda 2001). This leads to the non-recognition of the consumer with less obvious signs and symptoms of mental disorder. A referral is only made if the consumer shows obvious signs of mental disorders, and/or repeated self- harm attempts. These findings are supported by Hulse et al. (2001), and Stanley and Manthorpe (2001).

Delays in the referral of the consumer to specialist treatment may also occur because:

- The procedures for accessing specialists are convoluted. For example, psychiatrists may have a waiting period (Fry et al., 1999); mental health services have separate catchment areas for consumers who must live in a defined geographical area and, as a result, consumers may be divided by a boundary from what they see as their nearest service (Australian Health Ministers 1992);
- Consumers themselves need to contact the service for help, for example for drug and alcohol problems as policy dictates (Central Sydney Drug and Alcohol Program 2000);
- There is a general lack of information about sources for help or points of referral for consumers (Hiersteiner 1999); and
- Administrative procedures are often perceived as burdensome, time consuming and prone to clerical error (including the omission of urgency). Insufficient

detail may cause delay for the consumer in accessing care (Oiesvold et al., 1998).

Other research discusses psycho-pathology and psycho-social factors in the pathway to care. The psycho-pathology study by Gater and Goldberg (1991) found that patients with somatic problems had the longest pathway to care, especially the interval between seeking care and referral to specialist services. Difficulties with the referral pathways to mental health services, and factors affecting the referral processes among young people, highlight the need for further study.

2.2.2 Developmental pathways

Research evidence from the pathway to care studies suggest that the pathway of mental disorders is influenced by the interaction of biological, psychological and psycho-social processes (Davis et al., 1999), and these will be discussed under the headings of sign and symptoms, causes and influencing factors. The results of these studies have been used to target better intervention or treatment strategies (Davis et al., 1999; O'Hanlon et al., 2000).

2.2.2.1 Signs and Symptoms

The majority of the pathways to care research consist of quantitative studies looking at discrete symptoms of mental health disorders. This pathway essentially means the developmental course of the mental disorder (Loeber et al., 1993). For example, when a conduct disorder is identified, the pathway begins with the emergence of aggressive and oppositional disorders in the early pre-school period,

and then progresses into the most serious symptoms in adolescence and adulthood (Steinhausen et al., 1998; Webster-Stratton 1997; Loeber et al., 1993).

Many researchers such as Loeber et al. (1993) and Keenan et al (1997) have argued the usefulness of a developmental pathway in early intervention, prior to symptoms becoming serious disorders in adolescence and adulthood. Rickwood (2000), however, identified the difficulty in tracing the cause over time, given that there are not clear-cut stages when a disorder is present or is not present. Hence, delays associated with seeking care for individuals involve problems in diagnosis, and care initiation.

In Durlak's study (1997), the pathway to initial care was described as a road-map, illustrating the course of psychological processes over time, and the possible links to early and later social, emotional and intellectual behaviour. The difficulty for identifying evidence of these processes over time is costly involving tracing the course of disorders (Rickwood 2000). This difficulty is compounded by Cicchetti and Cohen's (1995) findings that there are multiple contributors to each consumer's mental health disorder and outcome despite the fact that there may be homogeneity in the development of mental disorders. Cicchetti and Cohen's (1995) perspective focuses on the nature of the mental disorders, the behaviour of a person who is suffering with the mental disorder, and the diagnostic process.

People with depression and anxiety, particularly the latter, may undergo a number of costly tests, may be misdiagnosed and receive incorrect treatment over a period

of time, as the symptoms frequently mimic symptoms of physical conditions, such as asthma and coronary heart disease (Coie et al., 1993). This group's pathway to care is frequently via primary care professionals such as GPs, unskilled in mental health knowledge (Graham and Potter 2002; Garralda 2001; Bower et al., 2001; Veit et al., 1995), resulting in inappropriate and costly investigation and treatment. This suggests a deficiency of skills and knowledge amongst primary carers.

2.2.2.2 Causes and Influencing Factors

The literature has identified that there are many factors that cause and influence mental disorders. Several studies view mental disorders as multi-factorial disorders which include predisposing genetic influences (Sullivan et al., 2000; McGuffin et al., 1996); exposure to a disturbed family environment (Holmes and Robin 1998); childhood sexual abuse (Fergusson and Mullen 1999; Martin et al., 1993); premature parental loss (Tennant 2002); predisposing personality traits (Schwitzer et al., 2001; Hirschfeld et al., 1989); early onset anxiety or conduct disorder (Moffit et al., 2001); dysfunctional self-schemata (Stewart 1994); exposure to traumatic events and major adversities (Kessler and Magee 1993); low social support (Henderson 2002); substance misuse which is especially important for young people (Rao et al., 2000; Whitmore et al., 1997; Kessler et al., 1995); relationship difficulties (Whisman et al., 2000; Gasquet et al., 1997); and recent stressful life events and difficulties (Tennant 2002; Kessler 1997; Birmaher et al., 1996).

While these identified causal factors potentially provide a conceptual basis for clinicians in their treatment of complex and multi-faceted mental disorders, many studies have failed to find consistent support for common relationships of recent precipitating factors for mental disorders (Mazure et al., 2000). At the same time, few studies have addressed the etiological complexity that is likely to be realistic for mental disorders (Flament et al., 2001). Felner et al.'s (1995) study concludes that due to a wide range of developmental outcomes and pathologies, the efforts to identify specific aetiological causal agents are not appropriate, hence the recognition of the disorders is varied and delay in any pathway to initial care is inevitable. However, recent studies in ADHD, which investigate the role of childhood adversity, show that to provide individualised care it is important to understand the cause (Dadds et al., 1997).

The process of separation from parents is critical for the healthy growth of individuals and for their decisions making (Pearson, and Love 1999; Gasquet et al., 1997; Kosky and Hardy 1992). Kendler et al. (1995) refer to this as 'affectionless control' and Johnson et al. (2000) term it 'neglect'. Any difficulty with this process can contribute to major changes that will determine outcomes in adulthood as well as contribute to the development of psycho-pathology (Harkness and Monroe 2002; Tennant 2002) can contribute to problems in educational, vocational and peer group affiliations as well as the formation of intimate relationships. In severe cases it may lead to depression (Harkness and Monroe 2002; Gasquet et al., 1997; Kosky and Hardy 1992).

Consumers with psychosocial causative factors, such as parents living apart, frequent absences from school and financial problems, or health worries with associated suicide risk, seek help more than those with depressive feelings (Gasquet et al., 1997). In Gasquet et al.'s (1997) study eighty per cent of their subjects with psychosocial problems had contact with GPs for general health care during the previous year.

Studies in the United States have emphasised the limitations which socio-economic factors impose on help seeking behaviours (Saunders et al., 1994). However, in France, where the health care system provides free access to medical care, studies have found the same level of untreated young people with affective disorders as Gasquet et al (1997) found – nearly seventy per cent (Flament et al., 2001). There does not appear to be any similar studies, e.g. looking at untreated affective disorders in the Australian environment.

The above discussion leads to the conclusion that there is a need to understand the interpersonal experiences and circumstances directing individuals towards seeking and receiving help, extending the concept of a pathway prior to the point of contact with recognised health professionals to initiate early treatment.

2.3 The consumer's perspective

There is relatively little attention focused on the mental health consumer's perceptions of the causes of their illness or how and why these perceptions may vary (Maher and Kroska 2002). However, personal narratives have given some

insight into the consumer's experiences of the pathway to care process (Strauss 1994). The collective voice of consumers is central in arguing for a strong focus on improving access to mental health care.

Champ (1998), a consumer, said there are many forms of mental illness and many differences in the individual's experience of the illness. He believes that persons experiencing mental health problems can, to some degree, actively participate in their own intervention, if encouraged and supported. It is only when engaging this participation that the real treatment process is accomplished that is a *real* intervention is done *with* the person rather than *to* them. He emphasises that there are still marked differences between what mental health professionals think is helping in the treatment intervention and what consumers know works for them. Lincoln and McGorry (1995) argue that so far their studies of personal stories have been used only as a contribution to a discussion, not as evidence in the development of care practice. The system continues to adhere to prescriptive documents to decide how and when intervention will be managed (Lincoln and McGorry 1995). It highlights the invisibility of the consumer in developing care practice.

2.3.1 Personal accounts

Consumers have written about their life experiences with disorders, mental health systems and treatment (Deegan 1996). Personal narratives provide a critical view of pathways to care and while each personal history is unique, many similarities exist within the stories. Many have struggled with concomitant alcohol and drug

abuse, poor physical health and other interruptions in their personal development and life course (Payne 1992).

There is limited literature addressing the issues related to the pathway to care of acute mental disorders, e.g. affective disorders, from the individual perspective, though there are a number of studies of individual experiences with chronic mental health disorders such as schizophrenia (Deegan 1996; Walsh 1995; Rogler and Cortes 1993; Strauss 1994). These studies give a better understanding of the pathways to care, in terms of help seeking behaviour/s and eventual access to care.

Champ (1998), an Australian consumer experienced his pathway to initial care through involuntary admission to a psychiatric centre and seclusion. He describes the process of being brought into the hospital by the police, an experience that was to him a terrifying ordeal. He argues that this aspect of protocol and policy is one of social control. Flynn (1990), an American consumer, voices similar issues to Champ, but emphasises the stigmatisation and marginalisation of the illness.

Champs (1998) and Walker (1986) describe, in stages, the devastation of the initial onset of symptoms and the process of the illness. These stages occur over a period of time (some 3-5 years) with difficult changes in social and psychological behaviour, leading to a great sense of insecurity, instability and lack of safety. For example, they describe feelings of isolation, remoteness, and separateness, family problems, erosion of strength and hope, and loss of a sense of humour. Access to

health care is affected by the fluctuations of symptoms, interruptions to employment, and the lack of connection with mental health professionals.

Payne (1992), an American, does not fulfil the stereotype of a person with a mental illness. She has a high level of education (a doctor) and is able to function in society. When her first symptoms emerged, she struggled with feeling ostracised, as well as with high levels of anxiety and fear of the future. She describes the horrible impact of hallucinations, paranoia and a sense of unreality in her life. She details her struggle with alcoholism as a form of self-medication to treat her symptoms, ultimately becoming involved in Alcoholics Anonymous where an effective and competent therapist turned her around. Payne highlights the importance of recognising the warning signs of mental illness and access to early intervention, but also points out the diversities that exist in the mental health field, such as personnel, the types of health care institutions and entrance criteria to health care.

2.3.2 Research Studies

Several recent research studies reflects a growing interest in qualitative research in trying to understanding the experience of the consumers with mental health disorders as well as their resulting perceptions, of and interactions with, health care services.

An eight year study by Sourander et al (2001) employed the methodology of self-report and evaluation of families and teachers in the community. It drew the

conclusion that a greater understanding of psychology and family disruptions was associated with increased service use. These findings emphasise the need of early intervention for this group, before the mental disorder becomes chronic, leading to poor results in adulthood (Flament et al., 2001).

Hayne and Yonge (1997) analysed 40 written personal accounts of the life-world of the mentally ill so as to observe mental illness as it is lived rather than as it is conceptualised. A number of concepts emerged from their data including *Corporeality* which is *confinement* to a mental space that cannot be evaded. *Relationality*, *estrangement* from self and others, often occurs concomitantly with mental illness. *Self-retrieval* and connection with others develops through grieving for the past and restructuring a sense of self in the present. *Temporality*, or the experience of time, is also affected by mental illness. This is exemplified by individuals struggling with symptoms often feeling that their sense of time is distorted or ruled by the emergence and/or remission of symptoms.

Each of these concepts affects the lived experience of the mentally ill. Hayne and Yonge (1997) assert that first-hand knowledge of what mental illness feels like and how it affects the lives of people should promote a deepened understanding in the process of care, and a greater respect for people struggling with an illness of this nature.

Similarly, Williams and Healy's (2001) grounded theory explanatory model looked at the perceptions of newly referred consumers and the cause of their

psychological problems. They found that people want to make sense of their psychological experiences and discover their causes. Their core category depicted the changing nature of human beings and how meanings can change. They suggest that consumers need time to search for reasons for their experiences.

However, Mcnaughton (1998), in an early intervention study using qualitative methodology where 107 consumers were interviewed in the community, asserts that young people with mental illness need to be connected to mental health services as soon as possible. The common practice of withholding support until a firm diagnosis is made is unproductive, in that it increases the chance of a relapse and, in so doing, it increases the chances that the illness will take a chronic path (Rickwood 2000). Lincoln and McGorry (1995) acknowledge that sensitivity to the needs of young people requires time and this sensitivity is important for the acceptance of their illness and their participation in treatment.

Barker et al.'s (2001) study used semi-structured interviews with eight clients and eight close relatives (25-50 years of age), to explore the narratives used by consumers and family members to explain the process of developing chronic mental disorder, a 'sense making process'. The impact on the consumer's sense of self and social relationship over time, and the narrative used by the health professionals contributed to this 'sense making process'. Four stages are described: (1) before the first episode happened; (2) during the first episode; (3) hospital admission; and (4) current experiences. The authors suggest that consumers and family members need continuous support to develop their

understanding of a complex process traditionally dismissed as madness. Barker et al's (2001) study identified the significant processes emerging from mental health disorders, that mental health is multi-dimensional in nature and impacts significantly on clinical work and services.

Frese (1993) detailed aspects of how the mentally ill coped with having mental illness. The first response was denial and ambiguity arising from the difficulty of reconciling the diagnosis and illness as a permanent part of one's life in a world that greatly discriminates against the mentally ill. He stresses the importance of having knowledge and understanding of the illness. In particular, he stresses the importance of knowing the psychopathology of the mental illness.

Hiersteiner's (1999) study used an ethnographic approach to describe the experiences of women, who have been long-term consumers of mental health services, to understand the meaning of accessing care. She found that the (USA) mental health system might be better described as a maze or as a 'non-system', because it required the manoeuvring skills of the individual to successfully access the service. Women are the largest group of consumers of mental health services and, historically, this group are generally described as suppressed and marginalised (Schreiber et al., 2000). It can be argued that females better perceive themselves within the environment and are expert observers of the people processes in this network.

A recent grounded theory study by Robinson (2001), concerning the health behaviour processes of young people generated a conceptual model identifying four major categories: assessing/valuing, confirming, choosing and safeguarding. The findings described the drastically altered environment in which young people must develop in today's society in which the environmental influences outside the family and close friends were unlimited (Hamburg 1993). Young people described making health decisions as a process of assessing, confirming, and engaging in many behaviours with numerous influences until they believed something was 'right' for them and safeguarded the chosen behaviour. Robinson considers that the processes identified in her study offer the potential to develop new strategies for the school nurse so as to influence health decisions creating positive process outcomes among young people.

Milliken (1998) provides important information regarding the experiences of family members who often bear the responsibility of caring for their children diagnosed with chronic mental illness. Her study illustrates the changes that occur in the parents' identity over time as they cope with their children. She interviewed twenty nine parents about their experiences, and developed a grounded theory of 'redefining parental identity'. A basic difficulty identified for these caregivers was the lack of recognition of the parents' rights by the legal system, the mental health profession, and often the children themselves. There seemed to be little respect, understanding and support for these parents. As a result, they became disenfranchised and discouraged. According to the author, the stages in this process include the clients becoming disenfranchised from the parent/s; the

parent/s becoming marginalised; parental suffrage; parental evaluation of life; and the parent/s retain parental responsibility. The findings suggest that parental identity or roles were challenged while living with children who have mental health problems. The processes have changed the parents' life patterns. They became disenfranchised and discouraged by health services and health professionals, but they were expected to retain responsibility for their children. Parents cannot be expected to continue to handle the demands from the mentally sick child without changes in the support mechanisms and the mental health system and society within the health care policies and setting. This study constitutes an effort to explore yet another important area involving the role of the family, which must also be taken into account in terms of access and treatment.

Lincoln and McGorry (1995) conclude that an exploration of the consumer's experiences would give rise to strategies to reduce treatment delay. These could then be developed and evaluated. Increased consumer involvement may help ensure that services are better tailored to suit the needs of consumers. For example, Aboriginal people developed the Aboriginal Medical Service, the Gay Lobby have some say in the management of HIV/AIDS; the Heart Foundation, Asthma Foundation, Diabetic Association etc. all of these groups are consumer groups with some input in the development of associated services.

Geller (2000), reviewing the personal accounts of consumers diagnosed with chronic mental health disorders published during 1950-1974, identified many issues associated with the plight of consumers with mental health disorders. These

include: stigmatisation, hopelessness, abandonment, family burdens, and community reintegration. For this group of individuals, access and intervention issues were crucial to their survival and social functioning and, they remain a great challenge to mental health services of consumers today.

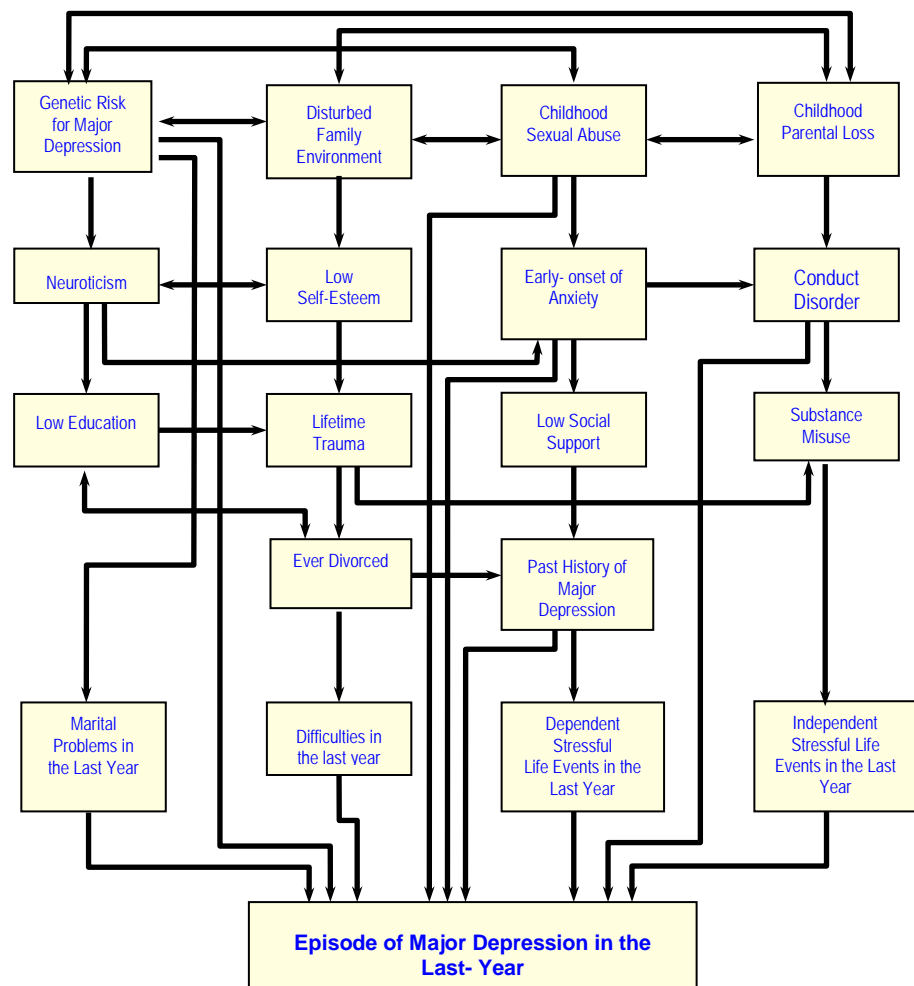
2.4 Models of care

There are a number of models of care for the person with a mental health disorder. These models have been developed from studies of human behaviour and they attempt to explain behaviours that signify mental health problems and identify frameworks for effective management in an effort to minimise the ill health of the individual. The following discussion of the existing models of care provides some insight into these models as well as allowing the pre-care model developed in this present research to be situated within the literature (see chapter six).

The literature search revealed that most of the models are statistical 'risk' predicting models. It is rare in mental health to have a model of care that involve family members and consumers in accessing care and care planning (Furman and Jackson 2002). Providing consumers with the opportunity to be an integral part of their own intervention would allow them a great deal of autonomy and self-determination. For example, Kendler et al's (2002) model of a pathway for major depression in women is a statistical 'risk-predicting' model that suggests the risk of the development of major depression in women results from three broad pathways reflecting internalising systems, externalising systems and psychosocial adversity. The model (Figure 2.2) includes six correlations and 64 paths that

explain and predict episodes of major depression. It is very complex and assumes that multiple independent variables act additively and linearly in their impact on a dependent variable. It emphasises the importance of combining diverse risk factor domains within the model.

Figure 2. 2 Developmental Models for Major Depression in Women (Kendler et al., 2002). (Modified)



However, analytical difficulty lies not only in ascertaining the incidence of risk developing among those who develop depression, but also in determining the likely significance of the problem in the decision-making processes of the individual accessing care. Depression is an etiologically complex disorder and these results, while plausible, should be treated with caution, because of problems with causal inference, retrospective recall bias, and the limitations of a purely additive statistical model. It also raises the question, is real life as simple as this? Does the model take into account societal and environment impacts on the individual?

Other studies include those by Compas et al (1995) who addressed the etiological complexity that is likely to lead to a major depression, and by Felner et al (1995) who showed that social, emotional and adaptive difficulties are generally complex and shared by more than one disorder. Coie et al's (1993) study argued that the processes of interaction are complex and non-linear.

Davidson and Strauss' s (1995) study contends that, unlike model(s) that focus primarily on the pathology of the mental illness/disorder, a mental health disorder has multiple factors and that a bio-psychosocial model is more complete in describing the stages of the illness. Davidson and Strauss (1995) proposed a 'life context' model incorporating adverse life events such as bereavement that may contribute to feelings of depression, in order to address the gaps between research and practice. This model contrasts with the more traditional models that view the disorder as an entity in and of itself, e.g. the recovery model (Curtis 1997). The

traditional models make it difficult to focus on the person as an individual. Davidson and Strauss (1995) argue it is important to expand our ideas of health and normality in order to focus on the active role that the person can take in the determination of his or her life-course. In this way, the person's life is the defining construct. The illness is not viewed as a deficit, but is considered rather in terms of the impact that it has on an individual's life process.

An intervention may be classified as preventive if it reduces the likelihood that a disorder may affect an individual, if it interrupts or slows the progress of the disorder or if it reduces disability (Commonwealth Department of Health and Aged Care 2000). The theoretical basis for prevention hinges, for the most part, on the concept of risk or probability to suffer from a given disease in a defined future (Price 1996). However, translating this into action is much more difficult. There are a number of screening tools in use for the detection of either psychiatric or substance use disorders, but there are few that adequately cover the range of mental health and substance use disorders (Room 1997).

The current strategic direction relating to quality and effectiveness programs in mental health care has shifted the focus to evidence based practice (Clearly and Horsfall 2002). One of the difficulties of obtaining evidence relates to limitations in evaluation methodologies (Cantor 1994; Davis et al., 1999), particularly because of the small numbers of subjects, flawed design and methodology, a failure of significant effects to study and a lack of evaluation studies (Fry et al., 1999). For example, in the Suicide Prevention Programs, Gunnell and Frankel

(1994) noted that in order to demonstrate a statistically significant (15 per cent) reduction in the subsequent suicide of those who had attempted suicide, there would need to be 44, 914 subjects in the prevention program.

Apart from methodological concerns, a number of other problems related to the effective utilisation of promotion/prevention models have been identified (Davis et al., 2000). These include inadequate communication between policy makers, program developers, researchers and interventionists (Garland and Zigler 1993), and between the programs and those whom they target (Dudley et al., 1992; Davis et al., 1999). The strategies engaged in bridging communication gaps are ill-informed, inappropriate and indeed sometimes ineffective, and even potentially damaging (Garland and Zigler 1993). Further limitations in these programs include: system and resource issues; communication and attitudinal problems among health professionals; and gaps between practitioners, consumers and researchers (Clearly and Horsfall 2002).

In conclusion the majority of studies concerned with pathways to initial care report that there is a need for a pathway model that includes factors such as the individuals themselves, and the specifics of their life course (Lincoln et al., 1998; Macnaughton 1998; Malla et al., 1998; Looper et al., 1998; Spaniol and Gagne 1996). These studies confirm that the pathways to initial care are highly individualised and vary from person to person and for different populations. The authors anticipate that there are multiple contributors to the disorders and outcomes in each individual (Cicchetti and Cohen 1995). There is diversity in the

mental illness process and there are different pathways to initial care with critical points, thus the models are complicated and could discourage health service providers from engaging in intervention with the consumer.

2.5 Barriers to care

The literature is seemingly full of examples of health service accessibility. Much of the literature dealing with the ‘pathways to care’ focuses on a variety of factors deemed to be either obstructions or aids in the accessing process. These include insight (Brown 1995; Stewart et al., 1995); stigma (Markowitz 1998; Rosenfield 1997); type of personality style and attitude (Cook 1995; Fink and Tasman 1992); substance abuse (Cornelius et al., 2001); physical, emotional abuse (Kumpulainen et al., 2001); sexual abuse (Fergusson and Mullen 1999; Martin et al., 1993); and social support or lack of it (Henderson, 2002). These are discussed under the headings service barriers, social barriers, and individual barriers.

2.5.1 Service barriers

Frequently, when the accessibility and acceptability of services have been inadequate, mental health professionals have tended to blame the illness, the client or the caregivers, when the factors that may have lead to treatment delays may have been fear of consequences of having a mental disorder, difficulty in gaining access to services, poor screening by primary health professionals, inexact diagnosis by mental health workers, inefficient case management, and receiving sporadic or ineffective help. This is particularly so for suspected cases where

symptoms matching diagnostic criteria are not yet evident (Lloyd and King 2003; Lincoln and McGorry 1995).

2.5.1.1 Primary care services

The provider the young consumer first contacts may not be a speciality professional (Stiffman et al., 2001; Garralda 2001), but a primary health provider, such as the family doctor or health clinic. Their signs and symptoms may be overlooked and so the consumer loses the first opportunity for early detection and treatment.

Need may be conceptualised in terms of diagnoses, symptoms, or functioning. Many young people have clusters of symptoms severe enough to be distressing or disabling, yet do not meet diagnostic criteria (Stiffman et al., 1992). The primary care providers often do not perceive the existence of need (Horwitz et al., 1992), conversely, young people frequently do not discuss their emotional or behavioural problems (Cohen and Cohen 1996).

Gater and Goldberg (1991) argue that clients presenting in primary care have the longest intervals or delays before accessing care. Their symptoms may be overlooked or be treated inappropriately, and their 'pathways' are seldom documented in a systematic manner. One of the problems of psychological care may be attributed to the professional's anxiety in dealing with issues that involve emotional distress (Russel and Potter 2002).

A large proportion of anxious and depressed consumers are missed when psychological symptoms are mild (Buszewicz and Mann 1997; Coyne et al., 1995; Olfson and Mechanic 1996). These concerns about the adequacy of comprehensive care have led to calls for a consumer-centred approach (Ram et al., 1998; Weinman and Dale 1998).

Meeting the demand for treatment of young people is indeed a challenge the world over for mental health (US Public Health Service 2000). Garralda's (2001) Australian study of general practitioners (GPs) as primary carers co-ordinating the provision of medical care and providing continuity in the face of changing speciality, contends that general practitioners can play an important role in providing mental health care, but there are few professionals at all levels with the knowledge and skills to deal with these problems.

Susman et al., (1995) concluded that GPs recognise mental health problems in their patients, but hesitate to diagnose mental disorders because of a variety of reasons, including diagnostic uncertainty, perceived stigma, and desire to preserve the doctor-client relationship, time, financial pressures and a lack of supporting resources.

Potts et al.'s (2001) survey of primary carers (GPs), using self-reports and the case notes of 2359 young people, highlighted that this group rarely consults their GPs about their emotional well being. Yet the self-reported rate of mental health problems was nearly seven times greater than that suggested by these same

subjects' medical records. There are no distinguishable indicators to recognise when young people see GPs for mental health consultations or physical health consultation. This issue highlights the problems in distinguishing mental health presentations in primary care.

Del Piccolo et al's (2000) study of six GPs and two groups of matched control pairs of consumers (N=238), suggests that: (1) GPs need to improve their recognition of those consumers who are emotionally distressed and who are most likely to be missed. GPs should increase their attention to cues related to the life style and the background of life episodes, such as consumers with drug and alcohol problems, bereavement and abuse background; and (2) primary care professionals need up-skilling to increase their effectiveness in intervention. These issues are also supported by the systemic review of Bower et al (2001).

Hulse et al's (2001) study of young people accessing care through Emergency Departments in Australia, concluded that this pathway provided a small window of opportunity to provide treatment intervention. The authors also argued that there is currently a lack of evaluated interventions designed for this group at Accident and Emergency Department.

Commonly, most consumers in the community contact services when in crisis, at times leading to emergency intervention. Paradoxically, service systems developed to respond better to emergency and crisis situations may, if they are gatekeepers to

the service, discourage referrals at a less severe stage, thereby increasing delays and late presentations (Lincoln and McGorry 1995; Lessa et al., 1996).

Other research referring to engagement with the mental health services suggest that some professionals are loathe to refer their clients to the mental health system as they do not perceive it as preventive or effective in nature (Lincoln and McGorry 1995; Lessa et al., 1996). This raises the question as to the effectiveness of mental health services, the perceptions of health professionals, and why the families and consumers themselves said they have problems in trying to negotiate an inaccessible mental health system (Mcnaughton 1998). However, lack of recognition is a key factor in causing delays in presentation and treatment, which can have serious consequences, such as poorer prognosis, increased burden on the family and increased personal disability and psychological, emotional and financial costs (McGorry 1998).

The literature relating to the access to health care at the onset of mental health problems in individuals associated with the various pathways to care has been reviewed. One such study indicated that community psychiatric nurses were not part of primary care, as they did not feature in the professional pathway (Gater and Goldberg et al., 1991). Shortly after Gater and Goldberg et al's study was completed an experimental multidisciplinary team was first established in the United Kingdom. As a result the multidisciplinary team approach in the Australian mental health sector was established in the mid 1990s with the closing of psychiatric hospitals.

The findings of the above studies underline some important issues on the recognition and attribution of the emotional distress of consumers accessing primary care. The information is essential in the correct assessment of the consumer's mental health status so to avoid the pitfalls of creating barriers to the access of care.

2.5.1.2 Resource barriers

Growth in expenditure for resources and services has been inadequate. Despite increased funding to the total health budget over the last decade, there is no evidence that the ***proportion*** of total health funding devoted to mental health has increased. Increases in funding of services in the mental health field have simply mirrored increases (46 per cent) in the cost of providing other services, (particularly primary and general health), but expanded roles had to be financed from within the same overall budget. Consequently, local clinicians and service providers report actual declines in the total number of direct clinical services provided (SANE Australia 2003).

2.5.1.2.1 Implication of mainstreaming and integration

Recent and ongoing changes in mental health care and delivery has resulted in fundamental changes to psychiatric services. These changes, which involve both a mainstreaming of psychiatric institutions to general hospitals and an integration of psychiatric hospitals with community services, are causing major shifts in psychiatric care resources. The process has been labelled as a compromise solution and restrictive in the delivery of care to the mentally ill (SANE Australia 2003;

Australian Health Care Summit 2003; The Royal Australian and New Zealand College of Psychiatrists 2002).

In New South Wales (NSW) there are 900 beds for Acute Adult General Psychiatry distributed through stand-alone hospitals (242 beds) and co-located in General Hospitals (658 beds). This represents approximately 18 beds per 100,000 populations (Commonwealth of Australia 2002). Many have expressed concern that this is gross under-funding without any coherent State-wide population-weighted model (SANE Australia 2003).

For Child and Adolescent Psychiatry, there are only 81 beds, with stand-alone facilities accounting for 47 beds and General Hospitals with 34 beds. The mental health needs of the young people are as large as they are in adults and yet more resources are being allocated to adults. The argument is whether NSW takes serious enough the task of prevention and early intervention in the young, because of the limited available beds.

In reality, many young people are admitted to adult psychiatric units as there are no facilities outside the capital city areas to admit young people under the age of 16 year (Rey and Walter 2001). Research has shown that the admission of a young people to an adult psychiatric facility is destructive to their future health and health-care (Lincoln and McGorry 1995).

There is little change in funding for community services in New South Wales which now carry an increased work load. New South Wales (NSW) funding in 1999-2000 to non-government organisations accounted for 1.5 per cent (\$1.20) per capita, against the national average at \$ 4.42 per capita funding in 1999-2000, highlighting that NSW spends 69 per cent below the national average, the lowest of the jurisdictions (Commonwealth of Australia 2002). This suggests that communities in need are disadvantaged in relation to access to services.

The downward trend in the number of public sector psychiatric beds continued in 2000 (Commonwealth of Australia 2002). There is a reduction in inpatient beds with further decreases in expenditure of staffing, e.g. clinical staffing declined by further 3 per cent and expenditure increases another 2 per cent between 1993-2000.

The figures significantly point to service inadequacies in New South Wales, a falling behind other States, and a neglect to invest in the increasing the access to mental health care (SANE Australia 2003; Australian Health Care Summit 2003). Without appropriate levels of funding for mental health services, the future for young people remains bleak in terms of ready access to effective intervention and community support. Identified needs should be accompanied by concomitant provision of community based clinical staff on an equitable State-wide basis.

A recent review of mental health services in Australia, compiled from the experiences of users and providers of mental health services, support the view that

current community-based systems for people with mental health problems were failing to provide adequate services by restricting access, providing variable quality services with poor continuity, and lack of support for recovery from the illness (Australian Health Care Summit 2003). This would mean that system barriers have the potential to further increase the inaccessibility of health care services.

Private psychiatric hospitals accounted for 21 per cent of all psychiatric beds available in Australia in 1999-2000, rising from 14 per cent in 1992-93. A combination of growth in the number of private beds and reductions in the public sector has contributed to the increased private sector share. This highlights government expectations that the private sector will cover the shortfall in available beds and avert admission to public hospitals when clients are not serious enough to be admitted involuntarily (scheduled because of risk of harming self and other criteria).

The Commonwealth introduced the Private Health Insurance Incentive Scheme in July 1997 with fixed-rate rebates for low and middle-income earners to encourage more use of private sectors, but at present only 40.5 per cent of people in NSW have private health insurance. This rate has declined from 2000 when it was 46.8 per cent (Australian Bureau of Statistics 2003). The falling rate of private health insurance indicates that consumers are gravitating back to the public sector. This raises access issues for the consumers who need care, but have no private health insurance. Low income families, pensioners, people in rural and remote areas

where private hospitals are few, non English speaking group and homeless youth (SANE Australia 2003) again are the most disadvantaged. For example, 18 per cent of young people surveyed believed nothing could help and private counselling was perceived to be too expensive (Commonwealth of Australia 2002).

New South Wales has many programs that are exemplary and beacons of excellence for consumer and carer participation and National Standards for Mental Health Services, but the structural reform agenda is not finished and more time is needed for implementation programs to be effective (Commonwealth of Australia 2002). However, these programs remain isolated examples in an otherwise disappointing landscape. If these initiatives could be built upon and replicated through out the State in a systemic way, NSW would have a world class mental health service system (SANE Australia 2003).

In summary, system complexity, consumer needs, and provider ethics demand collaboration, co-ordination and co-operation on behalf of all consumers of mental health services; but the constraints on resources may have prevented the accomplishment of this for the younger groups.

2.5.1.2.2 Internet Resources

The opportunities afforded by online access to information help should help to ensure that all Australians are better able to access and benefit from information, specially young people who are more likely to use online services.

There are many web-sites concerned with mental health issues that can be easily accessed on the net, e.g. Sane Australia, Schizophrenia Fellowship, Beyondblue and Reachout. These sites provide information, and multimedia resources and guides for young people to access appropriate help. For people who may be shy, ashamed, feel guilty or very insecure who don't like face-to-face interactions, web-sites are very helpful, but people on low incomes, pensioners, those without tertiary education, people living in rural and remote areas, Aboriginal and Torres Strait Islanders, people with disabilities, people from non-English speaking backgrounds and those aged over 55 are less likely to access the Internet (Australian Bureau of Statistic 2001). Thus, options need to be explored for these groups of people to ensure that information is more available. On-line services provide information for young people in an environment that they are comfortable with. The process facilitates self-responsibility and self-empowerment (Wallerstein 1992).

2.5.2 Social barriers

Consumers with mental health disorders are stigmatised in the community. This is seen by the isolation of people who exhibit difficult behaviour despite the various means to support the status and rights of individuals (Valimaki 2002).

2.5.2.1 Stigma

Stigma relating to mental illness exists, even within the broader health profession (Goodman and Huang 2001). Too little accurate and up-to-date information is made available in the majority of programs for future social workers, nurses and

psychologists (Goodman and Huang 2001). Some professionals express surprise at the incidence of under-diagnosis and inadequate treatment provided in primary care (Klinkman and Okkes 1998). Some of the suggested reasons for misdiagnosis include inadequate interviewing and diagnostic skills, insufficient undergraduate and postgraduate training, and the stigma associated with psychological diagnoses and treatment (Valimaki 2002; Albright 1998).

Socio-economic factors, in particular education, highlight the inequality of access to health care for the mentally ill consumer (Beautrais 1997). This inequality has increased over the past years (Bagnall 1999). Societal values suggest that the deficiency may sometimes perpetuate outmoded notions of family causation in mental illness (Patton and Burns 1997). This inequality is enhanced by the low priority of mental health and is a reflection of professional and social values (Berman and Silverman 1997).

Where rejection and fear are the norms most often perceived by consumers, families are met with blame (Lincoln and McGorry 1995). Even a single episode of hospitalisation can dramatically alter community attitudes, not only towards the individual sufferer but also towards the family (Minas 1991). Some cultural perceptions of mental illness include the belief that mental illness affects only those of an evil or weak character, or is a sign of being guilty of some terrible sin and deserving of misfortune. Consequently, consumers and families are often not seen as victims deserving of support and sympathy (Minas 1991).

Frese (1993) described vulnerability to criticism as a facet of the illness. He discussed the importance of understanding in those people working and interacting with individuals with mental health problems. Stigmatisation and discrimination affect people with mental illness in the form of isolation and prejudice. Frese emphasises the importance of people with mental health problems becoming more open about the illness in order to educate the general public and counter negative images.

Lincoln and McGorry (1995) and Macnaughton (1998) explain that initial experiences with care can be highly threatening, traumatic, and demoralising to the young person and his or her family with involuntary admission. They argue that experiences that are traumatic and coercive can deter people from seeking help in the future, because negative emotional reactions relate to the fear surrounding the admission experience and the environment of the hospital wards.

The result of a constant series of rejections and exclusions on the life of a person struggling to overcome serious mental illness is an experience of stigmatisation. Lack of opportunity often leads to poverty, and the loss of family support leads to youth homelessness (Davis et al., 2000). Through observation and conversation with consumers, it is possible to understand how stigmatisation is conspicuous in conspiring to undermine the concept of self, with consumers often feeling no real future identity is possible.

Information sources contributing to the stigmatisation, e.g. the media, especially television, have done much to create and sustain a distorted vision of mental illness (Nairn et al., 2001). Social effects portrayed by the media are far removed from what experts advocate (Ward 1997). Television does more than just entertain; it is our common cultural denominator. Over 90 per cent of Australian homes own at least one television set, which is turned on for an average of seven hours per day (Australian Bureau of Statistics 2000). Approximately one out of seven prime-time television shows features a character labelled mentally ill (Ward 1997). Sadly, media portrayal of mental illness occurs in a highly power-oriented and violent world. For families, the negative portrayals are powerful reminders of how little our society knows or cares about the causes, course, and treatment of mental illness (Nairn et al., 2001). It is hard to overstate the impact of this persuasive communicator.

2.5.2.2 Abuse

The last decade has seen a surge of recognition of abuse. Prospective studies that have used rigorous methodological investigator-based assessments of young children, have revealed that parental neglect, physical and sexual abuse are associated with up to double the risk of mental disorders, especially depression disorder (DeGroot and Rodin 1999). These results show that particular childhood experiences may predict the onset of mental disorders (Fergusson and Mullen 1999).

2.5.2.3 Lack of support

There are many studies on adverse life events causing distress and unhappiness in young people. One such study of 15-17 year olds with depression found that poor interpersonal relationships (problems with parents, problems with friends and relationship break-ups) were among the most common causes of distress for young people (Dower et al., 2001) Other relatively common causes of distress related to schooling, parents divorced, university or work life, financial hardship, unemployment and bereavement (Hoberman et al., 1996). This view is supported by Cole et al., (1995), who found that people without ‘established relationships’ with family members, or general practitioners, took considerably longer to access care.

The literature is less developed concerning the nature of community support for young people with acute mental health disorders (Macnaughton 1998). It is assumed that their needs are similar to those of adult mental health consumers. The literature focuses on early intervention programs that are similar to older adult programs and discusses issues such as housing, income support, assertive case management, and support for maintenance or recovery role (Malla et al., 1998; Whitehorn et al., 1998). While these are important issues, attention is rarely focused on how they relate to young people.

There are many factors identified that young people facing a mental health problem for the first time, engage not only in an ongoing and uncertain process of

trying to make sense of the disorders, but in seeking meaning in their psychological experience as well (Lincoln and McGorry 1995).

2.5.3 Personal barriers

There are a number of factors that influence young people with a mental health problem to initiate or seek help in the early stages of the illness, for example, insight and attitudes.

2.5.3.1 Insight

Williams and Healy (2001) wrote that people facing a mental health problem for the first time engage in an ongoing and uncertain process of trying to make sense of, and seek meaning in, their psychological experience. Perceived causes of problems were conceptualised along the dimensions of origin (social or psychopathological) and relation to the self (internal, external or direct). Insight issues may not be clear-cut and easy to understand.

Jorgensen (1995) conducted a study in which 50 individuals struggling with the symptoms of mental illness were interviewed six times over an eight-week period. He concluded that insight operates, at least in some degree, independently of symptoms and is a distinct facet of recovery. It should be noted that this sample consisted of severely ill individuals with psychotic symptoms admitted to an acute hospital ward. The relationship of insight to the illness appears not to be a simple one. While insight promotes recovery, its relationship is not linear or consistent across individuals or situations.

Recent research suggests that insight may be conceptualised as a multi-dimensional construct involving psychological defences (Amador and Strauss 1993) or influenced by social and cultural factors (Johnson and Orrell 1995; Birchwood et al., 1994). This review captures the ambivalence of individuals and society in acknowledging the reality of mental illness and recognising the symptoms, for differing reasons, that largely remain obscure.

2.5.3.2 Attitudes

Meltzer et al (2000) argued that people with neurotic disorders, depressive episodes, obsessive-compulsive disorders, phobia disorders, generalised anxiety disorders and mixed depressive disorders are reluctant to seek help because of strong perceptions that no one can help them and that they should be able to cope themselves.

Furnham and Henry (1998) conducted an early study of a comparative heterogeneous group of 160 subjects in England. Their study considered that biological factors of the illness, social support, and professional help were essential components influencing the understanding of mental health problems.

It is apparent that a number of different variables also influence the coping process. The age of the person, their educational background, and personality traits such as optimism can act to influence coping and dealing with the illness (Carver et al., 1993). The family's view of the illness contributes to the individual's view

(Robinson 2001). Factors such as ‘trust’, may improve the individual’s ability to recognise the possibility of mental illness and seek help (Macnaughton 1998; Weinman et al., 1996).

2.5.3.3 *Substance misuse*

There are many studies about the association of mental health problems and substance misuse, suggesting that this is an important intervening variable, indirectly influencing the pathway of individuals to accessing care (Kendler et al., 2002; and Zubric et al., 1999). Substance misuse is seen as a significant contributing factor in suicide and depression and repeated interventions (Zubric et al., 1999).

One Australian retrospective review of hospital records of emergency department presentations of young people, in four metropolitan hospitals, found alcohol was the most frequent precursor to presentation (44 per cent), followed by illicit drugs, mainly heroin (15 per cent). The median age of subjects was 17 years (Hulse et al., 2001). Hulse et al's study highlighted that there is no evaluated model of intervention for this group at the emergency department.

Sanguineti and Samuel (1993) conducted a study of 401 patients who had been involuntarily admitted for short-term hospitalisation in psychiatric units, in order to assess co-morbid substance abuse. The study investigated how substance abuse affected the symptomatology and course of the illness. Prior research indicated that there were significant differences between active substance abuse and no

substance abuse. In contrast to the accepted notion that individuals with mental illness often abuse substances as a way to cope with the symptoms of the illness, Sanguinetti and Samuel concluded that patients diagnosed with chronic mental disorders were significantly under-represented in the substance abuse group.

2.6 The need for the study

The previous sections have discussed the literature which has been generated around the phenomenon ‘the pathway to care’. However, this review has shown a number of gaps in our understanding of this phenomenon, largely because of the way it has been studied to date and, from an Australian perspective, because much of the literature is from other countries where the social, economic and political contexts differ. These contexts are likely to influence how health problems are experienced and dealt with.

The extant literature suggests a need to adopt a new perspective on the phenomenon of the pathway to care if we are to improve the health outcomes of young people who develop mental health problems. As suggested above, the phenomenon has mainly been investigated using quantitative methods and, as a result, from the perspective of the investigators. It is considered that our understanding, and hence our ability to intervene to assist young people effectively, can be improved by investigating their experiences from their perspective. What happens after young people start to experience mental health problems? How do they go about dealing with them? What is it like to be in their position?

This review has also drawn attention to a number of models which have been constructed from research and which aim to guide clinicians. However they tend not to address the early experiences of young people and are not constructed from their point of view. Hence, one of the intentions of this research is to construct a model from the findings which reflect the experiences and perceptions of the participants on their pathway to care. The purpose of this model is to assist the development of effective early interventions, focusing especially on the factors which young people identify as helpful or obstructive.

2.7 Summary

In reviewing the literature a number of gaps in research have become apparent. There is no known 'pre-care' model using a conceptual framework derived from the experiences of the consumer's pathway to initial care. The models currently in use are geared towards early intervention, and focus on pathways of care once the consumer is in the system. There is a need to move from this treatment model and incorporate issues of the real world flexibility in the pathway to care, in order for intervention to be effective and timely, so as to prevent the development of chronic disorders.

These studies also highlight the fact that the pathway to initial care is the process of an 'individual' accessing care. There are many barriers preventing young people from successfully gaining access to care. Although many quantitative studies exist which assess discrete symptoms of mental health disorders, there are fewer qualitative research studies, which delve into the subjective experience and

perspective of the individuals 'pathway to initial care'. A number of researchers agree that qualitative studies are necessary in order to formulate new and more accurate conceptualisations of the experience of accessing care (Surf and Lynch 1999; Davidson and Strauss, 1995; Strauss 1994; Brekke et al., 1993).

While the literature highlights the importance of early detection and prevention, there are few studies which examine the issues from the perspective of those who experience the process, namely the young adults who experience mental health care. The views which consumers seem to hold about their experiences may help to explain further why there are delays in accessing care.

The present study is an attempt to address this gap in research; that is, to identify perceptions and voice the experiences of individuals seeking and participating in early intervention.

CHAPTER THREE

METHODOLOGY

3.1 Introduction

This chapter explains the methodological issues arising from the use of the grounded theory approach. It discusses how the data were collected and analysed, and includes examples of data analysis to illustrate the points. The use of the constant comparative method for the generation of the core category is detailed. The demographics of the participants, as well as how the participants were recruited, are described.

Grounded theory is an inductive, theory-discovering methodology that allows the researcher to develop a theoretical account of a substantive area while simultaneously grounding the account in empirical observations of data (Glaser and Strauss 1967). Through this process of data collection and analysis, the researcher elicits the theory, thereby uncovering the relevant understandings and explanations of the area under study (Strauss and Corbin 1990). Grounded theory is specifically suited to bringing depth and a fresh perspective to an unexplored area of study, such as this one (Strauss and Corbin 1990).

3.2 Grounded theory

The grounded theory methodology chosen for this study was originally developed by the sociologists Glaser and Strauss in 1967 (Thorne 1997). Grounded theory developed as both a research methodology derived from the assumptions and

theoretical underpinnings of symbolic interactionism, and as a method for systematically deriving empirically based theories of human behaviour and the social world through an ongoing process of comparative analysis.

The grounded theory method provides a systemic way of generating theoretical constructs and/or concepts that illuminate human behaviour and the social world (Chenitz and Swanson 1986). In this method, people who have problems in common are believed to have a basic common social problem that is often unarticulated. It is the interpretive researcher's work to discover and articulate the problem from the participants' perspective (Hutchinson and Wilson 2001).

Grounded theory has evolved since its initial development. Charmaz (1983), for example, reported that she had developed her own style of grounded theory, although it remained within the framework of the original method propounded by Glaser and Strauss (1967). This development of the data analysis technique is largely the result of the synthesis of the work of four grounded theorists, Charmaz (1983), Chesler (1987) and Strauss and Corbin (1990). Strauss and Corbin's (1990) work has been commended for providing novice researchers and doctoral students with direction in carrying out grounded theory analysis (Melia 1996), and the approach explicated in the present study is consistent with Strauss and Corbin's work.

Using grounded theory to study the pathways to initial care is appropriate. Grounded theory allows new insights to be found with solid, rich data required to allow accurate and complete development of the conceptual and analytic issues. Data collection is shaped by the analytical interpretations and discoveries of the researcher (Strauss and Corbin 1990). This process causes the researcher to sharpen her analytical skills, to be able to adequately substantiate explanations and theories that fully explain and interpret emerging ideas.

The present study used a semi-structured interview format, which allowed participants to talk about their experiences from their perspective. Interview questions were derived and developed by the researcher, based on information deemed relevant to the experience of individual participants with mental health problems. As findings emerged, they were compared with what was already known on the subject, enabling the researcher to refine questions put to later participants to ascertain further specific information (Strauss and Corbin 1998). The grounded theory approach also allowed the development of an integrative model of 'pre care', an area neglected by previous studies (Macnaughton 1998; Lincoln and McGorry 1995).

3.2.1 Symbolic interactionism

Grounded theory has social and cultural roots in the social sciences, most particularly in symbolic interaction (Blumer 1969; Chenitz and Swanson 1986; Mead 1964; Woods 1992). Symbolic interactionism is a theory about human

behaviour; it is an approach to the study of human conduct and human group life (Chenitz and Swanson 1986). Symbolic interactionism is concerned with the meanings of events to people and the symbols they use to convey those meanings (Baker et al., 1998). Symbolic interactionism focuses on the inner or experiential aspects of human behaviour, or how people define events and reality and how they act according to their beliefs. In other words, it emphasises the importance of interaction with self and others in how people think about, live with, and make decisions about a given situation - in this case, young people with mental health disorders and their pathway to initial care.

Symbolic interactionism uses a number of methods to gather and analyse data. The analysis is psychological in nature. It attempts to understand the cognitive interpretations that people give to their experiences, and it concentrates on interactions between participants as the source of the data. An example is the ethnographer who moves into the field to learn about a culture from the inside out (Bryman and Burgess 1994). The researcher can thus examine the cultural knowledge, behaviour and artefacts that participants use and share to interpret their experiences within that cultural group. The researcher can also examine the taken-for-granted but important ideas and practices that influence the way lives are lived and constructed in the group contexts (Bryman and Burgess 1994). Ethnographers examine what people say and do therefore it is possible to understand the way that everyday routines constitute social structures within a group. Human beings have their own stories about their experiences of being in

the world. The task of the researcher is to uncover hidden meanings and make sense of participants' description of their experiences.

Consistent with symbolic interactionism, the interactions between researcher and participants are central to the present study (Bryman and Burgess 1994). The researcher has to be sensitive to the nuances arising in the interview, because the information comes from the participant and, if the interaction is poor, then no useful information will be forthcoming and/or it will be misinterpreted. When analysing data, the researcher is sensitive to the symbolic meanings that participants give to certain acts or issues in the phenomenon being investigated.

3.2.2 Theoretical sampling

A key aspect of the grounded theory approach is the interrelationship between the collection, coding and analysis of data (Glaser and Strauss 1967). Theoretical sampling, the label assigned to this complex process, leads to the generation of a grounded theory. During the period preceding data collection, the researcher makes initial decisions about the kinds of data to be collected and the kinds of data considered relevant. For example, interviewing and observing behaviour may be considered useful and may proceed simultaneously. In this study, it was decided to ask young people who had recently successfully accessed mental health services to discuss with the researcher their experiences and their understanding of the problem under study. Inclusion criteria were sufficiently open to allow a variety of young people with different individual experiences to take part.

Theoretical sampling facilitates the development of theory by enabling new participants to be sought in response to analysis of the data. However, in this study, accessing other participants was not possible, since commitments had been made to the University Ethics Committee and to the mental health facilities about the participants who would be approached. Nonetheless, theoretical sampling did influence the interview process. As a result of the concurrent data collection and analysis, later interview questions became more specific, focusing more on testing and explicating the categories which seemed to be emerging. As the participants and their experiences differed in many ways (see section 3.3.1.2 and table 4.1), it was possible to explore the emerging theory with them as the interviews proceeded and to reach saturation after 16 interviews. A further four interviews were carried out to confirm relationships between the categories. Particular attention was also paid to the accounts of the five participants who had experienced involuntary care, to discover their understanding of the problem under study and how they resolved it, and to compare their accounts with those of the other participants. This examination of potential ‘negative cases’, i.e. those accounts which might refute emerging theory, is another component of theoretical sampling (Schreiber, 2001).

Coding and memoing are two key activities in theoretical sampling, with both commencing as soon as data collection begins. Soon after collection, each item of data is analysed line by line in an attempt to understand what is happening (coding). Concurrent analysis of early data may lead to decisions to collect additional data as appropriate in the setting (Strauss and Corbin 1990), for

example, the direction of the interview may change or be expanded to further explore issues/concepts that have arisen. Theoretical sampling continues until a core category is identified (Glaser and Strauss 1967).

Memos are written during the process of data gathering and analysis, detailing descriptions of the phenomenon under investigation (Martin and Turner 1986). Memos contain the researcher's emerging ideas, themes and interpretations from data. Spradley (1979) suggested that researchers keep separate sets of memos, for example:

- Short memos made at the time of observation or interview;
- Expanded memos made as soon as possible after the field session;
- A fieldwork journal that records problems and ideas that arise;
- A provisional running record of analysis and interpretation.

Field-notes in memo form are rarely published, because they are temporary and useful only to the researcher (Kirk and Miller 1986). The writer memoed after completing each interview and as the analysis proceeded. This activity allowed the writer to see the detail and nature of themes as they arose (Glaser 1978).

3.2.3 Theoretical sensitivity

Another significant point is the importance of theoretical sensitivity as without sensitivity to the participant, the process and scope of the research, and the phenomenon, the researcher may miss or misinterpret significant aspects of the study.

Theoretical sensitivity refers to the researcher's manipulation of the data to yield explanations that best reflect the reality that is being perceived (Glaser 1978). Glaser (1978) asserted that 'everything is data', but not all data are always visible. Such data includes: dynamic and continually evolving experiences in the researcher's own life; the active role of persons in shaping the worlds in which they live; the importance of change and process; the variability and complexity of life and the interrelationship amongst conditions, meanings, and actions (Strauss & Corbin 1990). The researcher's knowledge, background and experience are seen as advantageous. This was the case in the present study, as the researcher is a mental health worker who has worked in a variety of clinical, education and research areas. However, the researcher must faithfully describe what is, and not make descriptions of assumptions of meaning (Beck 1992).

Sensitivity also refers to an understanding of the myriad confusing interactions that occur in the researcher-subject interview. Interviewers should be responsive to environmental cues and be able to interact with the situation; use their ability to collect information at multiple levels concurrently; and process data as soon as they become available. This allows for the provision of immediate feedback, verification of data where necessary, the exploration of atypical or unexpected responses (Morse 1992).

Glaser (1978) believed that theoretical sensitivity has two characteristics. The first is the involvement of the researcher's personal and temperamental bent. It refers to

the tendency of the researcher to start data processing as soon as the data are collected. The second characteristic of theoretical sensitivity involves the researcher's ability to have knowledge of, and some insight into, the area of study combined with an ability to use the insights to expand the knowledge base, and to know where to look for 'gaps' in participant information. Knowledge base expansion refers to the ability of the researcher to extend knowledge into the 'realm of the felt, to silent sympathies, to the unconscious wishes and to the daily unexamined usages that will lend depth and richness to our understanding of social and organisational settings' (Guba and Lincoln 1981, p. 135).

It is important to note that grounded theory is theory generating, not theory testing, and the researcher must have no preconceived ideas about what kind of general theoretical account is likely to emerge from the study (Glaser and Strauss 1967). If a theory exists, it must be acknowledged; otherwise it may reduce the researcher's sensitivity to the emergent theory (Glaser 1992; Strauss and Corbin 1990). Glaser and Strauss (1967, p. 38) and Glaser (1978) referred to a model generated in this way as an 'emergent fit' model, whereby prior understanding must not be allowed to force the development of some theory that does not itself emerge from the data. For example, to study pain management qualitatively, one must observe the processes. Similarly, to research the pathway to care qualitatively, one must be able to account for the process, and be able to recognise what has emerged.

Bryman and Burgess (1994) pointed out that ethnography and other qualitative methodologies, such as discourse analysis, are also concerned with theory building, but that grounded theory is the approach most concerned with moving past the descriptive stage and on to theory generation. Descriptive research answers the 'who, when, and where' questions, but it does not answer the 'how and why' questions (Pettigrew 1990), an integral part of theory generation. (Glaser and Strauss 1967). In this study, answering the how and why may provide theory to further understand the pathway to care for health care providers, consumers, and the wider community.

During the process of data collection and analysis, literature is considered to be data to verify the emerging theory, and at the end of the study the researcher should be able to place the developing theory in the context of existing theories.

The literature review allows the reader to identify the issues under study adding power and depth to the developed theoretical scheme. Thus, the reader is able to trace the process, progress and evolution of the research questions, as a backdrop against which the new findings can be evaluated (Smith and Biley 1997).

3.2.4 Issues of rigour

Grounded theory shares strengths and weaknesses with other forms of qualitative research. There are some issues that specifically relate to grounded theory.

Rigour in quantitative research stems from the procedures that the researcher uses to ensure that the method is reliable and that the conclusions are valid, hence the

terms validity and reliability (Silverman 2000). Criteria for rigour in qualitative research such as relevance, plausibility, and reproducibility acknowledge the ways in which data are produced. The criteria for rigour, as developed by Glaser (1978, 1992) and Strauss and Corbin (1990, 1998) are concerned with the verification, craftsmanship, and effectiveness of knowledge for prediction and control of the method (Hall & Callery 2001). In fact, claims that encompass prediction, control, and change (Hall & Callery 2001) also imply access to knowledge that represents those aspects of life and outcomes that are significant to the study of the participants.

The reliability issue is different from that of quantitative methods, where reliability is present if the testing can be repeated and when repeated give the same result again, and is stable over time (Hoepfl 1997). Morse (1997) argues that, because qualitative theory is by its nature confirmed in the process of development, it fits the empirical world and testing would be redundant. Instead, substantive theories evolve and are modified in response to new information (Morse 1997). Reality changes over time, so it would be quite difficult to find contexts exactly the same in which to replicate the study, but the key is objectivity within the data collection so that when the findings are ultimately presented, they are dependable (Sandelowski 1986). The aim of this present qualitative study was to provide information from a variety of cases to substantiate the final findings, so that the information can be used effectively to predict and plan future study.

Rigour is judged on the explanatory value of conceptual density and scope, which relies on detailed description to ensure credibility (Glaser 1978; Strauss and Corbin 1990). Detailed description is a quality indicator, because this description of the contexts surrounding experiences, and the participants' perceptions of and responses to them, increases the likelihood of reaching an explanatory power (Popay et al., 1998).

In this study, grounded theory is justified by the provision of a detailed, carefully crafted account of the procedure. The processes of the description, definition, and specification of relationships, push the research toward a higher degree of rigour in the handling and interpretation of data. Reliability is determined by the researcher documenting the procedure used and demonstrating that categories have been used consistently (Silverman 2000). The theoretical account not only enhances the researcher's understanding, but provides a means of communicating findings to others, including health care providers and consumers, in the area studied. It becomes the knowledge base for implementing change. This account also enables the researcher to ask questions about the similarities and differences between developed theory and other more general theories in the field, especially with respect to the fit and scope of the research (Hall and Callery 2001). Such an exercise generally provides a perception that some elements may be relevant to, or applicable in, a wider context (Martin and Turner 1986). For example, in their grounded theory study 'Becoming a mother', Rogan et al. (1997) researched the real-world experiences of a group of mothers in order to address problems in the

discipline of nursing, and to assist health professionals to provide high quality care by improving their knowledge.

In conducting this study, the researcher followed the criteria of standards, or rigour in qualitative research. To increase the rigour of the study, activities to increase trustworthiness of the data were incorporated into the study design (Brink 1991) and included: the use of a field journal by the researcher to log field notes and reflexive and introspective ideas as they occurred; careful checking of data codes; triangulation of data; and the use of peer debriefing to identify and maximise distortions or errors in the emergent core category and findings.

Triangulation of data covers a range of collection modes from multiple sources such as interviews, observations or focus groups that are all relevant to the study phenomenon (Locke 2001). The grounded approach advocates the use of multiple data sources converging on the same phenomenon and terms these 'slices of data' (Glaser and Strauss 1967, p. 65). The technique used in this research was by prolonged engagement in interview, checked memos, and field written records (Lincoln and Guba, 1985). However, constant comparative analysis is the set of practices 'defined as the joint coding and analysis of data offering a logic for composing conceptual elements that hinges on their articulation through close reading, comparison and attendant conceptualisation of data' (Lock 2001, p. 45). Peer debriefing assisted in clarifying aspects of data analysis that may have been missed by the researcher and remained in an undeveloped form. The peer debriefers reviewed each transcript and help test emerging proposition to 'keep the

inquirer honest' (Lincoln and Guba 1985, p. 77) and serving as meaning makers. The theory is grounded directly in the data derived from the participants and reflects the levels, dimensions, and conditions of the participant's experience.

Triangulation and peer debriefing were used to improve the probability that findings and interpretations would be credible (Cutcliffe and McKenna 1999). Triangulation involved comparison of findings from one interview to another, between the participants, and with the literature thus lending credibility to the findings (Munhall and Boyd 1993). Discussion with others is a useful exercise. For instance, there may be issues or patterns the researcher has missed which a colleague may highlight. Furthermore, through explaining the thinking behind choices made, and the reason for following one line of enquiry as opposed to another, the researcher can be assisted towards a more reasoned and complete interpretation (Eaves 2001).

Credibility is the naturalistic analogue of internal validity (Lincoln and Guba 1985). To increase credibility, the researcher leaves an 'audit trail,' so that the pathway of decisions made in the data analysis can be checked by other researchers (Lincoln and Guba 1985). Glaser and Strauss (1967) advocate the process of 'memoing' and using the actual words of the participants to provide an audit trail. In the present study the researcher made a note of key thoughts, hunches and lines of enquiry during data collection and these memos served as a form of audit trail.

Other ways of assessing the validity of grounded theory include fit, understandability, generality, and the control of the method (Hall and Callery 2001). '*Fit*' indicates that the theory must fit the substantive area to which it is applied. Silverman (2000) asserts that a theory may not support the existing literature, but if the variation can be explained by substantive differences in the research situation, then the theory can be said to be reliable. This study relates to the substantive area of the young peoples' pathway to initial care. Further research will be needed to determine whether the theory generated in this study is applicable to other situations in the same substantive area.

A grounded theory needs to be '*understandable*' to people working in the substantive area so that they can recognise the experiences described (Strauss and Corbin, 1990). The use of quotes from the interviews helps to convey the reality of the situation and the theory to readers. Similarly, other researchers can follow the events in the study and understand the logic of analysis.

The criterion '*generality*' demands that the theory is sufficiently general to be applicable to a range of situations. The theory is conceptual in nature rather than being based on factual knowledge, that is, the facts change from case to case, but the concepts are more generalisable (Rose et al., 2002).

All the strategies used in this study were devised to gather data from the experiences of the young adults. At all stages, care was taken to ensure that the

study would be credible and that the insights of the participants were faithfully and accurately described by the researcher.

3.2.4.1 Potential weaknesses

The potential weaknesses inherent in the method have been identified as including premature commitment to analytical categories, unnecessary jargon, lack of clarity of key terms (for example, theory, category and saturation) and the failure of a core social process to surface (Charmaz 1990; Wilson and Hutchinson 1996). However, Eaves (1997) argued that, in the latter eventuality, it is still worthwhile to write a descriptive research report so as to offer directions for further development of the study. The underlying assumption of grounded theory is that if the data are sufficiently rich and the analysis thorough then a meaningful explanation will eventually evolve (Eave 1997).

3.3 Data collection

Data are facts or information to be collected as a basis for this study. They are the building blocks to theory and are important for description and initial analysis of qualitative research. The collection of data involved a selection of participants necessary for theoretical sampling. The method used was a semi-structured, open ended interview (see Appendix B for the interview guide) with the participants, so that full descriptions of categories and their links may occur. Aside from gathering usual demographic information, the participants were asked about the illness and their pathway experiences.

3.3.1 The recruitment of participants

The selection of participants occurred by 'purposive sampling' (Patton 1990), that is, sampling where the phenomenon is known to exist. Site selection was based on appropriateness and accessibility of participants, a mixed gender group of young people aged 18-23 years. They were drawn from clients accessing a metropolitan area health service in Sydney, Australia during 2000 and 2001. There were 20 participants, who were recruited from three community mental health centres located in one Sydney Area Health Service. The three health centres are similar according to most characteristics, for example policy and management, multidisciplinary staffing and staff-client ratios. The population of this health area is generally economically advantaged, although there are pockets of higher need. Average income was \$800 per week (Australian Bureau of Statistics 1996).

3.3.1.1 Inclusion criteria

Participant recruitment was based on predetermined criteria:

- male or female adults aged 18-25 years ;
- contact made within three months of a first time referral to the community mental health centre;
- able to describe 'reality' as well as able to give written informed consent and be articulate in the English language;
- able to consent to tape-recorded interviews and follow-ups and understand the potential impact of being interviewed (e.g. that it may, or may not, trigger psychological distress).

3.3.1.2 Participant characteristics

There were twelve females and eight males who were willing to participate in the study and satisfied the inclusion criteria. They were aged between 18-23 years; the mean age was 19 years. All participants except one were single. Six were students, four worked in the hospitality industry, one was an unskilled labourer and eight received sickness benefits. The only married participant was a nurse. Most lived at home, but five participants lived away from home in low cost rental accommodations-two in supported accommodation and three in private rentals.

3.3.2 Procedures

The participant group has been recognised as vulnerable and difficult to access due to the nature of their illnesses (Seeman and Cohen 1998). To ascertain full co-operation from each community centre, the researcher took the following steps:

1. The researcher approached the community mental health centre manager with full disclosure of the purpose of the study, to ensure trust and co-operation.
2. Group discussion occurred with key personnel to provide information about the study and to elicit support in choosing the young adult participants, ensuring that it would not impose unduly on the workload of the team.
3. A meeting was held with the Medical Director to discuss the proposed procedures and protocols, and the use of the centre's facilities and resources, where and when applicable. As a result, rooms were assigned at the centres for interviews.
4. The researcher had the support of one staff psychologist in case of any adverse effects from the interview or for counselling if required by any

participant (Ethical issues are discussed in the next section. For the participant information sheet, flyer and consent form, see Appendix A).

5. Upon approval from the University and the Area Health Service Human Research Ethics Committees, recruitment proceeded. The researcher checked daily with the health centres to identify all newly referred participants who satisfied the inclusion criteria. Potential participants included those seen in the community, on medical wards and outside normal working hours.
6. Information about the study was left with the centre staff who, at their discretion, distributed it to any/all young people accessing the service for the first time. No coercion was used in the attempt to recruit participants; participation was entirely voluntary. The researcher met with individuals who met the criteria, to seek their agreement to participate in the study and in any subsequent follow-up. Full information about the study was provided and discussed.
7. Confidentiality was absolute. If significant new information was uncovered, the participant was advised to confide in his/her doctor or therapist. No serious new issues arose during the interviews. In some instances the interview triggered slight distress or stress, but the participants found debriefing to be all that was required.

In conclusion, in order to enter into the participant's world, the researcher made every attempt to develop a relationship, which was characterised by mutual respect, and concern for the participants' well being.

3.3.2.1 Ethical considerations

This research was conducted in accordance with the requirements of the University's Human Research Ethics Committee and the Area Health Service Human Ethics Committee. Written permission was gained from participating community health centres. No case records, file information, or stored data of subjects were used in this study. Participants were selected according to selection criteria. Only willing participants participated in the study. The written consent of the participants was obtained. Full information was given to participants and confidentiality was absolute.

Confidentiality issues were also respected when transcribing. Tapes and transcripts were coded so that no names could be identified. The tapes were stored in a locked compartment during the transcription process and destroyed at the end of the study; transcripts continue to be stored in a locked place. No one other than the researcher and supervisor had access to original data.

There are important issues of informed consent for those involved in mental health research, as it impacts upon participants with psychiatric disorders. Such participants are viewed as vulnerable. The premise has been that as such participants demonstrate an inability to control or cope with their life (Wilson et al., 1999); by definition, they are subject to the actions of others. This sense of vulnerability and passivity dominates the depiction of this group of participants and, because they have a mental disorder, it is felt they may need protection from research. In fact, plentiful evidence exists that many such individuals do not have

impaired decision-making abilities (Byrne 1999; Grisso and Appelbaum 1995).

The criteria for a valid consent are capacity to consent; being fully informed; preserving autonomy. The notion of capacity implies that a certain diagnosis, such as schizophrenia or learning disability, renders a person unable to consent (Byrne 1999). The human rights discourse assumes the existence of rights to which any person is entitled (Wilson et al., 1999) and no diagnosis should automatically exclude a person from participation in research, as this may contribute to stigmatisation. An assessment of each participant's capacity is preferred (Elliot 1998) because each individual will respond differently to the illness. Autonomy means freedom in the individual's choices. The participants rights were respected with the agreement to participate in this study.

Finally, the researcher planned for the convenience of participants. Small things like flexibility in scheduling and providing convenient meeting times and places were helpful in conveying that the researcher valued the time and energy expended by the participants. Participants choose to participate in research for reasons other than tangible rewards, such as the opportunity to help others (Souder 1992). The participants in this study were willing and appeared to want to share their world with the researcher. For example, John said,

'I hate doctors. I'm sorry, I'm not comfortable with them, they never listen to me, but you are'.

They trusted the researcher to maintain their anonymity and to ensure that the report would not have any unwanted ramifications for them personally, as Peter said,

'Thanks for not using my real name; Dad doesn't know all my stories'.

It has been documented that consumers have found participation in studies to be useful as they feel that their feelings are being validated and acknowledged (Bridgeman et al., 1998), as seemed to be the case in these interviews.

3.3.3 The Interviews

Semi-structured interviews of one to two hours duration were conducted around the issue of the pathway to initial care, allowing considerable flexibility in the scope and depth of the discussion (Polit and Hungler 1991). The researcher's initial approach was informed by previous knowledge, observations and experience, with the aim of ascertaining the participant's perspectives on the topic (Polit and Hungler 1991). The participant's story thus served to structure the interview as it unfolded and, to minimise misinterpretation, the interviewer clarified the discussion with the participant throughout the interview.

Interviews began with broad, open-ended questions and minimal topic control. Probes (prompts) and reflective techniques followed the line of thought to encourage descriptive answers, depending on the participant's responses, to the broad open ended-questions (Jezewski 1989). The purpose of gathering responses to open-ended questions is to enable the researcher to understand and capture the points of view of the participants without predetermining those points of view,

such as through prior selection of questionnaire categories (Patton 1990). These broad open-ended questions helped in developing the ‘thick description’ desired for this study (Geertz 1973).

Detail is important, but an overly structured interview format can hinder data collection, especially so in the early stages of interviewing (Chenitz 1986). The detail of subsequent interviews depended on the analysis that was undertaken of earlier interviews. Hence, interviewing followed a flexible guide, not a rigid or structured format. An interview guide was used (see Appendix B), which the researcher found helpful as a reminder of issues that needed to be addressed.

In the early interviews, participants controlled the direction and specific content of the interviews with minimal direction from the researcher. As the study proceeded, interviews became more focused, and questions modified as the researcher used topic guidance to explore the areas under study, began to test the findings, and to look for areas of commonality and difference, or gaps in participants’ stories. To enhance data collection, the researcher kept fieldwork memos. In this way the context in which the interviews took place, and aspects of non-verbal communication, were recorded (Couchman and Dawson 1995).

With relevant prompts, the interviews focused on the young adults’ perceptions of themselves and their experiences prior to accessing mental health services, their thoughts, feelings, adaptive strategies, and perceptions of the responses of others. Further, the interviews sought their account of their experience of their disorder

and the treatment they received, along with their attitude to health and illness. Lines of inquiry were pursued, permitting a closer inspection of reality, and the researcher explored any theme(s) that became apparent (Minichiello et al., 1990). The researcher found herself becoming involved, to a high level of intensity, in the participants interview and the stories as they told them. Thus, the researcher, throughout the study needed an increasing level of sensitivity to maintain objectivity in the analysis.

Some participants were particularly loquacious and interviews often exceeded the planned time. Two participants seemed to be less talkative in nature than others and thus were more challenging to interview and caused the researcher to wonder if they wanted to withdraw, although they adamantly denied it when asked. Also, the emotional intensity of the experience of interviewing could be high. For example, Peter said,

'People look at you like you're trash when you come from a bad neighbourhood. I had this teacher; he would challenge me and try to humiliate me in front of other kids. It was like every day... so, I hit him. I let him win. Anyhow, they don't expect you to make it. They're just waiting for you to go down. When I took an overdose, no-one asked me why. I was treated like a piece of shit most of my life.'

Following the completion of the interviews, emotional reactions to the procedures

were assessed. None of the participants seemed to have any adverse reactions to the experience.

3.4 Data analysis

Data analysis is the procedural process used by the researcher to illustrate the experiences of participants with mental health disorders in their pathways to care. Analysing data by the grounded theory method is systematic. Each phase in the analysis builds up to the next each phase is necessary to develop a grounded theory (Strauss and Corbin 1990).

Analysis was undertaken concurrently, using the computer software program NVivo 1.1. The capabilities of the NVivo program is designed to aid users in handling non-numerical and unstructured data in qualitative analysis. It does this by the supporting process of indexing and searching. The program helps the researcher to manage and handle data consisting of transcripts of interviews, field notes and memos, and to explore and search the text documents. The program helps to manage and explore ideas about the data, to link ideas and construct theories about the data, as well as to generate reports and memos (Richards 1999).

3.4.1 Open coding

The data from the participants were transcribed verbatim, with all identifying characteristics removed and fictitious names substituted. The process used for analysing the data followed that recommended by Strauss and Corbin (1990). The data were coded. Both Glaser (1978, 1992) and Strauss and Corbin (1990)

described coding as an essential aspect of transforming raw data into theoretical constructions of social processes. Strauss and Corbin (1990) described three levels of coding: open, axial, and selective. They defined open coding as ‘the process of breaking down, examining, comparing, conceptualising and categorising data’ (p. 61).

The process of open coding begins with physically breaking apart each interview’s narrative or observation, line-by-line, into fragments for analysis. This precludes any tendency to assign meaning in a general way, for example, by reading over the data and quickly creating impressionistic ‘themes’ rather than data-specific grounded categories (see Table 3.2 for an example of this process from this research).

Fracturing data into fragments helps the researcher to step back and conceptualise, in a way that transcends the particular interview or situation in which they were embedded. It helps the researcher ‘get into’ data and initiate naming activity, examining for meaning by noting provisional names for each data item. Glaser and Strauss (1967) called the codes substantive codes, because they come from the substance of the data *in vivo*, e.g. words identified by the researcher that the participants themselves have used.

Table 3.1 Conceptualising the data (Construct diagram)

Open Coding:

Intact Narrative:

1. *Something was wrong.... Ump... my friends and I figure ... Um.. I did not realise something... Ump.. around '95, final exam at Uni. (chuckles)...*
2. *My friends and my mum I wished they would talk to me, sometimes I thought they tried to hurt me, comment that's crazy, that what's they said... Ump...right...*
3. *I hated myself, I took an overdose of Aspirin. I thought the drug would put me to sleep and never wake up, but I was vomiting for hours and had to tell my mum.... laugh)...*
4. *The way I was thinking and being down on myself and get very anxious and have anxiety attacks. Like, anxiety attacks. I put it down to me...right...just the part of a normal day. I did not realise that it was an illness and can be treated (chuckles).*
5. *The people around me – family and friends recognised it. They told me that it was not normal and that...whereas (it) the way I was living and reacting to thing which was not normal. They said I should see the doctor and that ...to get help.*

For a long time I had not been doing much at all. I spent my time alone at home ...for months...yeah...yeah...

Fractured Narrative:

- 1-2 *Something was wrong...Ump.. I did not realise ..chuckle...comments like crazy...*
- 2-3 *I wish my friends and my mum would talk to me....I thought they tried to hurt me.*
- 2-4 *I took an overdose....vomited for hours....laugh... had to tell my parents...*
- 3-4 *I was down on myself and get very anxious and have anxiety attacks.....*
- 4-5 *people around me recognised it...they told me I should see the doctor...for help?*
- 5-6 *I spent time alone at home for months...yeah...yeah..*

Similar code phrases are then grouped together to create clusters, which are given labels. These labels became concepts, a slightly higher level of abstraction than the raw data. At this point, in the early stages of concept analysis, the use of concept cards (Martin and Turner 1986) was found to be effective. Concept cards provide a record of each concept created by the researcher, and include the related data incidents from which the concept is abstracted. Incidents accumulated under a concept label are used later to develop a statement of the concept's definition, theoretical meaning, or substantive content. No addition or subtraction of data incidents to a concept is considered irreversible. Later, when working out definitional statements, one either explains explicitly what qualities the incidents have in common or drops from the card those incidents no longer considered illustrative of the concept. For this and other reasons, Glaser (1978) and Martin and Turner (1986) recommend recording each incident in more than one concept category, particularly during the early stages of concept generation.

Concept cards are used for keeping track of the source of each data incident, for ongoing refinement of concept names, and for noting any possible connections with other concepts. This recording on paper allowed the researcher to more clearly 'see' concepts and to recognise relationships early, as compared to the more complex computer program (for an example of a concept card from this research, see Table 3.2).

Table 3. 2. Example of a concept card

Card no. 1		Working label: 'unready'	
Data source and location:		Data incident:	
IV-1 (8-10)		My friend tricked me into the car and took me to the hospital... I was having good time, I thought...	
IV-2 (6-7)		I saw a GP. He was scared out of his wits... gave me a referral to see a psychiatrist...	
IV-18 (10)		... my relationship break up... I think I was depressed, but... I saw a counsellor at 18, but couldn't tell her...	
Links with:		Earlier concept names: 'denial' and 'support'.	

Similar concepts are grouped together to develop categories. Categories are classifications of concepts, and are discovered when concepts are compared with one another and found to pertain to similar phenomena. Categories, then, are of a higher, more abstract order than are concepts. All the concepts are grouped within the category they seem to 'fit' (Strauss and Corbin, 1990). Embedded in this step are Glaser and Strauss's (1967) technique of constant comparison, which is a method of comparing concepts and categories for similarities and relationships that exist among them.

Sampling, data gathering and coding continue until all categories are saturated. Saturation means that all levels and properties of categories seem complete, and that new data adds no new insights to the categories or relationships between them (Glaser and Strauss 1967; Strauss and Corbin 1990). Saturation represents a

closure, by which all data fit into existing categories, and behaviour within the context of a category can be predicted (Hutchinson 1986).

In this study, major categories emerged after the completion of 16 interviews (time frame 15 months). Four additional interviews were conducted until categories were saturated and confirmed and relationships among categories were clarified.

3.4.2 Axial coding

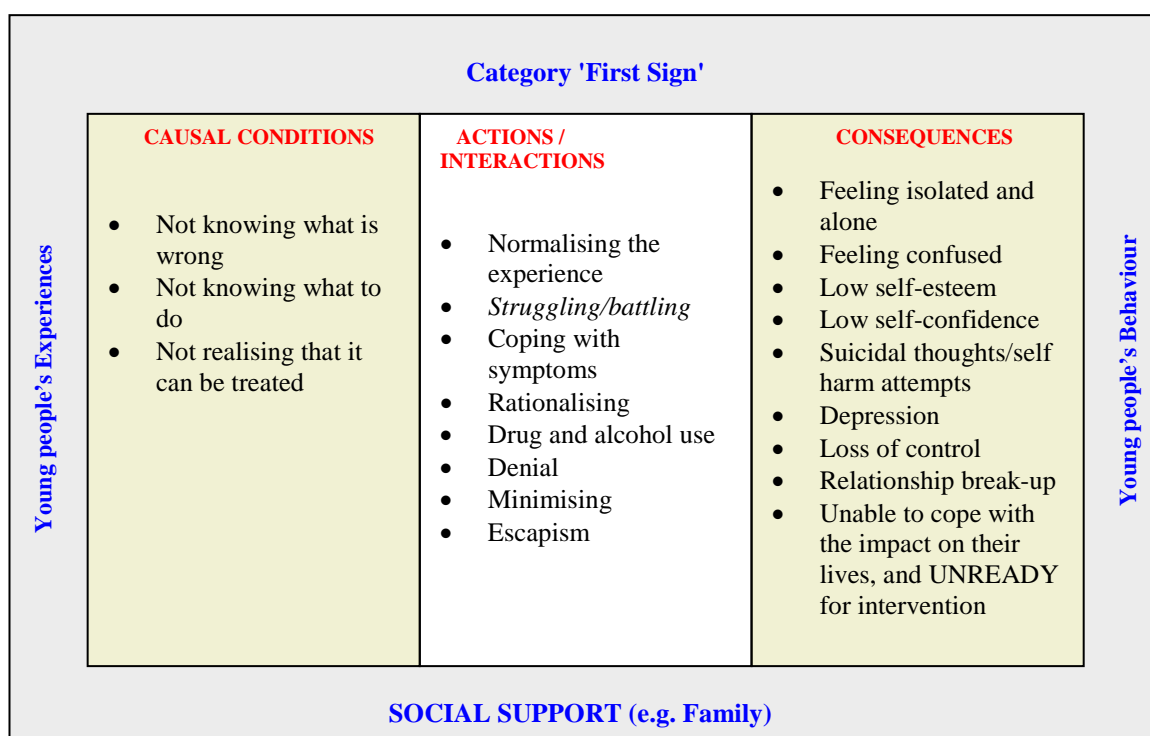
According to Strauss and Corbin (1990), axial coding elaborates upon the nature of categories. Axial coding is the process of relating sub-categories to a category, and categories to each other, around a complex process of inductive and deductive thinking (Strauss and Corbin 1990). Whereas open coding fractures the data into concepts and categories, axial coding puts the data back together by making connections between categories and sub-categories. Properties (characteristics or attributes) and the dimensions of categories are developed throughout the analysis. They form the basis for linking categories and sub-categories.

Axial coding focuses on conditions that give rise to a category (phenomenon), the context (specific set of properties) in which it is embedded, the action/interaction strategies by which processes are carried out, and consequences of the strategies. Each of these features is examined in terms of its links and, according to Strauss and Corbin (1990, p. 96), systematically examined in relation to a paradigm model. This paradigm model develops the categories further (that is, beyond their properties and dimensions) by specifying the relationships between each category

and its sub-categories. The application of this technique is somewhat contentious (Glaser 1992; Locke 2001), but it was found to be helpful in assisting the analysis to emerge rather than being forced.

The paradigm model is used to show the decision-making processes of the researcher, in constructing a reliable, complex and meaningful theory. The technique specifies (a) causal conditions, (b) the context, (c) actions and interaction taken in response to the phenomenon, (d) the intervening conditions that assisted or hindered the actions and interactions taken, and (e) the consequences of the actions and interactions taken (Locke 2001). For example, Table 3.3 shows a paradigm model from this research for the category ‘first sign’, with the sub-categories grouped into three columns. In the left hand column are events or variables which are causal conditions. In the centre are the actions performed by the participants in response to these and, in the right hand column, are the consequences of the actions, which can be intended or unintended. The outer field represents the wider contexts within which individual actions and behaviour take place and which influence those actions and behaviours. In this case, context includes the support systems of family, peers, teachers and health professionals.

Table 3. 3 Paradigm model for the category ‘First Sign’



The following major categories emerged from the data: **first sign** in the early stages of the illness; **recognition** of the illness; **understanding** of symptoms as indicating that one needs help; and **resolution**, when those who have yet to access care successfully finally do so, either voluntarily or involuntarily. These four major categories, which are discussed in more detail in the next chapter, represent a process which participants went through before accessing appropriate care. The paradigm models for these categories are described below, (Table 3.3 illustrates **first sign** and the other paradigm models can be found in Appendix D).

A fifth major category also emerged called **barriers and facilitators** to care; this refers to those processes and factors which the participants identified in their

accounts as speeding or impeding their progress to care. These were often recounted by the participants in terms of particular incidents which prevented or allowed them to achieve a goal or purpose (see chapter five).

In finalising these categories the researcher asked the participants if they agreed with the researcher's interpretation of the findings. Nine of the participants read the same description of the categories without additional explanation or prompting from the researcher. They were asked if the description reflected the processes they experienced. All nine agreed, many adding comments such as, 'that sounds like me'.

The first stage in the participants' pathway to care is conceptualised by the major category called ***First Sign***. The central idea here is the period of time associated with a set of experiences that marked a change from the participants' previous way of dealing with life events and interacting with others. The feelings they experienced at the time were inchoate, characterised by 'not knowing' (what is wrong, what to do), but which were later identified by the participants in their accounts as the onset of their mental health problems. They attempted to handle the onset of unexplained and, to them, inexplicable feelings in a variety of ways; by pretending that all was well, by struggling against them, by rationalising them away, denying or minimising them, or by using alcohol and other drugs.

The way that they handled the causal conditions depended on their social context; the extent to which their feelings and changed behaviours were recognised and dealt with by their families and, to a lesser extent, their friends. Their actions had a

number of consequences for them, most unintended. They experienced feelings of isolation, loss, confusion, low self-esteem, depression and other unpleasant outcomes such as relationship break-ups.

The second stage is characterised by the participants' ***Recognition*** that something was indeed wrong. This recognition occurred either through an awareness of the increasing intensity of their symptoms, or their increased difficulty in coping with life. For example, they deliberately avoided situations they would have previously enjoyed, worried what others would think of them. They felt out of touch with reality and knew it. As a result of this recognition, the timing of which depended on the individual's social, personal and familial contexts, they began to develop a sense of change. Some with supportive social contexts and with personal insight into their problems developed a sense of resilience; they began to seek out information and tried to come to terms with their symptoms in various ways. For others, recognition of 'something is wrong' brought increased loneliness and loss of self-confidence, and they tried to continue with their earlier strategies of denial and self-medication with alcohol and other drugs. For these participants, the consequences were, in many respects, a continuation of their previous experiences, including altered personal relationships, especially with partners. They were less likely to attempt to seek out help at this stage than were the participants whose sense of change included actions (such as seeking information) which allowed them to develop more effective coping strategies.

Understanding is characterised by the participants changing their perceptions of their illness as a result of connecting with others, choosing to accept their help and trusting they would understand. These participants wanted to gain control of their lives by seeking out the right support and professional help, not always successfully, but they found the courage and commitment to keep going. Those participants, a minority, who had failed to develop effective coping strategies, and who continued to experience devastating symptoms and self-destructive behaviours, were more likely not to enter this stage in their progress to care. They did not experience the causal conditions which led to understanding. On their own, they could not take control.

Resolution is the final stage when all the participants accessed care. Some, as a result of their decision-making and help seeking, were able to find positive support and appropriate treatment. Others were defeated by the symptoms of their condition and experienced the trauma of involuntary commitment to care.

3.4.3 Selective coding

According to Strauss and Corbin (1990), selective coding, the last coding process in grounded theory methodology, elaborates on the relationships between categories, with the aim of determining core or sub-core categories. Strauss and Corbin (1990, p. 96) suggested a number of questions, the answers to which would indicate the identity of the core category, which integrates all other categories at the highest level of abstraction. They are: in all of these interviews or observations, what seems to be the main story line, the main pattern or theme that I see happening over and over

again? What category do all other categories seem to be pointing to or leading up to?

Which category seems to be of a higher level of abstraction than the others are?

Which category could the others be subsumed under?

The main pattern or theme in this research which was mentioned most often in different ways by the participants was their struggle to find a way through to appropriate care. The phenomenon under study, the pathway to care (what happens after young people first experience mental health problems) had the characteristics of a maze for these participants. They had to find a way through the **first sign** (causal conditions) of debilitating symptoms which they could not initially understand and which they dealt with poorly by behaviour such as denial, social withdrawal, alcohol and other drug use. The first sign was characterised by the participants not knowing what was wrong and experiencing sadness, fear, loneliness, and self-blame.

The dawn of **recognition** (consequences of the causal conditions) is characterised by the individual developing a sense of change as a result of their illness which altered themselves and their personal relationships. The participants began to develop coping strategies while continuing to experience the distressing emotions and symptoms associated with their illness. They could no longer deny that something was wrong, but this knowledge could be experienced as devastating while at the same time leading to personal growth and the discovery of resilience.

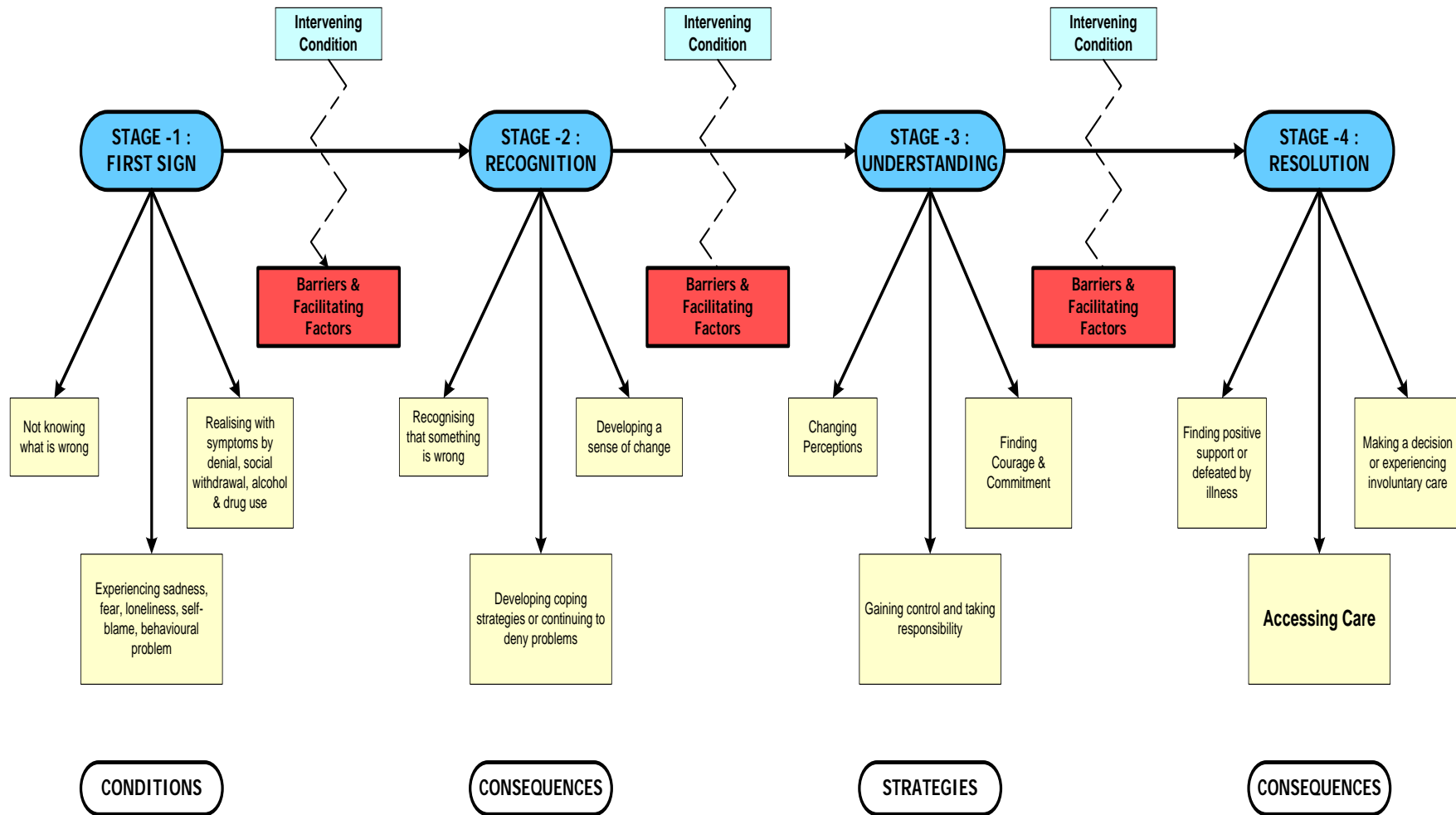
Understanding (strategies for action) is characterised by gaining control and taking responsibility. Many participants found courage and commitment during this stage,

and learnt acceptance. Finally, the participants were able to find a way to **resolution** (consequences of the strategies, both intended and unintended) which is the final stage in the process. For some, this meant that they were able to find supportive care as a result of their determined attempts, while others experienced the trauma of involuntary commitment.

At each stage, **barriers and/or facilitating factors** (intervening conditions), which are to be found in the social, personal and health care environments, could delay or speed their progress. The four-stage process of '**finding a way**' is shown in Figure 3.1 p. 105.

This story line of 'finding a way' is the core category. As this core category accounts for change over time, it is also a **basic social process**. Fagerhaugh (1986, p. 135) emphasises that most but not all core categories will be social processes. A social process is a process which is connected with human beings and their relationship to each other. Fagerhaugh (1986, p. 135) noted that basic social processes should be expressed as gerunds, which means that they should end in 'ing'. Fagerhaugh provided examples such as 'becoming', 'limiting', and 'routing'. Irurita (1996) theorised around a basic social process called 'optimising'.

Figure 3. 1 Four-Stage Process of Finding a Way



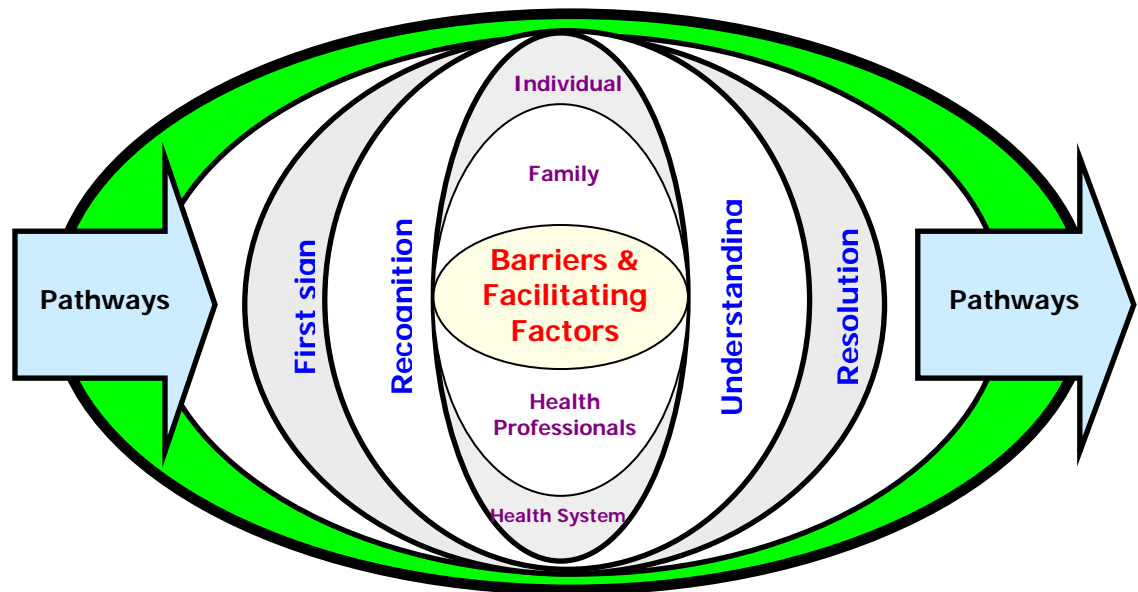
‘Finding a way’ indicates the life-changing process that the participants undergo in response to and as a result of the onset of mental health problems. Not all participants experienced each stage in the process, as will be explained in later chapters, but all at some point experienced barriers which impeded their progress to care, and factors which facilitated their movement from one step to the next. These could occur at any stage of the process depending on the life circumstances of the participants. Although these life circumstances are to some extent peculiar to the individual, there are common patterns and themes, which will allow development of interventions aimed at removing barriers and supporting facilitating factors. Chapter four discusses the stages in the process in more detail and this is followed by an exploration of the barriers and facilitating factors in chapter five.

3.5 Developing a model

One of the intentions of this research was to construct a model from the findings which, unlike existing models, would reflect the experiences and perceptions of the participants as they moved through the pathway to care. As previously stated, the purpose of the model is to assist the development of effective early interventions (section 2.6, p. 65). The model (Figure 3.2) provides a pictorial representation of the ‘maze to care’ through which young consumers must ‘find a way’. It utilises the concept of the four-stage process of finding a way to care and places ‘barriers and facilitating factors’ in the centre, since these may occur at any and all stages. Indeed, in terms of interventions, it is appropriate that the barriers and facilitating factors, which impede or speed young consumers to care, take

centre stage. The model is discussed in more detail, together with its potential applications, in chapter six.

Figure 3. 2. Model of "Maze to Care" illustrating 'Finding a Way'



3. 6. Summary

The aim of this study was to investigate the process of pathways to care from the participants' perspectives. Grounded theory was the method used to research these processes. Grounded theory draws upon a range of theoretical traditions, including ethnography, phenomenology, and symbolic interactionism. The integrating theme running through the theoretical traditions of grounded theory is that the research attempts to uncover the meaning participants attribute to the phenomenon under investigation. In this study that phenomenon was the pathway to initial care.

A central tenet of grounded theory method is theoretical sampling. Theoretical sampling involves sourcing data in order to develop the explanatory theory as it emerges. The content of interviews revolved around critical incidents associated with the process of accessing care, from the participants' perspectives. In the process of grounded theory construction, the researcher made many choices about paths to follow that are influenced both by data, and the researcher's theoretical sensitivity.

Participants also shaped the inquiry. The data were constantly compared, such that the researcher's interpretations and those of the participants were incorporated into the final conceptualisation. Twenty participants whose mean age was 19 were interviewed over a fifteen months time-frame.

With grounded theory, data analysis is undertaken concurrently with data gathering. This process requires the researcher to move back and forth continuously between analysis and gathering data. Data collecting and initial analysis run simultaneously, wherever possible, with the writing of field notes and with transcription of tape recordings immediately after the event. It is like a 'zigzag' process – to the field to gather information, analyse the data, back to the field to gather more information, analyse, and so forth, until the categories of information become saturated and the theory is elaborated in all of its complexity. In this study, the NVivo computer program was used to record and managing data.

Categories are groups of concepts, and higher level categories are those that explain similarities or differences between lower level categories. Two or more lower level

categories can be subsumed within higher level categories. This process results in the emergence of a core category which explains the totality of the phenomenon under investigation. In this study, the core category is also a basic social process called *finding a way (through the maze to care)*. A model of the ‘**Maze to Care**’ was developed from the findings of this research to assist the development of early intervention strategies.

CHAPTER FOUR

THE PROCESS OF ACCESSING CARE

4.1 Introduction

The core category, and basic social process, which emerged from this research has been given the name 'Finding a Way'. Each of the five major categories subsumed under the core category represent an aspect of the process, from the **first sign** of illness, often greeted with denial and incomprehension, through to **recognition** that something was wrong, increasing **understanding** about what is happening and, finally, **resolution**. At this point, effective care is successfully and, for most, voluntarily, accessed. People progress through the process at different rates and, for some, the journey to resolution may be short-circuited at earlier stages by particular incidents or exacerbations of their illness which lead to their commitment to involuntary care.

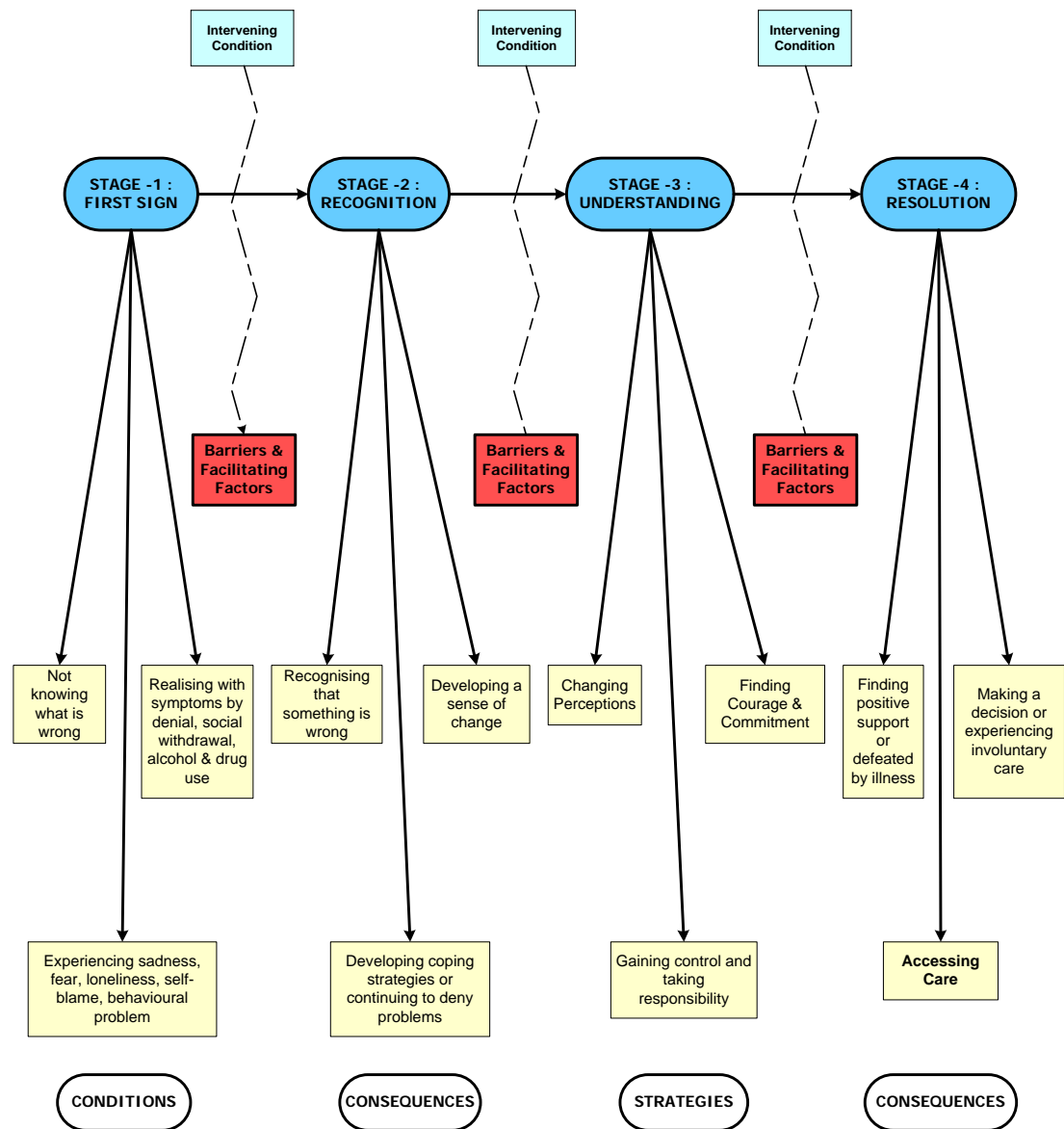
Barriers and facilitators to care, the fifth category, can occur at any stage of the process. They appear at the centre of the model '**maze to care**' which was developed from this research and initially presented in the previous chapter. Barriers and facilitating factors are discussed in the next chapter and the model is discussed in more detail in chapter 6.

In this chapter, each step on the pathway to care is described and discussed using, where appropriate, the participants' own words to allow the reader to enter their

social reality, and also to demonstrate the connection between data and theory.

The process of accessing care is summarised in Figure 3.1

Figure 3.1 Four-Stage Process of Finding a Way



4.2 First sign

‘First sign’ represents the period of time between the initial awareness, or suspicion on the part of the young person that something is wrong and confirmation of the diagnosis. The length of time from first sign to resolution varied from days to years (range from two weeks to 12 years, with a mean of 2.5 years), depending on the progression of symptoms, the problems encountered problem and the behaviour of the participants in response. In this study, the age of onset for the youngest of the participants was eight years old. However, the mean age of onset was 19 years.

Table 4.1 (page, 113) illustrates the progression of each individual. It also shows the high incidence of stressful life events, e.g. parents divorced, leaving home, family conflict and abuse. These are significant factors for this group. These disturbing life events may have been implicated in the onset of their disturbed behaviour. It may also be that these events, especially those which involve relationship breakdown within the family, may be a factor in the individual not accessing treatment early since their support base is fragmented.

The phase ‘first sign’ was characterised by the individual **not knowing what was wrong**. The participants reported being either increasingly concerned about their symptoms or, for some, increasingly enjoying the experience. Symptoms tended to escalate, but the participants were generally unready to seek help at this stage.

Table 4. 1 Duration of progression to care (mean = 2.5 years)

Name	Life-events	D&A	Self-harm	Professional services utilised				Voluntary	Time access
		Y/N	Y/N	Counsellor	GPs	A&E	Crisis-team	Y/N	
Jos	Left home, started new job and partied very hard (was in a manic stage)	Y	N	N	N	N	N	N	2 weeks
John	Grief and loss, studies and work pressure	Y	N	N	Y	N	N	Y	3 weeks
Sue	Drug & alcohol, loss of job (manic stage)	Y	Y	Y	Y	Y	N	Y	6 weeks
Fred	Study, leaving home and arrested by police (drug induced psychosis - robbed the bank)	Y	Y	N	Y	N	N	N	4 months
George	Conflict with parents, left home	Y	N	Y	N	N	Y	N	1 year
Cath	Physical abuse, break up with boy friend, grief and loss (drug induced psychosis).	Y	N	N	Y	N	Y	N	1 year, worse last 3 months

Name	Life-events	D&A	Self-harm	Professional services utilised				Voluntary	Time access
		Y/N	Y/N	Counsellor	GPs	A&E	Crisis team	Y/N	
Jess	Socially withdrawn, parents divorced moved school and home.	Y	N	Y	Y	N	N	Y	1 year
Peter	Parents divorced, moved home, lost job, depressed due to drug used	Y	N	Y	Y	Y	Y	Y	16 months
Cas	Parents divorced, relationship break-up work pressure.	Y	Y	Y	Y	Y	Y	Y	18 months
Nat	Mother depressed, leaving home, grief & loss.	N	Y	Y	Y	Y	N	Y	18 months
Joe	Parents divorced, in a gang and homelessness	Y	N	N	N	N	N	Private first Y & N	18 months
Cathie	Father an alcoholic (physical and psychological abuse), eating disorder and lost of job	Y	Y	Y	Y	Y	Y	Y	18 month

Name	Life-events	D&A	Self-harm	Professional services utilised				Voluntary	Time access
		Y/N	Y/N	Counsellor	GPs	A&E	Crisis team	Y/N	
Abe	Bullied at school, and parental conflict	N	N	N	Y	Y	Y	Y	18 months
Chris	Relationship break-up, left home	N	N	N	Y	N	N	Y	18 months
Mary	Stressful living (illegally in US), worked in the media industry	N	N	N	N	N	Y	Y	2 years
Mark	Car accident, joined the body building industry, lost of job	Y	N	N	Y	N	Y	Y	2 years
Sam	Boarding school, stressed with work and family conflict	N	N	Y	Y	Y	Y	Y	2 years
Laura	Survivor of domestic violence, grief and loss	N	Y	N	Y	Y	Y	Y	2 years

Name	Life-events	D&A	Self-harm	Professional services utilised				Voluntary	Time access
		Y/N	Y/N	Counsellor	GPs	A&E	Crisis team	Y/N	
Nikki	Family dynamics, sexual abuse job stress (modelling)	Y	N	Y	Y	Y	N	Y	2.7 years
Jane	Sexual abuse, mother with mental illness, married, death in the family and of a friend	Y	Y	Y	Y	Y	Y	Y	12 years

4.2.1 Symptoms

For participants, the onset and progression of symptoms was uncertain and erratic.

'I guess when I started to have weird thoughts, like ... it came on very quickly, but it only lasted a week or so, like a fit of rage.' (Laura)

Participants described a variety of symptoms ranging from paranoia to auditory and visual hallucinations, delusions, anxiety and depression.

Interestingly, participants described their response to the symptoms and the illness in term of a 'struggle' or 'battle' and, for some, this was connected to their soul or their faith. Unsurprisingly, they spoke of fear and anxiety.

'Part of the symptoms ... well, it can be very scary ... it was like a battle for your faith. I felt that my whole world collapsed and I felt very anxious.'

(Mary)

'Part of the psychosis was like a battle for your faith, it was a struggle.'

(Joe)

'Well, [the battle's] been exasperating and serious, and quite hopeless I felt at times, and at other times I've experienced highs. I did really well at school ... It wasn't until I was so frightened that I couldn't do anything.'

(Catie)

4.2.2 Coping with symptoms

At the emergence of the first symptoms, individuals tried to implement strategies to deal with them. The strategies included denying anything was wrong; feeling sad and blaming themselves; being fearful and lonely; resorting to substance abuse; and, for some, enjoying the experience.

4.2.2.1 Denial

Research generally portrays denial as a fairly common response to the emergence of symptoms (e.g. Pollack 1995) and this was so for many of the participants. Others may notice the symptoms and realise the young person needs help, before the people themselves. Some of the young people cast around for other reasons to explain away what they were experiencing. While this may be characterised as denial, it also connotes a lack of information or knowledge about mental illness. Denial is the greatest barrier, and is expressed as repudiation of having the symptoms and the need for intervention. Denial, can occur at any point of the illness. Many participants identified denial as a defence when the symptoms emerged.

'I had some idea what was wrong with me, but I didn't want to hear about that. It was real upsetting to me. I didn't want to know.' (Nat)

'There were many possible explanations, a relationship busted up, moved out of home, lost the job, also, I was partying hard, using a bit of drugs.'

(Jos)

Cath initially thought it was okay to have anxiety, but eventually she became afraid to leave the house for fear of having an attack. Feeling depressed, she used marijuana to cope, and unaware that this only escalated her symptoms. Finally, her family gave her an ultimatum to seek help. The parents took her to see the GP. However, it took her nearly a year to finally accept help through her GP.

Cath isn't unusual. Some participants took months or years to 'see' the problem and interpret it as something that required outside help. They tended to normalise the experience, or view it through the lens of a less threatening or more familiar explanation such as behavioural problems, a phase, or the result of substance use. If they suspected that something was wrong they were unable to articulate their experiences, rationalising their experiences or minimising their symptoms. As a result, these participants became progressively more ill with the escalation of symptoms.

4.2.2.2 Sadness and self-blame

Feelings of helplessness, sadness and self-blame were commonly experienced by this group of participants, but not all had the words for it.

'When I was 15, I experienced a series of devastating losses. First, my puppy died suddenly. Then my grandfather, who I was very close to passed away. Soon after, one of my brother's friends died. He was only 17 years old, but he had a weak heart. It was tragic to think someone so young could die. Then my favourite teacher from school committed suicide. I was

shocked and in so much pain that I wished I was dead too. I tried talking to mum about it, but I did not know how to say, “by the way, I’m feeling really sad.” It just didn’t sound right.’ (Jane)

Many explained that, at times, as a result of the symptoms, they felt life was not worth living and contemplated death as an alternative to the end of their living nightmare; five participants did attempt suicide, some more than once.

‘The only thing ... to kill the pain, I thought, was to kill myself - and I wanted to rid the world of the useless creature that I felt I had become.’
(Nat)

‘I used to self mutilate ... since I was 14. When I drew blood, I’d put Perfume on the cuts to cause further pain. Although I thought about suicide, I was not doing it to kill myself - I was punishing myself for being repulsive. But, I did wear a T-shirt that showed the scars, hoping someone would notice. Finally, I tried to hang myself ... [it] came into their [parents] heads that I needed help ... but it would have been better if I had home help ... not the isolation room in the hospital.’ (Cas)

There are many examples of participants’ grief and sense of loss. These include losses in education, employment, relationships, and position in the family, financial stability, self-esteem and time.

'I had to deal with interruptions; it prevented me from fulfilling my life's Hope. Without the depression, I would have become more academically prepared for life.' (Nat)

4.2.2.3 Fear and loneliness

Some participants began to isolate themselves, as they no longer felt comfortable around others, but their behaviour could be misunderstood.

'I was paranoid and scared of going out. My father thought I was pretending ... said for me to just snap out of it. You have a family and friends who love you.' (Nikki)

'I couldn't move from bed and cried continually. I was aware friends were in the house. I became shaky and hot and felt like my heart would explode. I just retreated to my room and stayed there.' (Jess)

'I was transformed from a happy person into a new person, crippled with doubt, confusion, and unshakeable sadness. Too terrified to get out of the house, and the nightmare of depression lasted for months. I kind of knew I needed help, but I was scared to find out what it was.' (Cas)

'I know what schizophrenia is, my mother has it ... I was scared it may pass on to me. I would rather die than have to cope with it.' (Jane)

Some said the fear and loss of control that occurred as a result of voices made it difficult to function, others felt depression might be the cause of having to struggle with symptoms of low self-esteem, self-destruction and low motivation. The questions that identified 'fear' and 'loss of control' consisted of 'why do I feel this way?'

'My depression is from having a low self esteem. You feel like, you can't do anything right, you're hopeless ... helpless, and you're just going to rot in a chair for the rest of your life.' (Mary)

These symptoms also made it difficult to be around people. Participants also talked about not being able to sleep, or not being able to talk to others about their experiences for fear of 'being locked away'. As a result, participants often withdrew into themselves. However, some found creative ways of coping with symptoms.

'As I couldn't sleep, I found myself writing in my diary. It started with possible suicide notes, then dark poems and letters. Putting pen to paper was the only way I saw of getting rid of the feelings that were eating away inside me.' Catie)

'I was lucky that I had always had an interest in art and journal writing. The diary and my paintings externalise the inner communications that I'm constantly engaged in. That integrated the experience of the illness into my

life, and helped control its symptoms. In a diary, I was able to have a dialogue with myself in which I examined and expressed some of the pain, surprise and joys.' (Sam)

Not all participants were able to displace their distress in such a creative way, some were destructive.

'I was in a gang, it's cool ... and stole cars, I have so much rage and wanted to smash up everything.' (Joe)

Those who experienced auditory hallucinations could also end up doing something illegal. For example, Fred discussed an incident in which he attempted to rob a bank because the voices directed him.

'I heard the messages in my head that the bank belonged to Mafia, and had taken all my money ... I went to the bank with a knife and demanded that she [the teller] give back my money. I nearly got shot by the police.' (Fred)

Some participants felt 'disconnected' from their known self -

'It's like I'm watching a film. I feel void of all emotion, as if my real self is comatose. I see black, and I am running. I don't know from whom or what, but, it's fear that has provoked this flight.' (Mary)

4.2.2.4 Substance use

According to Hall (1996), mental disorders complicated by substance use and abuse often precede, are intertwined with, or are a result of, struggling with mental health problems. Substance use and abuse occurred in fourteen of the participants, with various degrees of seriousness. For some, alcohol or drugs were used as a form of self-medication in order to cope with the symptoms of the illness, though it is difficult to know whether drug use developed because of peer pressure or self-medication. Four participants said that substance use gave some relief to the symptoms, allowing them to go to school, work, or function in the day-to-day role.

For others, substance use and abuse in the form of hallucinogenic drugs preceded the emergence of the symptoms of the mental health disorder. For example, Peter described his descent into the illness as beginning when he took hallucinogenic drugs to assist him in achieving a spiritual ‘quest’. He explained that it was not the quest itself that brought on the symptoms, but rather his subsequent lack of judgement in adhering to extreme fasting, physical work, and the use of narcotics.

‘The quest itself was not insanity, but where it led me was insanity when I look back now.’ (Peter)

Other illnesses combined with the mental health problems experienced by the participants to make the struggle even more difficult. For example, Mark, who

had chronic pain at the time of interview as a result of a car accident, was using a combination of analgesics and alcohol to help with his pain.

'I was an alcoholic, but I think a lot of that was the frustration of having pain and the Physeptone didn't do the job, so [I was] self medicating myself with alcohol as well, you know.' (Mark)

Sometimes, the use of drugs led to dire consequences.

'I used a bit of drugs ... I was so ill that I acted out. I threatened my mother with a knife, they had to call the police. I was homeless after that.' (Joe)

While the participants may not understand fully about the effects of alcohol or other drugs, they often utilised them initially to ease anxiety, depression, or loneliness. The use of these substances ultimately served to complicate decision-making. The study by Drake et al. (1998) showed that there is considerable evidence to suggest that people with co-morbid disorders do less well than people with a mental disorder alone. While the presence of an alcohol or other drug problem is a barrier to care, finding a way to effectively manage them facilitates accessing care for the mental illness, as will be discussed in later chapters.

4.2.2.5 Enjoyment

Three of the participants enjoyed the symptoms, because being manic can give the effect of a high energy level. For example, Susan described that she did not want to let go of experiences that she had come to 'own'. She had an inner fantasy world and it fascinated her.

'Not all symptoms are bad, mine were very enjoyable. I could see colours very vividly. I lived in a fantasy world where I was Madonna. I booked into an expensive hotel and travelled.' (Sue)

Abe was fascinated with the experiences and unwilling to give up her 'good and crazy bits' for fear of their being devalued by others who might want to take them away. Jess enjoyed some of the symptoms until they got out of hand.

'I was a bit socially withdrawn ... [but] did not recognise it at the time. Some of the symptoms, I did enjoy the effect, like colours were more vivid. Do you know what I mean? Not all the symptoms were negative, so I did not see it totally as an illness ... until the only colour I saw was red like blood. My mum took me to see the doctor. He said it's not normal ... but what is normal?' (Jess)

4.3 Recognition of the illness

The 'recognition' category is characterised by the young person developing a sense of overwhelming change in themselves and their life, altering

relationships in particular with their family, and experiencing tremendous emotional distress, a continuation of the powerlessness, loneliness and loss they started to feel when first dealing with their symptoms and didn't know what was happening. Now, they cannot continue to deny that something is wrong and, while this knowledge can be experienced as devastating, it can also lead to personal growth and change. The importance of family and peers, both in a negative and positive sense is emphasised (this is discussed in more detail in the next chapter).

4.3.1 Distress and resilience

The sense of loss and grief the participants experienced when they began to realise something was wrong was intensified when they recognised that what they had was a mental disorder. They described becoming painfully aware of the chronic trajectory of their illness.

'I've lost my hope and dream of having a family and a career. I mourn about long term-loss, a future loss. With this, the mentally ill person ..., that mourning never really quits.' (Mary)

However, growth in personal attitudes and individual coping strategies are also elements of this recognition phase. These are often dependent on an empathic family and on peer support. Because of the fear surrounding mental illness, people in its early stages need to trust and to receive reassurance from their families, and from their peers.

'The only way I would go anywhere was if my mother took me, since my mother was the only person I trusted. If she suggested something, I would say OK.' (John)

A positive and determined attitude was continually indicated to be critical in the participant determination to deal with their illness.

'If you've got depression, get yourself out of the house, do something, you know, and just start somewhere. I think I helped myself a lot, really, more I think than any of the programs do. I read lots of self-help books.' (Peter)

'It's difficult at first, but gets easier over time ... optimism is the key.' (Fred)

'I think with an illness your mental state has a lot to do with how you respond to getting better. ... I don't think I've ever underestimated my ability to do whatever I put my mind to ... and I think that overrides the depression.'
(Jess)

'This is only my first breakdown ... I hope to have full recovery from it.'
(Peter)

For some participants, however, there was a realisation that their difficulties are likely to be a permanent part of their life.

'I've learned to live with it, this is me.' (Jane)

There was evidence in the data that older participants were more able to face their problems directly.

'As you grow up you start to realise about responsibility. I realised it was me that had to do something, that nobody could magic it away.' (Nat)

4.3.2 Delaying recognition

When others did not recognise the problem, the participants were left to figure it out for themselves. Many did not recognise their illness, and hence did not search for help, until they could no longer 'get by' in their roles, underscoring the importance of others in assisting young people to recognise that they need help.

'I was working as a chef in a restaurant. I was not bad at the job ... but I was creating problems ... got orders mixed up ... [after that] I got a job as a dishwasher, because I could get by without causing too much problem.'
(Sam)

'Even when I was hallucinating like crazy, I still worked and paid the rent. I kept up a good front and I don't think anybody I worked for ever knew.'
(Jos)

Enlightenment could come from an unlikely source.

'I saw the movie of Jack Nicholson ... he played the person with a mental health problem ... I had suspected for a long time that something was wrong with me.' (Nat)

4.4 Understanding

Understanding is conceptualised by the participants changing their perception of their behaviour and by an increase in their understanding that they needed outside help. This category is characterised by the participants searching for explanations and, hence, understanding of their constantly recurring symptoms. Accepting the nature and reality of the illness frees people to focus on making improvements in their lives. Understanding is concerned with finding ways to regain control, changing perception and expectations; and deciding to take responsibility for their illness. This leads to increased decision making ability, independence and autonomy. For understanding to take place, participants needed both commitment and courage.

4.4.1 Gaining control and taking responsibility

This aspect of understanding includes the difficulties that occur until the symptoms become unmanageable. The impact of the illness is significant on the individuals' lives during this time. Fear and loss of control may have to escalate to the point where seeking help, or being made to accept help, may be the only option. For some, this means that, through personal growth and the

development of more effective coping strategies, they become receptive to sources of information and assistance.

'There has been maturing through the course of the illness. As you grow older you can help yourself more.' (John)

'I started to think, oh God help me, I've got to change my life, somehow. Look where I'm now, you know.' (Catie)

Joe describes his experience as a 'sorting through' process that allowed him to make choices.

'You can make a decision to continue on doing the same thing over and over again or stop it.' (Joe)

With this statement, Joe acknowledged his increased understanding of his symptoms and his changed perception of his behaviour. On the other hand, some may never willingly accept help and intervention is needed by legal means. Five of the participants were involuntarily admitted, others were able to accept personal responsibility for their care with support from families or friends.

4.4.2 Commitment and courage

Committing is a sense of obligation to engage upon a course of treatment to alleviate symptoms. By this stage, many of the participants were well on their

way to accessing effective care, beginning the search once they had recognised that they had a mental illness. They could make judgements about whether their present care was appropriate or not, but they continued to be determined to find what worked for them.

'I just was determined that I was going to be the one that recovered ... the therapy cost me heaps, but I was getting nowhere.' (George)

However, there were no false expectations.

'There are no magic pills to take this pain away. It's for you to deal with.'
(Jess)

While accepting the illness, a positive and determined attitude was continually indicated to be critical in this phase. Sam talked about the importance of not focusing too much on trying to discern which aspects of functioning are due to the illness, because this was counterproductive.

'You just quit fighting. It takes energy to keep up those fences like that ... forget about it.' (Sam)

George likened the committing part of the process to learning to live with any chronic illness; it requires commitment to treatment, but also acceptance.

'I just try to get some acceptance that this is how I have to live my life.'

Courage is defined as the participants' strength in this process of understanding the illness. It was having courage that motivated the participants to seek help and, finally, to successfully access care.

'I used to grub for an existence. I think I have had this illness for some time now, and I have been utterly destitute many times ... I've managed to survive, but since I had the courage to walk into the Community Health Centre ... my life changed for the better. Now I am staying in their respite house and seeing a psychiatrist.' (Joe)

'I can't say enough, learning about the illness is so helpful. Don't worry about where it came from, whether it is hereditary in your family ... learn to accept it. Don't be ashamed because it is nothing you did.' (Nat)

4.5 Resolution

All of the participants were interviewed after they had successfully accessed care, but this 'resolution' was, for some, the end of several attempts to seek care, while others were successful on their first attempt. Five of the participants experienced the trauma of involuntary commitment. The 'resolution' category thus includes two sorts of experiences, one positive and one negative. The more negative aspects result from how the participants accessed the mental health system, the nature and the speed of the referral. The

positive aspects involved the participants making a connection with supportive people who respond to them in a positive and understanding way; accessing sources of information regarding their illness; and being able to effectively access the health system. The factors, which influence this part of the process are discussed in more detail in the next chapter.

4.5.1 Duration of progress to care

As mentioned earlier, among this group of participants, the length of time from first sign to resolution varied from two weeks to 12 years, depending on the individual and the contributing factors in their lives (see Table 4.2). Sixteen participants had contact with two or more health professionals for extended periods, mainly GPs, but without effective resolution.

It appears that for acute psychotic symptoms the time delay before successfully accessing care was reasonably short, between two weeks to two months. In Jos's case, for example, it took only two weeks to access care (admission), because Jos was in a manic stage and there are specific policies and protocols in place to identify and treat such cases. This is similar to findings from research on acute mental health problems (psychosis) by Lincoln and McGorry (1995) and Mcnaughton (1998).

John and Sue each reported that they received help fairly quickly because they had private health insurance. They were admitted promptly via GPs to private clinics within three to six weeks of displaying 'bizarre behaviour'.

'I saw that in having a psychotic [episode] was good for me as well. It got me to treatment sooner. Well, I couldn't have gone much lower than that. I would have killed myself or someone ... my mum took me to see the GP ... I must have scared her out of her wits. The GP rang ahead to a psychiatrist for me to be admitted the next day.' (John)

In cases of depression or non-specific mental illness, however, the time delay was longer. For Catie, Nikki and Abe, easy access and non-specific symptoms made consulting a GP the first option. Yet each said they were frustrated that their GPs failed to detect that they were ill, despite a picture of evolving symptoms and several consultations. Nikki took nearly three years to finally be seen by a psychiatrist. Catie took over 18 months after being seen by two private psychologists and being unable to pay the fees after she lost her job.

'I knew from when I was little, 10 years old, that I can't cope with pressure well. I panic instead of trying to work through things and my depression is intertwined with anorexia and bulimia. I was not formally diagnosed. I saw a few psychologists through the years, but they never mentioned that I have depression. I have only experienced since last year or so. I have an abusive father so it's just coming through now. I went to community health because I couldn't work any more ... they said I have depression.' (Catie)

Jane took twelve years to access effective care. She speculated that growing up with a parent with a chronic mental health problem made it hard to distinguish

normal from abnormal behaviour and she was reluctant to acknowledge her own feelings because of her poor experiences with mental health professionals. She had taken a few overdoses and was treated at the emergency department. After the last overdose she went to see her chaplain who convinced her to see a counsellor. Her reluctance to seek help diminished when she was no longer able to cope.

Interestingly, it seems symptoms such as social withdrawal and paranoid delusions were also associated with a delay in presentation. For example, it took Joe, who suffered from both depression and paranoia due to marijuana use, 18 months to find help.

4.5.2 Involuntary care

An issue raised by participants was the impact of their initial experience of the hospitalisation process, especially if it included aspects such as police involvement, a seclusion room and an emergency ward. McGorry et al (1991) have argued that the experience of scheduling which is traumatic and coercive can deter people from seeking help in the future. Police were involved with five of the participants, a quarter of the group. Coercive services, such as involuntary hospitalisation, reinforced their powerlessness, as indicated by the use of the word 'drag'.

'The most frightening thing was not knowing what's going on, and to find myself being dragged to the unit in the police van.' (Cath)

'I didn't feel right for years and saw few people ... I was so sick I pulled a knife at home ... the police came, and I was dragged to hospital.' (Joe)

Several comments suggest that the young adults in this group felt that the comfort and empathy they felt should be associated with the hospital or community team were not apparent at the time when they were most vulnerable and most needed understanding. As George said after his involuntary admission,

'You suspected that there was something so fundamentally wrong with you that you couldn't hope to be a real human being, ever.' (George)

Others suggested that many people with mental health problems lack the contacts, the assertiveness, and the persistence to gain timely access to care. In the majority of cases, people with mental health problems have little means for negotiating their care. For example, in acute psychosis, the person is not operating within reality and the intervention is based on the professional skill and ability of those who assess him/her.

There is a risk that professionals may fail sufficiently to take into account the perspective of the consumer and carers in their intervention but, on the other hand, the participants genuinely lacked knowledge about services available to them, and opportunities for informed choices about intervention and care options.

4.6 Summary

The core category of this study is finding a way, which has four inter-related processes. *First sign* begins when individuals struggle with the beginning symptoms of the illness. They often try to escape from them through denial, and alcohol and other drug use. They experience fear, loneliness, sadness and self-blame. *Recognition* of the symptoms as a sign of a disorder sets the stage for change, and is much influenced, both positively and negatively, by family and peers. *Understanding* entails the involvement of support systems, discovering information regarding the illness, personal growth, the development of coping strategies, and having the courage and commitment to help oneself.

Resolution means effectively accessing care. At this point, the participants' lives have been made unmanageable by the illness, and they need to gain control or to have control imposed on them. For some, the process is relatively straightforward, but others experience many barriers along the way. For some, the process is short-circuited by involuntary admission. The barriers which impede progress to care and factors which facilitate movement through the process are explored in more detail in chapter five.

CHAPTER FIVE

BARRIERS AND FACILITATING FACTORS

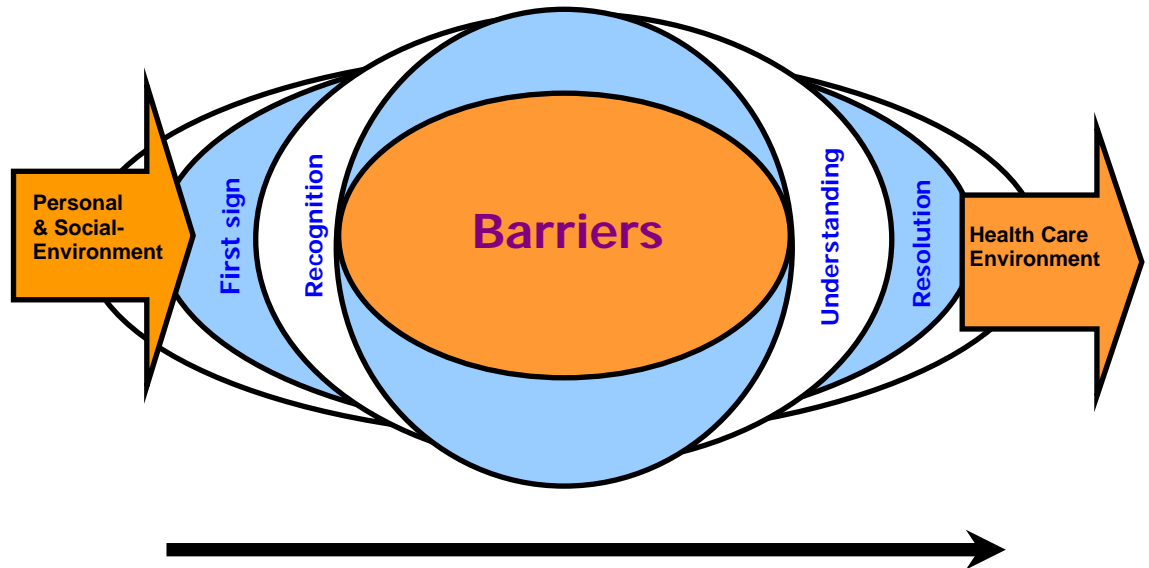
5.1 Introduction

Barriers are the phenomena that delay young people experiencing mental health problems from accessing health care. The phenomena include individual and family barriers, and barriers encountered in the health care area, which may be system barriers or health professional barriers. However, there are also facilitating factors which allow movement from one stage of the process to care to the next. To some extent, both barriers and facilitating factors are peculiar to the individual and depend on their unique circumstances, this is demonstrated, for example, by the wide variation in the length of time it took participants to progress from first sign to resolution, but there are common experiences and common responses which allow patterns to become apparent. This is important since, to be useful, the theory must indicate when and what type of intervention would be appropriate. Barriers to care need to be identified and, as far as possible, removed or attenuated; facilitating factors should be assisted and strengthened.

This chapter is organised into two parts; dealing with relationships with family and friends, and negotiating access into the health care system. It is argued that lack of knowledge about mental illness continues to be widespread, as is stigma. Further, the way health care is funded and organised can lead to access barriers for some. As a result, young people may not be able to access care until they are very sick, and this problem is compounded by a perceived lack of expertise of some health

professionals (see Figure 5.1 and 5.2).

Figure 5.1 The Maze to Care Model showing barriers delaying access



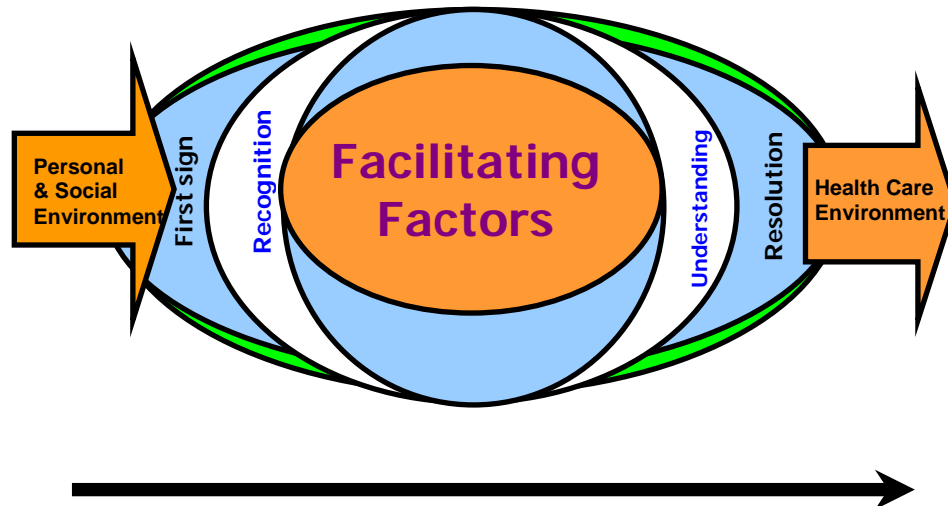
Personal and social environments include:

- Stigma surrounding mental health
- Lack of knowledge of symptoms
- Lack of family and peer Understanding
- Confusion with 'normal' behaviour
- Experience of sexual abuse
- Alcohol and illicit drug use
- Denial, fear and isolation
- Inability to articulate distress
- Fear of appearing weak or different to Peers
- Negative life experiences, e. g. death and relationships break-up

Health care environments include:

- Consumers not taken seriously
- Poor assessment and referral
- Lack of co-ordination of services
- Poor experiences at A & E departments
- Fear of lack of confidentiality
- Perceived lack of professional knowledge
- Involuntary care admission traumatic
- Lack of timely and appropriate information

Figure 5.2 The Maze to Care model showing facilitating factors assisting access



Personal and social environments include:

- Trusting and supportive Relationships
- Symptoms recognised early
- Appropriate care sought
- Personal resilience

Health care environment include:

- Supportive health professionals
- Good experience of crisis teams
- Prompt referral (private sector)
- Appropriate and timely information

5.2 In the beginning: supportive and non-supportive environments

Ideally, all adolescents and young adults would live in supportive family environments where the symptoms of mental illness could be quickly picked up and dealt with appropriately, where friends stayed loyal, and the health service was always responsive to their needs. The reality for many in this study was quite different. Families may mistake the early signs of mental illness for ‘normal’ behaviour, because they expect people of this age to be moody or difficult, but

consider that eventually they would come through it. As a result, and because the young people themselves often did not realise that they needed help, nothing was done for some time until symptoms worsened and could not be ignored. Lack of knowledge about the symptoms of mental illness remains widespread in the general community, of which the participants and their families are a part.

Undoubtedly, and the literature supports this, young adults whose family or friends realise that help is required achieve access to care quicker than their less privileged counterparts. However, alcohol and other drug use can complicate matters, as can sexual and other abuse within the family. Even where families are generally supportive, they may fear a diagnosis of mental illness, perhaps because of previous experience within the family or, more generally, because of stigma. The young adults themselves may express these views. Even when a problem is identified as serious, knowing what to do and how to obtain help may constitute significant barriers (Brown, 1995; Weiner, 1999).

5.2.1 Relationships

The influence of significant people, such as parents and partners, in individuals' lives is paramount during progress to care. As has been mentioned, it was frequently others who saw the importance of symptoms, and recommended (or took) the young people to see a health professional, though the person concerned may have taken a lot of persuading if they were denying that their experiences and behaviour meant that they needed care. Cath, as was seen in first sign, eventually

had been made to see a doctor by her parents, but it took more than a year for her to accept that she needed help. Friends can also do this job.

'I had partied very hard ... My friend tricked me into the car and took me to the hospital ... things got ugly and I was committed. I was having a good time [in a manic phase], I thought.' (Jos)

Jos now believes that his friend contributed to his good recovery, but not all friends were so loyal. Most participants said that some friends stayed with them through the illness but some 'drifted away'.

'Well, the friends that I had prior to my breakdown pretty well have left me and they didn't want to continue in a friendship relationship with me except for maybe one person.' (Abe)

Some parents initially put difficult behaviour down to the normal mood swings and moods of adolescence. They got angry (Nikki's father thought she was 'pretending', for example), or accepted it as best they may, but it meant the pressure to see a health professional was not there and a delay occurred in treatment intervention.

'I knew there was something wrong, but I could not put my finger on it. I was pretty ignorant about the whole thing. My parents thought I was being difficult.' (John)

'No one knew I was sick, my grandparents thought I was just plain lazy.' (Chris)

Joe said that his stepfather considered him to be a *'lazy, spoiled brat, a wayward bum'*, because he could not maintain his employment. He also felt that his mother never really accepted the fact that he was mentally ill, and just thought that he was going through a *'bohemian phase'*.

The behaviour of some participants would have been hard to cope with as they took out their frustration and despair on those nearest them. They could be violent, as when Joe threatened his mother with a knife, and their relationship with their parents could break down completely when these sorts of incidents occurred. In hindsight, participants were able to describe what they had done although, at the time, they could not control their behaviour.

'When I was 17, I became more erratic. I began to lose my conscience. I took every bit of pain I was feeling out on my parents. One night, mum was crying, asking what she'd done wrong, can she help. I said I hated her ... I felt nothing even though I could see her pain, and felt sick satisfaction at what I'd reduced her to. I'll always feel remorse for that night.' (Catie)

As Dixon (1996) has pointed out, the family influences beliefs and values about mental illness. Again, this could be a positive or negative factor for the participants.

'In our family ... just like everything else, you just cope, that's how I've learned to live with it, it's always been that way.' (Jess)

'My family believed in churches, not doctors ... and I thought I was just nuts, and I didn't think there was anything you could do about it.' (Joe)

'In my family everybody's very self-sufficient, it's like you do not talk to other people about stuff, you sort it out yourself.' (Jos)

Family dynamics often influenced the extent to which parents made decisions for their children, or allowed them to make their own. This could delay or expedite help seeking.

'My dad is the decision-maker at home. I don't mind listening to friends, but ultimately dad has to okay it.' (Mark)

For some participants, family members encouraged them to seek treatment, called them regularly to inquire about their well being, and assisted them when they could not get out of the house due to anxiety or paranoid symptoms. Sometimes just being available to talk and listen, without being judgmental, was enough.

'She's [sister] really contributed immensely to my well-being and the recovery is a gift that family can share; it's no shame being ill.' (George)

'He [husband] really cares and contributed immensely to my well-being. He is

the only one to stand by me, my mother is the type that worries about what others people say about me.' (Jane)

Sometimes the participants' expectation of others was too high, but their realisation of this led to personal growth and maturity.

'I also struggled with the feeling I had to justify my condition to people so they could sympathise. At first I was so angry and frustrated that people couldn't be more supportive, but then you can't expect people to know how bad depression is. I accept that it's not easy for friends to come to terms with the fact that I have a mental illness without forming a judgement.' (Catie)

5.2.2 Awareness of stigma

Stigma is a negative concept associated with a particular phenomenon, for example, mental illness. It may inhibit objective self review as one may not wish to be associated with the negative connection of mental illness. A more recent definition by Link and Phelan (2001) states that stigma exists when elements of labelling, stereotyping, separating, status loss and discrimination co-occur in a power situation that allows these processes to unfold.

There is a degree of awareness among participants that whereas physically ill persons usually elicit sympathy, mentally ill persons are negatively valued and discriminated against (Cook, 1995; Fink and Tasman, 1992).

'There is a shame attached to this condition. Why can't people normalise the

experience like a physical illness, like... you're having a heart attack and working together to get the best treatment? All of a sudden it goes bang ... you're stuck with it for the rest of your life.' (Catie)

Interestingly, private institutions can be seen as places where stigma is less likely to occur than in the public system, and where control by the consumer is more likely, but this may not be the case.

'I first got help from the counsellor who referred me to a private hospital, to avoid stigma and let me have control over my problem, but they [hospital] discharged me because I didn't want to take medication. I was later admitted to a public psychiatric hospital.' (Joe)

Joe said that it was his family rather than the community, which labelled him 'mentally ill'. This undermined his confidence and challenged his control over his illness. Catie had the same problem, exacerbated by her experiences of sexual abuse.

'My problem is sexual abuse. Mother would take me to see counsellor at the hospital about my problem at school, but never talk about my abuse or depression. I was told that mental illness is bad. I grew up with this attitude that it's shameful to be a nut-case.' (Catie)

In the present study, some participants were uncomfortable around others with a mental illness, appearing to buy into social stereotypes. They felt that they were not like 'them'.

'Meeting with other people with the illness may not have been helpful to me because I was uncomfortable around people with mental illness. It makes me depressed more.' (Laura)

However, while diagnosis can have a negative impact as a label, many participants talked about the relief they felt when they were told what they had. Subsequently, they could gather information and learn more about their situation.

'It is very stressful not knowing ... since then, the reward is tremendous in self-esteem and self-liking ... the psychological benefits are tremendous.' (Jane)

'There was a major turning point and a change in my life when I saw this GP, she told me I'd got depression and it can be treated, she actually put a label on me ... I felt relief that I'm not just being lazy and felt drained all the time. It was a relief. I felt like it was something I could live with.' (John)

It may be unclear to professionals what constitutes the most appropriate response. Some professionals empathise with the consumers by avoiding psychiatric labels and services that they consider may be 'damaging' for the consumers (Markowitz, 1998; Fink and Tasman, 1992). For some young people, crossing the boundary from a medical to a psychiatric setting as a consequence of referral may incur feelings of guilt or shame (Fink and Tasman, 1992).

5.2.3 *Being a young adult*

At this point in their lives, young adults are subject to peer pressure and the desire to conform or to fit in. This can lead to the wish to cover up any troubling symptom they may be having. Males in particular may not want to be seen as 'weak' by admitting to difficulties. Their use of one of the first lines of defence, school-based counselling, may be affected. Other school-based approaches, such as suicide prevention, also tended to be discounted by the participants.

Some participants suggested that someone who talked about their problems would be seen as 'a hypochondriac or something', as a 'bit of a bore' or as 'somebody who goes on a bit', and that they risked becoming an outcast. They made comments about feeling 'lumped in' with the 'losers', or their fear of being teased by peers as having 'a weak personality'.

'You expected me to raise my hand and walk across the playground to see a counsellor, that I had these bad thoughts ... what do you think [would happen] when I returned to the class?' (Mark)

However, some were able to get beyond this perception.

'If you need help then you're quite strong, because you've got the nerve to go and ask for it.' (Jos)

A wide range of comments from both female and male participants suggested that it was much harder for young men than for young women to discuss problems or feelings.

'You'd feel a bit wimpy going to tell your mates and saying, I've got this problem ... they'd probably laugh at you.' (Fred)

Many female participants shared this perception of gender differences concerning emotional expression and the discussion of personal issues.

'I think boys tend to keep their feelings inside more than girls, you know.'
(Mary)

'[Young men] feel they have an image to keep up with everybody - nothing bothers me, I've got no problems or anything.' (Jane)

Some made clear their expectation that if they disclosed a problem to a counsellor, then they would be expected to agree with him/her and that counsellor would want to take over.

'Counsellors just see thing totally differently. They're not willing to listen and take on a kid's view, and the expected responses from them include, 'You got yourself into this, sort it out yourself', and 'What did you go and do that for? - that is a stupid thing to do.' (Mary)

Among this group of participants, some were not in favour of the idea of peer-based education, for example to address suicide prevention in school.

'It's good to have suicide prevention in school, but my experience was that the information at school hasn't reached where it should go.' (Cas)

'The frustrating thing about it is that funding is concentrating on schizophrenia. There are no early intervention things for depression ... school based Interventions are useless.' (Jane)

Although some participants were reluctant to associate themselves with a mental illness, they suggested ways that were more successful for them, such as, stories, tapes or having consumers visit and talk about the illness in a positive way.

'Personal stories help, like the ones you can get off the Internet.' (Joe)

'The information should be more about what is mental illness. Maybe it should be a component in school about a developmental component and what is mental illness as well as connection with drugs, how they can lead to mental illness, and they should do a better job with kids. Kids do discuss a lot among themselves and find out about different issues, often the information are better than information supplied by school. If I had the knowledge, possibly ... I possibly [would have] got help earlier.' (Peter)

5.3 Negotiating access to care

The health care system can appear complex to the outsider and, decidedly, not user-friendly. There are a range of practitioners, agencies and institutions which

operate more or less independently. Lincoln and McGorry (1995) study suggested that some professionals are loath to refer their clients to the psychiatric system, as they do not perceive it as preventive or effective in nature. Delay in contacting services until a crisis arises is particularly common, at times leading to emergency admission.

Service quality is experienced as variable, with the skilful professionalism of some contrasting with the lack of care and attention by others. Using this complex health care system made the participants anxious and at times they were unable to manage themselves.

'My mother had to navigate the system for me. She is my gateway.' (John)

Again, this underlines the importance of supportive family, and the problems in accessing care which can arise when support is not available.

'I kept going back and phoning my mum to say something was wrong, but she wouldn't believe me ... [later] I rang her again to say my thoughts were jumbled and I was having trouble figuring out what was real and I was scared. She told me to go to the hospital, but I couldn't get myself there.' (Cath)

Other participants, who have supportive families, feel that they can return home and get support.

'I told them [parents] that I had this attacks, and did not know what to do the

day before and then I left my flat, did not know where I was going or when I was coming back. Mum said I should go home. They try to help me ease my burden, day to day [things] that I've to do, like paying the bills. ' (Chris)

Participants discussed the positive effects of linkage with supportive professionals (not necessarily health professionals) and facilities.

'One of the best places that I've been was [Youth Health] ..., because they treated me well, the staff empowered me and help link me with the appropriate provider.' (Jess)

'When I was 15, didn't know what to do ... I went to see my school chaplain and he said I should see someone at the community health, and he took me there.' (Jane)

5.3.1 Finding the right professional

The health system is a human web, a community of people whose job it is to help those in distress. Some did this to great effect, but participants were very clear in their identification of professionals who were unhelpful, hurtful or ineffectual. Many participants saw the GPs as having a key role in the initial pathway to care. Most of them had visited the GPs as a first port of call, but found the encounter did not lead to action or an adequate response, and further delays still occurred, these making the access process longer.

Another point made by the participants was that health care professionals tended to lack specialist mental health expertise. These professionals could minimise or downplay the significance of the problem, or fail to do proper follow-up and referral. Garralda 's (2001) research supports these findings.

'At one interview, I was told I have schizophrenia, the doctor kept saying 'there's no hope, there's no hope'. I took the overdose the next day.' (Fred)

'Any information about my circumstances of coming from an abusive mother and going to an abusive relationship should have been taken into account when he [doctor] assessed me ... Basically hospital is just a holding facility ... no one offered any counselling, and I didn't know about it. It's like you need two psychiatrists. One for medication and another for talking.' (Sue)

'The problem was ... I can't seem to get help ... it is a big frustration to find GPs who are appropriate for an incest survivor program ... they don't have the skills. [I had] a lot of feelings of being shuttled from doctor to doctor, place to place, you know, a lot of frustration, a lot of anger, a sense of futility, for my mum and myself ... another thing that has happened is that I keep losing counsellors ... I just kept being switched from one to another.' (Jane)

Many participants talked about the importance of a professional responding to them in a positive and understanding way. They explained that it is very important

for health professionals to listen, try to understand, and to respond to their experiences and symptoms, and for them to be allowed to have choices. Others talked about the importance of personal qualities, sound knowledge and having good diagnostic skills. All of these would help make accessing care to be a more positive option.

'[Health professionals should] take a global and holistic approach, you know.

Try to treat the person and not the illness. All of these things tie into treating a person, you know, it's a lot more than just writing a prescription for antidepressant. If I like the person ... I would go back to see them.' (George)

Some people felt that their GPs were not treating them aggressively enough, and were giving ineffective medication and intervention. Others felt that they were not given enough explanation as to the diagnosis, biological basis and prognosis of the illness. Most said that the GPs were too quick to write out prescriptions or referrals, when what was needed at the time was a sympathetic ear and information. Some participants reported trying to seek help from health professionals many times, consulting GPs or just wanting information, only to have their concerns dismissed. The participants described an array of experiences in the search for answers to their distress, and barriers thrown up by providers added to their own fear.

'I remember lots of forms of dismissal, with little input or information from me.

Or go away - you're not interesting enough. Several times in my life I've gone trying to find help, knowing that something's wrong and not knowing quite what, only that I know I don't want to feel lousy anymore.' (Jane)

'I felt like crap, went to see the GP when I was 18 and he gave me the script. It was at one of the medical centres, you know what I mean. He just wanted to get me out of there quick. He gave me the script for an anti-depressant.' (Cas)

A fear that confidentiality would be breached could stem from previous experiences when health professionals had not respected their wishes. For example, Jane described her experience with a school counsellor with whom she had discussed her abuse,

'He said 'Do you think you should tell your parents?' and I said 'No, definitely not, I do not want them to know' ... he kind of kept on about telling my parents. I really didn't feel equal enough to say, 'No I don't want them told' ... then I thought it was too late anyway, because I'd told him ... he got my parents into school and told them ... and it was horrible.'

Apart from GPs, other access points to care are emergency and crisis teams, and Accident and Emergency (A & E) departments. While emergency teams were seen as responsive, A & E departments were not.

Emergency mental health teams were identified by many participants as being responsive in the participants' search for care. This is especially so when the team is presented with a person with acute psychotic symptoms, as acute psychosis is considered a serious mental problem needing urgent medical care (McGorry et al, 1996). Cath (was in acute psychosis at the time) stated,

'My father rang the mental health centre ... she [person spoken to] recognised the urgency, so she put him in touch with the crisis team who came to the house and did the assessment. They were very efficient, they phoned for the doctor to see me straight away.'

Paradoxically, because of a lack of mental health resources (see chapter two), some emergency and crisis services may discourage referrals to them at a less severe stage or phase, thereby increasing delays and late presentations (Lincoln and McGorry, 1995). There is a prevailing attitude amongst some healthcare providers about the severity of the illness necessary for admission. Many consumers become disillusioned and do not return to the health care system, or return under more dire, involuntary circumstances.

When they had tried to access care through Accident and Emergency Departments, the participants reported feeling that the staff often underestimated the severity of the situation.

'Emergency was a very dehumanising process. I was waiting for hours ... not a good place for someone who has a mental problem ... some people just got up

and were leaving. I ended up in ICU with all the other emergencies, and was referred to as 'one of the psychos' by one of the staff.' (Nat)

As evidenced in other research (Lorenc and Branthwaite, 1993), long waits for assessment decrease positive self-care decision making. Long waits suggest little respect for consumers' time and this aspect explained why consumers leave prior to seeing professionals.

5.3.2 Public versus private care

Some participants felt that the private system was more sensitive to their needs than the public system. In the private system, for example, there is no seclusion, patients can be admitted quickly according to specialist consultants, they can stay longer for their care and the environment is less threatening. The private institutions only accept voluntary patients and assure confidentiality. The drawback, of course, is the need to have adequate private health insurance.

'The clinic is better than public hospital. I was there a long time having ECT treatment, the nurses were supportive, I had time to arrange my discharge. I don't think I would be treated as well in a public [hospital] ... also, I don't have a label, and no one knew I was at the clinic.' (Nikki)

'Sometimes I wonder if I am getting quality care [in the public system]. There are no luxuries and minimal care, also I've this file following me every where I go.' (John)

5.4 Summary

This chapter, dealing with barriers to care and with facilitating factors, has emphasised two areas:

- when the participants are dealing with families and friends;
- when they are negotiating access into health care system..

Family and friends may not know the best way to broach the subject when faced with mental illness for the first time. This may be due to lack of knowledge about the symptoms of mental illness, which remains widespread in the general community. Some families have difficulty differentiating between the early symptoms of mental illness and ‘normal but difficult’ behaviour which they expect from young people. In addition, young people may be made fearful by their initial experience of the illness, especially when positive support from family and friends is not available. They, and their families, tend to accept the stigma, which still accompanies a diagnosis of mental illness.

One issue for some is the trauma associated with finding care: police involvement, the emergency ward and isolation in the hospital. Another barrier is presented by some health professionals themselves, which can result in ineffectual treatment. While this in part relates to the unstable profile of the early symptoms of the illness, participants noted a number of other issues such as limited assessments, and failure to elicit key information. This may relate both to their own inability to describe their own symptoms in concrete terms, and the lack of flexibility and persistence shown by health professionals during the assessment process. This can

result in a failure to detect a mental health problem or a substance abuse disorder. Many consumers become disillusioned and do not return to the health care system, or return under more dire circumstance, such as involuntary care.

Facilitating factors are the positive aspects that allow movement from one stage of the process to the next. An important factor was the positive support of family, friends, professionals and healthcare facilities. The participants saw this as critical, because positive support helped them to recognise and deal with the effect of the illness.

Information was not always gained through direct personal contact, however, but could come to light through other means, for example internet websites. School-based interventions may be seen as threatening for young people who have a desire for conformity and acceptance by their peers.

CHAPTER SIX

DISCUSSION AND CONCLUSION: THE MAZE TO CARE

6.1 Introduction

The pathway to care can be thought of as a map of a person's journey into care, that is, an itinerary of personal experiences and events in the process of accessing care. The benefit of understanding this process is to shed light on how young people experience their illness, seek help, and ultimately access mental health services. There are many studies concerned with accessing care, but these studies focus more on care after consumers come into contact with health care services (see chapter two). This present study has explored, from the perspective and understanding of a group of young adults, the process they undergo from the first sign of their illness to successfully accessing care, the aim being to open up possible solutions for earlier intervention.

This grounded theory research resulted in the emergence of a core category, and basic social process, called 'finding a way'. As well, a model has been developed from the findings which conceptualises the phenomenon (see chapter three). Rather than using the more usual term pathway to care, the model has been called the 'maze to care model' to more accurately reflect the experiences of the participants. The name comes from the remarks of two participants.

'It's like a maze...incredible...difficult to know where to go, what to do. You waited for hours and they said "this service [adult mental health] is not for you". I was almost 18. I went to another, but it's a crisis service. They said "we don't do counselling for drug and alcohol."'
(Peter)

'I'm not kidding...talk about a maze. Have you ever tried to get into the mental health system? You have to be a raving lunatic before they will see you ... I still see myself running around in a box looking for a place to exit.' (Joe)

While these quotes refer to the dealings of some of the participants with the health care system, which is experienced as complex to negotiate and unhelpful, this research showed that family and social environments are also important influences on the journey to care, particularly in the early stages of mental illness when the struggle to make sense of what is happening and to know what to do begins.

In this chapter, the achievement of the aims of the research, its significance and contribution to the literature are discussed. The Maze to Care model is reviewed and utilised to identify potential points of intervention, where this research indicates that present endeavours are proving limited. Throughout the chapter, comparisons are made with the literature to support the findings.

Suggestions for further research are made, and the limitations of the research are discussed.

6.2 Achievement of the aims of the research

This research, as stated in chapter one (1.3), had two aims, both of which have been achieved. The first aim was to explore the experiences of a group of young people who had recently come into contact with mental health services for the first time. The purpose was to identify events and incidents critical to their decisions to seek this care, factors that helped or hindered them, and the nature of the support or otherwise that they received during this time. This was to be done from their perspective, to investigate their reality. It sought to document *their* 'pathway to care'.

The rationale for this study was that information about the early experiences of young people with a mental health disorder accessing care is scanty. The majority of information and theories focus on the care pathway once the consumer has accessed care (Macnaughton, 1998; Lincoln and McGorry, 1995), by which time some consumers may have had the mental health disorder, as this research has shown, for a number of years. This means the possibility of optimal outcomes is diminished leading to the probable development of chronic mental health disorders. Further, most research to date has been dominated by quantitative methodologies which aim to generalise to the population rather than investigate experiences in depth and which focus on the concerns of the researcher rather than the researched.

The second aim was to develop a ‘pre-care’ model that explains what happens before a young person accesses the mental health service. The purpose was to turn the attention of health professionals to the early recognition of problems, and to lead to intervention that could be situated within the philosophy of the young person. This model is discussed below.

To investigate the phenomenon ‘the pathway to care’ and to identify the process of care access, the researcher utilised a grounded theory approach in order to understand the young peoples’ experiences from their perspective, including the difficulties and significant points of their journey to care. The understanding of this journey or process will provide the knowledge to enhance current health care practice, including health promotion activities, by means of the development of the pre-care model.

The study addressed two research questions:

- What was the pathway like for young people, how did they understand what was happening to them?
- What were the extent and nature of delays in diagnosis and treatment?

This research showed that concept of a ‘pathway to care’, a term used frequently in the literature to refer to either what happens once the consumer has accessed care or to the developmental pathway of the illness itself, is a misnomer when applied to what happens at the outset. The term suggests a smooth transition to care along a defined and known route, but the participants

did not experience such a pathway. The maze metaphor used by some of the participants more accurately reflected the experience of all.

‘Finding a way’ through this maze to care, the core category and basic social process which emerged from the participants’ accounts, involves the active accomplishment of a number of complex and interconnected tasks. The participants had to learn about their illness and themselves, deal with changes in personal relationships, and seek out suitable professional help in an often hostile social environment. These are all difficult propositions for young people experiencing mental health problems.

Participants attempted to cope with this problem of finding a way to care through a four-stage process (see chapter three, figure 3.1). The stages which emerged from the data included a) **first sign** in the early stages of the illness, often involving denial or fear, and self-medication with alcohol or other drugs and characterised by not knowing; b) **recognition** of the symptoms as a sign of mental illness, indicating that one needs help; c) **understanding**, discovering information about the illness and its impact on themselves and others; and d) **resolution**, when appropriate care is successfully accessed.

The journey to resolution may be short-circuited for some at earlier stages through involuntary commitment after a particular incident or exacerbation of the illness. These participants were less likely to enter the stage of understanding in their pathway to care. Finding a way for them required the

active interventions of others (see chapter four). At each stage, **barriers and facilitating factors** are the phenomena which either delay or assist movement from one stage to the next. They are to be found in the personal, social and health care environments (see chapter five and discussion below).

6.3 Significance of the thesis and its contribution

This thesis is significant and contributes to the literature in a number of ways. One is in the area of research methodology. Better understanding of the phenomenon of the pathway to care, and the process of finding a way, has been achieved through the methodology used in this study. Quantitative designs have overwhelmingly dominated research in this area (see chapter two) and, as a result, few studies look at the experience of mental health problems from the consumers' perspective. A grounded theory approach focuses on how people view their circumstances, how they interact and how these processes change (Wilson and Hutchinson, 1996). The four-stage process of finding a way which emerged from the accounts of the participants is the result of employing this methodology and demonstrates the efficacy of grounded theory to investigate this phenomenon. 'Finding a way' indicates the life-changing process that the participants underwent in response to and as a result of the onset of mental health problems and accurately reflects their lived experience.

This study has allowed us to appreciate the complexity of the pathway to care for young people experiencing mental health problems. Other research has focused on discrete parts of the pathway to care, notably the barriers to care and

the outcomes from delayed care, but by focusing on *process* this research has demonstrated the interconnectedness of problems which must be overcome and issues which must be faced by young people. This research indicates that the pathway to care must be thought of as a multifaceted journey, commenced in ignorance and confusion but, if young people are able to call on personal resilience, family support, and helpful and knowledgeable health professionals, completed successfully; they are able to find a way through the stages to care. While some factors assist young people through the process, others can impede and these are found at all stages and can occur simultaneously. As a result, some participants experienced the trauma of involuntary commitment.

The findings of this grounded theory research are of direct relevance to health professionals. The model of the maze to care, discussed below (6.1), which is derived from the findings of this research, more accurately reflects the experiences of the participants than existing models. Hence, we can have more confidence that the model can be used to assist the development of effective early interventions, which is its purpose.

Qualitative research is rare in this area as mentioned above; none is available from Australia and none utilises the full grounded theory protocol. For example, Williams and Healy's (2001) Welsh study 'drew on' grounded theory in terms of data collection and analysis but not theory formation and Macnaughton's (1998) Canadian study explored themes but did not discover a core category (see also chapter two). This present study confirms many of the

insights uncovered by these qualitative research studies but it also significantly extends them by its focus on process and its inclusion of contextual sensitivity. Williams and Healy's study, discussed below, illustrates this point.

Williams and Healy looked at a similar group, that is, people facing mental health problems for the first time, though not specifically young people and in a rural rather than an urban environment. The authors focused on the participants' perception of what had caused their mental health problems and on the strengths and status of those beliefs, rather than on their experiences of finding and accessing care. The authors suggest that people actively attempt to make sense of what is happening to them, but that such beliefs do not form a coherent explanatory model 'but rather as a set of possibilities, which provides a framework for the ongoing process of making sense and seeking meaning' (p. 473). They concluded that belief and experience are unstable, and characterised by uncertainty.

While these insights, particularly the instability of experience are confirmed by this present study, Williams and Healy's more psychological study did not, as this one did, incorporate the social context of the illness experience, in particular the interactions of the participants with family, friends and, later, health professionals, in an often stigmatising environment. These interactions impacted on their ability in the first instance to recognise that the problems they were experiencing were mental health problems. This 'not knowing' by the participants and, frequently, by their families, is probably the most significant

finding of this research since it is from this causal condition that much else follows, including many of the delays in seeking care. The process of ‘finding a way’ begins at this point. The participants’ initial attempts to make sense of their experiences, to find a way to interpret them, and the actions they took in response had specific consequences for their health, for themselves and for their relationships with others. Once recognition occurred, while uncertainties remained, they had to continue to find a way and to develop strategies which would lead them to access the care they felt was appropriate for them. Not all the participants succeeded, the reasons for which are discussed in the following section.

6.3.1 Personal and social environments

The discussion in this section focuses on the personal and social environments of the participants, and on their experiences of the health care system, which the study indicates may either throw up barriers to care or facilitate access. This is followed by a discussion of potential points of improved intervention.

While most participants had difficulty recognising initially that they were experiencing symptoms of mental illness, their progress to recognition, understanding and resolution was influenced by their immediate family and peer environments and by the general community environment in which they were embedded. Ideas about ‘normal’ adolescent behaviour, unhelpful family dynamics, the desire not to seem different, and the stigma attached to the mentally ill, made the onset of symptoms and what they might mean a time of

fear and isolation for some of the participants. Other negative impacts included experiences of sexual abuse, the use of alcohol and illicit drugs, and traumatic life events such as relationship breakdown and deaths within the family or peer group. At the same time, the ability to communicate their distress effectively was compromised by their illness and by their fear of acknowledging it. However, where symptoms were recognised for what they were by supportive family or friends, the process of persuading the young people that something was wrong, and that they needed help, could begin. Some young adults also had more resilience than others and are able more actively to seek care, to find out what was wrong with them, and to see a future for themselves. Of course, the type of mental illness they experienced affected these behaviours.

The perspectives of the participants and their families may differ in understanding symptoms, and accessing care strategies. Strategies may be independent or linked in a variety of ways, and related to the degree of understanding or misunderstanding of mental illness and health care. For example, three participants enjoyed having the symptoms, thus seeking help deprived them of this enjoyment. Such misunderstanding constitutes a problem, resulting in postponing access to initial care and creating a barrier to health care. Similar phenomena were discussed in the studies of Williams and Healy (2001); Lincoln and McGorry (1995); Strauss (1994). In other words, there is no clear and direct relationship between the young person with a mental illness, understanding of symptoms and accessing care. As the Maze to Care model

suggests (Figure 3.1), a variety of mediating factors is involved in a complex process of interpretation.

Five participants of this study group experienced negative life events such as sexual abuse, physical abuse and emotional abuse. Reports into regard to sexual abuse however have been given less public focus. Apparently only seven per cent of all abuse cases are reported to the public (Fergusson and Mullen, 1999). Yet, it is increasingly apparent that there is a correlation between sexual abuse and suicide (Fergusson and Mullen, 1999), as well as leading to massive decompensation and failure in the ability to cope with and adjust to future life stresses. This study highlights study participants who show a high degree of low self esteem, hopelessness, and conflict behaviour which is often expressed in violence against self (self harming in many of participants), relationship break ups, alcohol use and suicide ideation.

The Commonwealth recognises the need for a national agenda on youth suicide and youth sexual abuse. Unfortunately, the federal agenda is geared more towards preventing suicide among previous attempters (Fry et al., 1999). Even though an increasing number of counselling and therapy programs exist in New South Wales, many young people perceive that not enough has been done in order to increase public awareness or implement provision of effective treatment. If this had been done statistics of abuse would be lower and not increasing in numbers (Western Australia Government, 1994). This study informs and reflects the concern of young people on these mental health issues.

One of the main concerns may be the reluctance of the young person to reveal the existence of their problems through fear of how others might then view them. They hold to the belief that others may regard them in a negative manner, that they were 'weak' individuals, possessed limited self-control and could not either solve their problems or suppress their emotions, lacked 'inner strength' and that they were incapable of coping with life issues. These findings support the Manktelow (1994) concept of 'discreditable attributes' in that individuals regarded themselves as having attributes that were potentially stigmatising. The participants were consequently involved in a process of attempting to conceal their problems or reduce their significant problems to minimise perceptions of the severity and duration of symptoms. As some of the male participants in this study expressed, their gender may have affected their ability to get help early.

The stigma issue is arguably most relevant in mental health where the application of a label of 'mental illness' may attract stigma (Markowitz, 1998). Stigma have applied where there is a perceived mismatch between 'virtual social identity' (the stereo typed attributes of another we make in social interaction, which are transformed into normative expectations as to what individual 'ought' to be) and 'actual social identity'. The dilemma for the individual is in how to avoid the possible application of stigma, and how to manage it once it has been applied. Indeed stigma can effect their decision to consult a health professional or raise the issue of illness with anyone at all. The discriminatory policies regarding the treatment of mental disorders are

based on persistent stigmas about psychiatric disorders and outdated myths about the efficacy of treatment (Glass, 1995).

The findings support the perception that stigma is still widespread in the community, and that information about mental illness is minimal. This is surprising given the efforts of government and non-government agencies to address these issues in recent years. Stigma itself may be either 'felt or 'enacted' (Cutcliffe, 2001), indeed felt stigma may be regarded as more disruptive and problematic than enacted stigma. Felt stigma, however, is more difficult to address as its origins remain internal and thus pervasive. Stigma it has been argued, like many cultural health beliefs, are supported and influenced by the media (Cutcliffe, 2001). Ongoing media debate over whether mental illness or chronic fatigue syndrome is a biological or psychological illness has highlighted how mental health problems continue to be publicly stigmatised, thereby perpetuating felt stigma. This raises the question as to why mental health problems are not able to be discussed by the health profession and general community in the same way as physical health problems are discussed.

Young people typically experience a wide range of social problems, pressures and conflicts, all of which vary in complexity and in severity of consequences. The participants of this study were no exception. From these experiences, they develop reasoning skills and social behaviours, learning from the outcomes they experience. However, young people with problems such as depression, anxiety,

loneliness, and social withdrawal perceive and process social problems differently from those who are 'normal' or those with externalising problems such as aggression (Erwin, 2002). They are more likely to select negative alternatives behaviour to social problem such as alcohol abuse and isolation (Adams and Adams, 1991). Victims of abuse and self-harming often feel powerless to control or influence their lives. They are also pessimistic about experiencing positive social outcomes (Haines and Williams, 1997). Protective factors within individuals and their environment, such as a positive relationship with parents can act as buffers against negative outcomes such as risk of alcohol abuse and low self-esteem (Aseltine and Gore, 2000). The participant group exemplified all these issues.

The participants did not experience school-based prevention, education and counselling services as useful. Partly this was the result of not wanting to seem to be 'losers' by going to the counsellor. The desire to be 'normal' and be like their peers is very strong, as is the fear of stigmatisation. Other participants found they could not relate the information presented to them and preferred other avenues, such as the Internet. Some participants had concerns about confidentiality.

An element of peer pressure is the internal capacity of the individual to handle the pressure and make positive decisions (Erwin, 2002). The 'pressure' comes from the conflict between desired social outcomes, such as a relationship or status with peers, and developing values that effect one's self-esteem. It can be seen as a conflict or a struggle between this need to fit in with one's values and the possible

outcomes. It seems plausible that young adults are reluctant to seek help outside their normal informal support network. The difficulties of this group seeking help with personal or emotional issues are echoed in the findings.

6.3.2 Health care environment

The health care environment is a complex one to negotiate for young people experiencing symptoms they do not understand, or distress they cannot effectively articulate, especially if they do not have supportive family or friends to help them. The participants tended to feel they were not taken seriously, or given the information they wanted, or appropriately referred to specialists. This was seen to be easier for those who had private health insurance. Those who did manage to find a supportive health care professional whom they trusted spoke positively of their care.

When experiencing an exacerbation of their symptoms, the participants had negative experiences waiting in Accident and Emergency Departments where they could be viewed as less urgent than those with physical illnesses. Non-specialists were often seen to lack knowledge and understanding. Crisis teams were experienced as supportive but, of course, their situation had to be very poor to warrant such intervention. Those with alcohol and other drug problems, as well as a mental illness, were particularly ill served as these conditions were the province of separate services and the young person could fall between them. Police involvement when dangerous situations occurred, were traumatic and shocking.

Participants reported that primary care providers, especially general practitioners often fail to identify their mental health problem. Many participants had to return many times for consultations. This claim is in line with research studies of Muhlbaure (2002) and Garralda (2001). In relation to interactions with health care providers, the majority of participants stated that there were significant problems in communicating with providers within the health care system, noting that providers often did not listen or failed to provide important information. However, when there is positive interaction between providers and young people, the former respond more readily and progress quickly through to successfully access appropriate care. The participants in this study offered insights into their relationship with trusted providers, often expressing notions of a caring perspective from their provider, but further study needs to be undertaken to understand more fully this complicated relationship and its implications to service provision.

Some participants in this study five of whom came into care involuntarily) discussed the fear associated with the initial experience with mental health system intervention. Involuntary care may be initiated due to barriers in detection at an earlier stage and problems/symptoms increase to a point where emergency care is necessary. The process of involuntary care may increase their problems, adding to their primary symptoms with post-traumatic stress disorder (McGorry et al., 1991).

The ethical dilemmas related to control, autonomy, independence, privacy and freedom of the participants needs to be examined for ways of lessening the emotional impact of the first experience with accessing care. However, there is the need to balance individual rights against the ill young person's inability to comprehend the consequences (often dangerous) of their own behaviour against health care providers, community and family. Police involvement may not be necessary if mental health agencies were involved (Mcnaughton, 1998), but crisis team and staff resources are not always available in all Sydney areas, and non-existent in more remote rural locations, whereupon family and providers must rely on the police as a means of transporting people into care. Such an approach could amplify societal norms about mental illness and discourage young people entry into care. For those young people who do require emergency care, there is a clear need for the mental health system to develop strategies that minimise the need for police involvement. The capacity to do assessment and intervention on an outreach basis is crucial, as Sharfstein (2000) prefers to term 'compassionate coercion', in getting young people into care. Ideally mental health care should be an integral part of health care services, whether in the community or general hospital.

Statements generally expressed by the participants portray a fairly common response to the emergence of the symptoms, with a pattern of recognising a problem, seeking assistance, and having concerns negated, this may be related to systems fragmentation, consumers-centred service co-ordination, and policy (Hiersteiner, 1999).

6.4 The maze to care model.

The maze to care model has two dimensions (see chapter three, page 107). The horizontal dimension represents the time taken by the young adults from the onset of symptoms, through the stages to the successful accessing of care. The vertical dimension represents the barriers and facilitating factors which impede or assist progress through the process. These may occur at any of the stages and are therefore placed in the centre of the model. They are guides to possible interventions which may speed up the process of accessing care for young people with mental illness.

The complexity of the young peoples' experiences is indicated in the model by the oval lines and concentric circles that surround and delineate the different stages, rather than by the more usual arrows which would imply a more un-problematic progression than is really the case.

The model differs from those discussed in chapter two because it focuses on the pre-care rather than the post-care environment and is orientated towards the perspective of the consumer rather than the health professional. It also differs from behaviour change models which have been used to predict behavioural choices. Instead the Maze to Care Model directs the focus to broader social and systems interventions which would enhance the capacity of young people and their families to recognise the symptoms of mental illness and to access appropriate and timely support. It also demonstrates that failure to access effective care is not the result of personal or social factors alone, but is compounded by failures in the

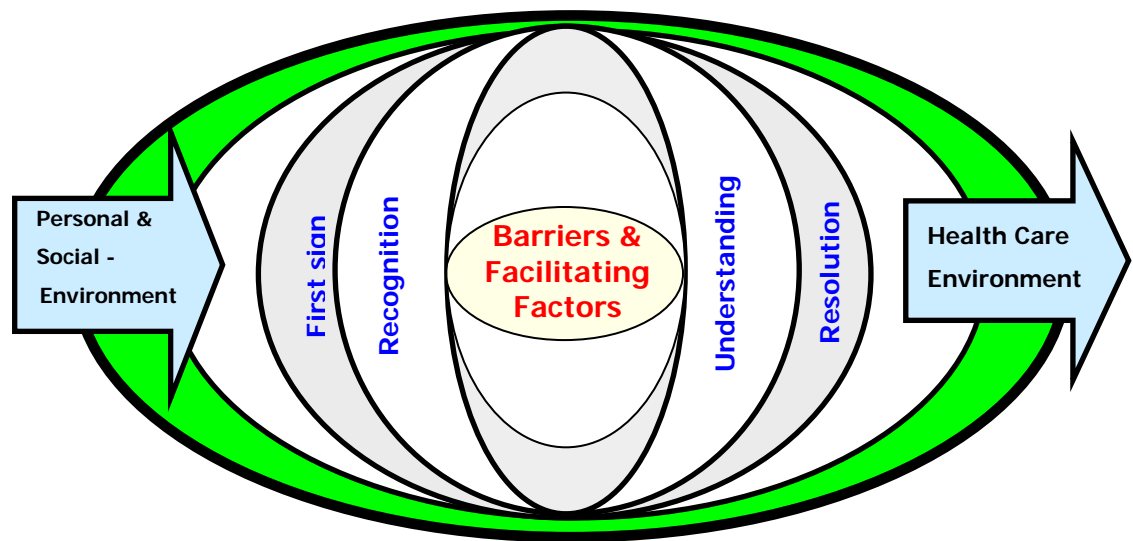
healthcare system. While it can be used as a guide with individuals, careful assessment is required to understand which of the variety of possible factors are influencing that individual's personal journey.

6.5 Using the Maze to Care Model to identify interventions and improve services.

As mentioned earlier, the maze to care model directs the focus to broad social and systems interventions which would enhance the capacity of young people and their families to recognise the symptoms of mental illness and to access appropriate and timely support (see Figure 6.1). This section deals firstly with enhancing facilitating factors. This concentrates on personal and social environments, especially important at the beginning of the process. Current interventions are identified and discussed.

Secondly, the section addresses the removal of health system barriers, including the lack of coordination of services, and the lack of knowledge and understanding of some health professionals. It is argued that, to ensure consumer empowerment, which is often taken to be the aim of mental health and drug and alcohol services, true partnerships must occur between professionals and consumers, and the consumer voice must be listened to. Again, existing initiatives in the mental health system are discussed.

Figure 6.1 Maze to Care Model showing areas for intervention



Personal and social environments

Reduce stigma in the community
 Improve knowledge of mental health symptoms
 Improve knowledge of 'normal' behaviour
 Increase effectiveness of school-based services
 Tackle sexual abuse
 Better harm minimisation for alcohol and -
 illicit drugs
 Increase availability of appropriate information

Health care environment

Better service coordination
 Prompt assessment and referral
 Education of health-
 professionals
 Improve mental health funding-
 percentage from over all health
 care expenditure
 Take into account consumer
 voice.

6.5.1 Enhancing facilitating factors in the personal and social environments

Poor environments, sexual abuse, family breakdown, and alcohol and other drug use all contribute to poor outcomes. Although it is beyond the scope of this research, it would appear that more attention could be directed towards family support systems and the resilience of individual members in times of stress and when young people experience mental illness.

Health promotion and other activities need to be directed to the reduction of stigma, which this study showed is still surprisingly prevalent in the community, to the recognition of the symptoms of mental illness, and to the dissemination of appropriate information. There are already programs and initiatives in many of these areas but this research suggests that the outcomes have not been optimal.

Young people may be reluctant to access health services face-to-face, but they do want information as indicated by the study participants. Web sites orientated to young people are an innovative way of delivering reassuring and non-threatening information to this group. This is especially important for those living in rural and remote areas, but it can be of use to all. Sites such as that of Reach Out! (www.reachout.com.au) mentioned in chapter two target young people aged 15 to 24 and provides information about many social and health issues. Other useful sites include those of the health departments of the federal and state governments (perhaps less likely to be seen as a potential source of information by young adults), and those of organisations such as Beyond Blue, which are supported by government. The latter has a site which deals with depression, though not specifically for young people (www.beyondblue.org.au). There are many other examples.

The drawback of relying on the internet is access, which is less likely for lower income groups, low education, living in rural and remote areas, homelessness. Parents in this category may also be less likely to access information designed for them. It is still important therefore to use more ‘traditional’ means of

communication such as TV and magazine advertising. However, it may well be that more can be done with technology.

The findings indicate that community awareness is still limited. There has been campaigns in the past such as World Mental Health Day, A Victory for the Mental Health of all Australians, and National Youth Week (5-13 April, 2003), and Fifteen-year-old Dan Halloran with SANE Australian launched 'You're Not Alone', a cartoon-book to help children who have a parent with a mental illness. However, these initiatives need to be further encouraged and built upon on a regular basis to keep the issues before the public eye and higher in the political landscape.

Another possibility is that collaboration between media representatives and mental health professionals could improve the accuracy of the portrayal of characters with mental illness in Australian dramas, and hence improve mental health literacy in the general community. At present there is a tendency to stereotype and as a result to reinforce negative attitudes to those with a mental illness. For example in a recent (2003) program of 'Stingers', a prime time TV series about undercover police operation, a central character who is the head of the unit had been diagnosed with Bipolar disorder. He is compelled to keep his condition a secret or lose his position and possibly his career. An alternative approach in the storyline could have highlighted that compliance with his medication regime allows him to manage his illness and effectively command his unit. News and current affairs are

other areas of potential misinformation depending on how people with mental illness are presented.

Public education advertisements whether offered on television, over the radio, on billboards or any other appropriate medium should emphasise the treatable nature of the illness and 'normalise' it. The ads should contain more than content alone. The content should be clear that mental illness is as common as diseases such as diabetes may help to minimise the stigma. Inviting family members of the person who has experience of mental disorders to join in the decision making about the development of services, and of an individual's own intervention (SANE Australia, 2003) would decrease stigma over time.

Greater attention should be given to the effectiveness of school-based services. As this study showed, many participants did not find this 'outreach program' helpful. Young people who experience difficulty in adapting to developmental changes are at increased risk of developing mental health problems and disorders; specifics such as family, school and individual factors have been identified that can assist young people to negotiate their life changes (Erwin, 2002) and reduce the risk of the development of mental health problems. The importance of positive school environments has been emphasised and many psychological disorders and problem behaviours may either be exacerbated or ameliorated by a person's school experience (Rutter, 1985). There are few evaluated programs for school-based services and prevention interventions that target young people. The programs tend to focus more on specific disorders such as conduct disorders and substance abuse,

or just focus specifically on depression and suicide (New South Wales Health Department, 2000). While the argument as to whether schools are appropriate settings for the promotion of mental health issues of young people, a number of barriers to effective mental health promotion exist. These include a lack of insight and sensitivity in addressing mental health issues, poor classroom resources and a crowded curriculum (Resnick et al., 1997).

There is also criticism which agrees with study participants that specific suicide awareness education programs in schools have little impact and may contribute to increased feelings of hopelessness among vulnerable young people, who may view suicide as an acceptable solution to problems (Beautrais, 1997). Resnick et al. (1997) highlighted the need to include strategies to enhance protective factors in the program. However, suicide tendencies will escalate rather than decrease when the community ignores its existence or denies discussions of the contributing factors.

It is imperative that programs are evaluated for effectiveness. The school-based program called Resourceful Adolescent Program (RAP-P) started in 2000 and was designed to identify and prevent depression among young people aged 12-15 years. This program includes training parents, but the program is yet to be evaluated for outcomes. There is no comparable program for young people who have dropped out of school, nor home school-based learning programs in remote rural areas, which means that the one at a greater risk of developing mental illness are still not able to access effective program.

A new initiative for 2003-2007 may hold some answers. The Adolescent Health and Social Environments Program (based in Melbourne) aims to secure better health and life outcomes by improving the environments in which adolescents live, learn and work. This program is the only one to include schools, Universities and TAFE institutes in a social environmental program.

It is also clear that there is a need for better harm minimisation for alcohol and illicit drugs, a common factor with many of the participants. Adults such as parents, teachers, health professionals and coaches can help to change the norms of alcohol and drug use (Polce-Lynch 2002). Current initiatives include focusing on discouraging binge drinking in young people, drink/drive campaigns and promoting alcohol-free events, parties and football games. When norms change, young people seek alternatives to some of the existing stereotypes. Rather than shunning them or shaming this troubled group when they choose the alternatives, it is important to help them process their experience and channel their direction into more positive activities (Polce-Lynch 2002).

The Mrazek & Haggerty (1994) review of programs aimed at preventing alcohol and substance abuse found that many programs focused largely on preventing the initiation of substance use or reducing use among those who have initiated early use. These programs could also promote skills to enhance social competence, provide social influence and resistance training, and promote alternative norms to combat drug use. Generally, health promotion is poorly appreciated, not regulated, and the services are limited and fragmented.

No study of this type can ignore sexual and other abuse. Abuse is one of the negative life-events experienced by many of the study participants. Where assessment and investigation indicates that abuse has occurred, it must be appropriately recorded, and information made available to relevant agencies and specialist services providing treatment and support, with the proviso that young people are consulted throughout the process. A plan of care needs to include confidentiality, a particular concern of participants of this study, and should involve practitioners who have contact with the young person and who are in a position to contribute to the safety, welfare and well-being of the victim(s).

Physical abuse, emotional abuse, neglect and sexual abuse require different and specialised responses. The conflict behaviour becomes even more pronounced in adulthood when child abuse is found to be directly related to the degree of adult psychopathology (Ferguson and Mullen, 1999) where self-harm, substance abuse and a continual trend toward becoming, or forming a relationship with, an abuser. Currently, the New South Wales Child Protection Act 1998 recognises that serious forms of abuse can lead to death or long term harm to the physical or the emotional well-being of the young person. However, there are significant problems associated with accessibility, referral and management of consumers within the service (Australian Health Care Summit, 2003) that provide assistance to the victims.

6.5.2 Removing health system barriers

System barriers confronted many of the participants in this study. Evidence given to the enquires into the care of the mentally ill in the community (Burdekin Inquiry, 1993) regarding the high prevalence of substance abuse in persons with mental disorders indicated that a pronounced lack of communication existed between mental health and drug and alcohol services. As a result and in the context of this study, young people with drug and alcohol tend to ‘fall through the gaps’ in the health care system. It was suggested that mental health services are unwilling to treat them due to their addiction and conversely detoxification centres and other health organisations treating substance abuse are unable or unwilling to treat people with signs of mental health problem. The issue is seen in the background of the differing philosophies and approaches that underpin treatment in drug and alcohol services (New South Wales Health Department, 2000). Whereas mental health workers generally aim for an assertive follow-up model, drug and alcohol put a greater reliance on self-motivation in helping clients abstain from substance use as a primary goal. This creates major difficulties and delays in treatment particularly where young people with substance use disorder may have unstable mental health symptoms and poor cognition and judgment in accessing appropriate services themselves. All too often they are refused entry to many services because they do not meet with strict entry criteria.

The barriers to mental health and drug and alcohol services are seen in term of organisations that have become more specialised and exclusive, when these services were once part of an integrated service framework. Primary care providers

have stated that they need to access a greater level of skills and knowledge (New South Wales Health Department, 2000), expertise and prompt back-up referrals (Penrose-Wall et al., 1998). However despite shortages, or perhaps because of it, clinicians in remote areas tend to be more accustomed to and accepting of the need to provide comprehensive and inclusive health care. The findings from this study suggest that the quality or effectiveness of service delivery could further be developed to address these issues. A consumer-centred health care system requires teamwork and a better integrated health care service. Participants have emphasised the importance of restructuring of the health care system so that physical and mental health care are provided in a more coordinated manner.

Finally, a recent review of mental health services in Australia recording the experiences of users and providers of mental health services voiced concerns that current community based systems were failing to provide adequate services (Australian Health Care Summit, 2003). This reflects the need for urgent attention together with the more important policy directions requiring review. The narratives of consumer and provider experiences should be shared with legislators to help them develop an appreciation of the importance of consumer-centred care.

6.6 Suggestion for further research

Further research is needed in a number of areas which the findings of this study indicate are important but which were not able to be pursued. In particular, it was clear that some parents, and other family members, had expectations about 'normal' adolescent behaviour which meant they confused the early symptoms of

mental illness with what they saw as a difficult developmental stage. As a result, participants were not supported and access to care was delayed. It would be useful to study qualitatively, from the perspective of parents, what these expectations of 'normal' behaviour are and how they decide when behaviour has departed from these expectations. This would lead to more informed health promotion initiatives.

The accounts of those participants who experienced involuntary care, particularly those who came into contact with the police, demonstrated that they found this process to be traumatic and shocking. It would be extremely useful to know what affect this experience had on future relationships with family, friends and with the health care system.

6.7 Limitations of the study

The information from this study must be considered within the scope of its purpose and limitations. The aim of this research was to understand and interpret the experiences of the participants, rather than to be able to generalise the findings to the wider population of young people with mental illness. However, the aim was also to generate a model from the analysis of the data, which could be applied to groups other than the participants and in different circumstances.

The Maze to Care Model is based upon data collected with a specific group of young adult participants, who were accessing care for the first time from one metropolitan area health service to which the researcher had been given access. Based on their accounts, it shows the process to care that they experienced and the types of barriers and facilitating factors that they encountered. Its shape reminds

the user of the complexity of the process, and the variety of influencing factors which may be at work at each stage. How these factors apply to individuals within the treatment situation can be elicited by careful assessment. The model can also be used, as in this chapter, to indicate where community health promotion or other social interventions need to be instigated, or where existing health care services need to be improved. However, to strengthen its explanatory power and utility, the model needs to be more widely used with other groups, so that it may be refined, modified or, indeed, refuted.

Guba and Lincoln (1981) point out that the researcher should be wary of generalisation in all areas of study, because it is virtually impossible to imagine any area of human behaviour that is not heavily influenced by the context in which it occurs. All participants were motivated to volunteer and share their experiences in time-consuming interviews. As such, it may be that positive motivation, and at least some positive experience with the mental health system by these participants, is reflected in their personal characteristics that may differ from others with similar mental health problems. Some of the participants were interviewed at a mental health service facility and may have felt obliged to be positive, though their responses indicate that this was not so. Further, the researcher is, in some ways, a representative of the health care system and it may be that, as a result, participants were not completely open and honest with her, although this was not sensed while conducting the interviews.

6.8 Summary

This research has shown the complexity of the process of accessing care for young adults experiencing mental illness for the first time and, hence, the model which was developed from the study was named the **Maze to Care Model**. This was first presented in chapter three as the outcome of the data analysis process. The aim of the model is to enhance understanding of the process from the point of view of the participants and to suggest points of intervention for health promotion and other social activities, and to improve existing health care services. It directs the focus to broad social and systems interventions which would enhance the capacity of young people and their families to access appropriate and timely support. The maze to care model was utilised in two modified forms in chapter five, showing the types of barriers which delay access to care and the facilitating factors which assist progress to care.

In this chapter, the five major categories, and the core category and basic social process ‘finding a way’, which were discussed in detail in chapter four, were briefly reviewed. The chapter continued with a discussion of the major findings of this study focussing on the personal, social and health care environments experienced by the participants. The chapter then turned to a discussion of ways to improve or instigate interventions at appropriate points, again utilising the maze to care model. The chapter concluded with suggestions for further research and with a discussion of the limitations of this present research.

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